



## **'Have Your Say' ACT Election Survey Report**

*A Report on the Carers ACT Survey of Membership Regarding  
Critical Issues of Concern to Carers Prior to the  
Australian Capital Territory Legislative  
Assembly Election 2008*

*July 2008*

Enquiries on this report may be directed to:

Dee McGrath  
Chief Executive Officer  
Carers ACT

Telephone: (02) 6296 9900  
Fax: (02) 6296 9999  
Email: [deem@carersact.asn.au](mailto:deem@carersact.asn.au)

This document was prepared by:  
***Dee McGrath, Chief Executive Officer***  
***Annemarie Ashton, Policy Advisor***

*All Carer quotations in this document are from completed surveys received for the 'Have Your Say' ACT Election Survey conducted by Carers ACT, and represent the opinions and views of individual Carers. As such, survey quotations should not be considered to be representative of any views or opinions held by Carers ACT.*

*Carers ACT wishes to acknowledge the many Carers who were so generous with their time in responding to the survey on Carer needs. A number of other people are also gratefully acknowledged for their contribution to the production of this report, including the Communication and Information Services team, the Administration team, and all the staff and volunteers who participated in the mail-out of the survey.*

## Carers ACT

Suite 5 Ground Floor	telephone: (02) 6296 9900
Churches Centre	fax: (02) 6296 9999
54 Benjamin Way	email: <a href="mailto:carers@carersact.asn.au">carers@carersact.asn.au</a>
Belconnen ACT 2617	website: <a href="http://www.carersact.asn.au">www.carersact.asn.au</a>

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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 their valuable contribution to the ACT community.*

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## ***1. Executive Summary***

Carers are those people who provide unpaid care for family members, neighbours or friends with disabilities, mental illness, chronic conditions or illnesses, who have palliative care needs, or who are aged and frail. There are an estimated 43,000 Carers living in the ACT<sup>1</sup>. Carers usually provide some kind of ongoing assistance to the care-recipient related to core activities of self-care, mobility and communication. Care must be provided for every member of the ACT community who is unable to live independently.

Caring may include the direct provision of life sustaining activity, but it also includes the added value of consideration, comfort, attentiveness and solicitude that gives quality to the life of the care-recipient. The role of a Carer is often demanding, stressful, self-less and complex, even though it can also be highly rewarding and valuable to both the Carer and the care-recipient. Carers make a vital contribution to the ACT economy. It is beyond the financial and logistical capacity of the government to replace informal care with formal care. It simply makes good business sense to support the work of Carers. Carers' work saves the Commonwealth and ACT Governments over \$524.6 million per annum<sup>2</sup>.

Carers ACT conducted a survey in May 2008 to identify key issues for Carers in the ACT prior to the next election for the ACT Legislative Assembly. The *'Have Your Say' ACT Election Survey* was included as an extra insert with the May-June-July 2008 edition of the Carers ACT newsletter. This newsletter was mailed to 1,754 members of Carers ACT and 259 Carers responded. The amount of written comment and depth of considered response to questions in the survey was unexpected and almost overwhelming. It was clear that despite being extremely time-challenged, often in poor personal health, and mostly very stressed, it really does matter to Carers in the ACT that their voices are heard on issues of concern to them. Carers are experts in their own needs and their voices best illustrate their own situations.

### **Top Three Issues of Concern to Carers About Their Own Situation:**

1. High stress
2. Poor personal health and wellbeing
3. Financial stress

The top three issues of most concern to the Carer about the care-recipient's situation were poor health, social isolation and the care-recipient's own high stress levels.

### **Impact of the Changing Economy**

The economy is also a critical factor affecting Carers' ability to provide care. Responses to the Survey indicated that inflation of basic staples, such as food, utility costs and the price of petrol are having a significant impact on Carers; with over 63% of respondents agreeing that the changing economy was impacting on their life. High credit debt and lack of capacity to access emergency funds are already issues of severe concern to many Carers. The high cost of housing in the ACT places also considerable stress on Carers, as they already have reduced capacity to earn income and higher living expenses due to the costs of providing care.

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<sup>1</sup> Data extrapolated from Australian Bureau of Statistics (2003) *Disability, ageing and Carers, Australia: Summary of findings*. (ABS Catalogue No. 4430.0) and applied to ABS Census 2006 population counts.

<sup>2</sup> Figure calculated by Carers ACT, using model developed in Access Economics (2005) *The economic value of informal care*. Canberra: Carers Australia, and applied to SDAC data.

### **Workforce Participation**

35% of respondents participated in the workforce (13% full-time and 22% in part-time). 148 (57%) respondents indicated that they were not currently in paid employment and were not presently looking for work. Of those respondents, 40 (25%) indicated they would like to increase their participation in the paid workforce. Time needed to care is by far the biggest barrier preventing workforce participation, and most Carers indicated that enablers included flexible workplace opportunities, and access to affordable, quality care alternatives.

### **Carer Health and Wellbeing**

A staggering 84% of all respondents agreed that they had felt at risk of being affected mentally, emotionally or physically because of their caring role. 70% of respondents considered high stress levels to be of most concern to them. Many Carers experience very high stress as a result of juggling the emotional, physical and organizational demands placed on them by the caring role. It is vital that Carers are properly supported to reduce unreasonable amounts of stress, as high and long-lasting stress levels are proven to have a negative impact on personal health. A big stress for many Carers is concern about their own ability to continue to provide care, and what would happen if they were ill or incapacitated.

Over half the respondents to the survey were concerned about their own poor health. Injury from caring activity and lack of time and money for preventative care were also significant factors leading to health difficulties for many Carers. In regard to psychological impact, 25 participants stated that they now suffered from depression, anxiety attacks or other stress-related illness at a level requiring medication or other medical care. Medical care is often difficult for Carers to access, as they struggle with the amount of time and cost needed to effectively access services for their personal needs. A number of respondents indicated that dental care and preventative care are the biggest unmet needs in regard to health care.

### **Top Three Needs Stated by Carers:**

1. Improved financial supports for the ACT Government to assist the Commonwealth in fairly meeting the costs of care provision
2. Affordable, accessible, safe, flexible, good quality respite options
3. Better funding for agencies/services to enable them to offer more services of higher quality, in flexible ways appropriate to needs, and to have sufficient numbers of well paid, trained staff

### **Need for Smarter Services**

Carers have diverse needs which can change greatly over their lifespan. Many care situations are complex and challenging, while others require only interim support and a 'safety net' to help deal with unforeseen challenges. Carers in the ACT have told us that they need flexible and responsive supports. They need specialized assistance to help them navigate their way through the maze of services, including advocacy services and additional support at times of transition. They also need support to maintain their connections with other family members, with the workforce, and with the wider community.

Carers report problems in accessing services. They advise that the 'system' is often difficult to negotiate, and funding criteria can significantly restrict eligibility for many people creating pools of unmet need, despite an apparent sufficiency of services at first glance. However, when things do go right, Carers very much appreciate the support.

A slight majority (52%) considers services to be satisfactory or higher, comments alongside many positive responses indicated that these respondents were most likely to be in receipt of home help services through HACC<sup>3</sup> funded services. The 26% of respondents who considered services to be unsatisfactory or very unsatisfactory provided some indication that the main problems related to:

- services that did not meet their needs
- poor quality service
- agency support workers not arriving
- high turnover of agency staff
- lack of training for support workers.

Real issues need realistic solutions. Priority development of strategic supports includes:

- a change in perception of care relationships, to develop a model of care which is the shared and equitable responsibility of families, community and government; supported by ongoing education across both government and non-government areas of the community services, health and disability services sectors
- strengthening of government policy is needed to enable better support of Carers, with a longer term goal to develop a charter of Carer rights based in legislation, which stands alongside the *ACT Human Rights Act 2004*
- working with the Commonwealth to achieve sustainable funding systems, which build community capacity through strategic investment in preventative care, building a skilled workforce, and needs-based funding
- working with the Commonwealth to develop programs to support and rebuild social connections for Carers, including access to flexible, safe and affordable respite
- adequate funding for community transport services
- quicker release of HACC growth funding with strategic criteria to meet evidenced shortfalls in service delivery; and supporting service providers to develop strategies for more flexible delivery of services
- a clear system of standards for minimum levels of service delivery and expected timeframes would greatly assist in resolving many issues, including required notification and follow-up when placed on a waiting list
- investment in better preventative care, in conjunction with the Commonwealth, to reduce unnecessary increase in demand on an already overloaded health system
- fair and equitable assessment of care situations needs to be developed around a matrix tool which examines the impact and intensity of care on a 'whole of family' basis
- centralised assessment and improved data sharing across the sector will assist in reducing the need for duplication and inconsistency of assessment, while also reducing the demands on Carers and care-recipients to continually repeat their story and/or medical history

### **Need for Practical and Financial Supports**

The Survey uncovered a range of hidden problems which can be solved by realistic and positive action. Practical and financial supports such as transportation, rebates

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<sup>3</sup> Home and Community Care

on utility bills, and expanded home care support are of critical need in the ACT. Changes in family and social structures mean that fewer people now have extended family to rely on. Economic pressures also mean that more people are in the workforce, having less time to offer support to those family members who are providing unpaid care.

Just as governments have recognized the importance and good economic sense of promoting healthy lifestyle programs to communities, so they must recognize that investment in a comprehensive system of support for Carers is the only option to help them continue in their role and maintain their irreplaceable contribution to the wider community. Current and future ACT Governments need to work with the Commonwealth to commit to inclusive strategies which recognize and address the costs of providing care, by:

- increasing the level of subsidy available for essential equipment and home modifications
- offering a low or no-interest loan scheme to help Carers on low incomes to get out of debt and/or to pay for unfunded portions of equipment or home modification costs
- extending the existing pensioner discount on utilities to all Carers where the care-recipient is co-resident (subject to reasonable income thresholds)
- introducing a Carer Card offering discounts on public transport and other ACT government services, and coordinating and promoting a discount scheme for Carers across the business community
- contributing to emergency assistance programs for Carers in need, to assist with essential items such as whitegoods replacement, car repairs and compassionate support after bereavement
- establishing a medical supplies service administered through ACT Health, where consumable medical supplies (including continence aids and tube-feeding formula) are available for registered purchasers to obtain on behalf of people with disabilities and chronic health conditions at minimum possible cost
- initiating a fuel voucher system for Carers who are required to make regular trips for essential medical needs such as dialysis or chemotherapy, where the need is medically unsuitable for delivery via in-home services

### **Post-school Options and Supported Accommodation**

Respondents in the survey requested the development of more suitable post-school options for young people and adults with special needs. There is an urgent, identified need to develop a range of options which offer a real quality of life, with meaningful activities and appropriate care levels to better meet the needs of people with disabilities in the ACT. The adjustment to post-caring, whether caused by bereavement or transition into residential care, requires a rehabilitative approach for many Carers, as they can struggle to reconnect to community after years of focus solely on a caring role.

### **Future Planning and Advocacy Support**

The majority of Carers are so focused on issues of day-to-day survival that they have little time or energy to devote to future planning, and have nobody who can effectively advocate for their needs without creating a conflict of interest in consumer representation. Future planning is needed by all Carers for emergency care plans if the Carer needs to go to hospital, permanent care options if/when a Carer is no longer able to provide care, and for wills and special disability trusts should the Carer die. Many Carers need specialist support to develop care plans,

and require access to appropriate legal and financial advice, to better enable them to provide long-term care.

## ***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. Carers usually provide some kind of ongoing assistance to the care-recipient related to core activities of self-care, mobility and communication. Care must be provided for every member of the ACT community who is unable to live independently.

Caring may include the direct provision of life sustaining activity, but it also includes the added value of consideration, comfort, attentiveness and solicitude that gives quality to the life of the care-recipient. Anyone can become a Carer, at anytime. We never know when someone we love may require our care due to accident, illness or simply from the effects of ageing. Carers come from every sector of society, and are in almost every workplace. Sooner or later, everyone either needs to provide care or requires someone to care for them.

Carers take on care roles for any number of reasons, and many make a life-long commitment to providing care. Every care situation depends upon there being a pre-existing relationship, whether partnership, kinship or friendship. Carers are not paid workers, but it is vitally important that their contribution is appropriately recognized. The costs of care must be suitably compensated, and Carers need to receive the best support available to assure their continued and future health and wellbeing. Carers bring humanity into 'systems' of care, whether they reside with the care-recipient or not. Their role is often demanding, stressful, self-less and complex, even though it can also be highly rewarding and valuable to both the Carer and the care-recipient.

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. Carers are affected by their caring role and need support to keep providing care; appropriate, timely, support that meets the Carers' own needs. The Australian Unity Wellbeing Survey<sup>4</sup> discovered that Carers are far more likely than any other Australian group to suffer from chronic health conditions and depression due to the demands of providing care. Isolation, depression and poverty are some of the negative outcomes of unsupported caring experienced by Carers throughout the ACT.

Carers need flexible and responsive supports. They often need additional and specialized assistance to maintain their connections with other family members, with the workforce, and with the wider community. Provision of supports and programs for people with disabilities and chronic conditions is only half the picture. The most significant barriers to social and workforce participation faced by Carers include the time needed to care, the cost of providing care, the isolation created by lack of appropriate supports to maintain community contact. Many Carers would like to rejoin the workforce. Most Carers would like to have a better system of supports that more adequately meets their needs. All Carers want a higher level of social equity and better quality of life for the care-recipient. Yet, Carers are not a homogenous group. They have diverse needs which can change greatly over the lifespan. Many care situations are complex and challenging, while others may require only interim support and the reassurance of a 'safety net' to help deal with unforeseen challenges.

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<sup>4</sup> Cummins, R., Hughes, J., Tomin, 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.

Social and economic inclusion depends upon the development of key strategic supports which facilitate access and redress structural inequities. A charter of rights based in legislation is the most effective means of enabling systematic reform of service structure and ensuring compliance from departments and service providers. While this may take time, it is also appropriate to consider interim strengthening of government policies to enable better support for Carers. A combination of strategic and practical solutions is needed to address critical shortfalls in current systems of support. Systemic barriers faced by Carers when trying to ensure the effective care and treatment of their loved one are also greatly reduced by an inclusive ethos of care which enables the effective and equitable contribution of care-recipient, Carer and health or community service professional. Ongoing sector education is a core strategy to address this need, across both government and non-government sectors of community services, health and disability services.

It is vital that current Carers are properly supported so that they, and the people they care for, are not added to existing queues within an already overburdened ACT health system. The Australian Institute of Health and Welfare<sup>5</sup> has stated that “the ageing of the Australian population and the greater longevity of individuals, including those with a disability, are leading to increasing numbers of people with a disability and a severe or profound limitation, especially at older ages”. The number of people available to provide care will greatly reduce in coming decades, as the population is ageing at unprecedented levels with insufficient numbers born in younger cohorts to enable a balance to be maintained.

Lack of investment in the community services sector has led to a crisis of inadequate funding, insufficient workforce, and a poor foundation of research and development. The sector urgently requires comprehensive and well-informed reform to more effectively meet the needs of Carers and care-recipients. It is vital that Carers are recognized as experts on their own needs, and that they actively participate in the design of future systems which aim to support them. Comprehensive reform also requires leadership and a commitment to ongoing investment. The challenges of the ageing population require the encouragement of innovative solutions, national standards of care, and greater cooperation between government, business and the community.

Carers ACT conducted a survey in May 2008 to identify key issues for Carers in the ACT prior to the next election for the ACT Legislative Assembly. The *‘Have Your Say’ ACT Election Survey* was mailed to 1,754 members of Carers ACT and 259 Carers responded. The amount of written comment and depth of considered response to questions in the survey was unexpected and almost overwhelming. It was clear that despite being extremely time-challenged, often in poor personal health, and mostly very stressed, it really does matter to Carers in the ACT that their voices are heard on issues of concern to them. Carers are experts in their own needs and their voices best illustrate their own situations. Information in this report is shaped by the input of Carers in the Australian Capital Territory and it is hoped that the ideas and perspectives contained herein will assist current and future ACT Governments to implement much needed better ways to support Carers.

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<sup>5</sup> Australian Institute of Health and Welfare (2007) *Australia’s welfare 2007*. Canberra: AIHW Cat No AUS 93.

### ***3. Survey Methodology***

#### ***3.1 Distribution***

A copy of the 'Have Your Say' ACT Election Survey may be found in Appendix A of this report. The Survey was included as an extra insert with the May-June-July 2008 edition of the Carers ACT newsletter. This newsletter was mailed to 1,754 members of Carers ACT on 14<sup>th</sup> May 2008. A reply paid envelope was included to facilitate response.

Carers ACT sends a complimentary quarterly newsletter to all members of the Association who have indicated their consent to receive information via mail or email. Membership of the Association is open to all residents in the ACT who are providing unpaid care for a family member or friend with a disability, mental illness, chronic condition/illness, who require palliative care, or who are aged and frail. Membership of the Association is free.

The 'Have Your Say' ACT Election Survey was also made available via the Carers ACT website at <http://www.carersact.asn.au> for download and submission via email or mail.

All participants were requested to complete and return the survey before 30<sup>th</sup> May 2008.

#### ***3.2 Data Recording and Analysis***

All surveys received by mail or hand-delivered to the Carers ACT office by the 11<sup>th</sup> June 2008 were included for analysis. One survey was disallowed as it contained no data except for a handwritten note advising that the recipient was no longer a Carer. A total of 259 completed surveys were included for analysis, giving an overall response rate of 14.8%. All responses were from the printed forms issued with the newsletter.

Quantitative data was entered into spreadsheets for analysis. There was a dense amount of qualitative data in response to the open questions. Qualitative data was extracted by identifying key themes and issues, recording both the overall number of comments made and selecting direct quotes to provide indication of both the 'typical' response and/or evidence of any diversity of opinion. Any suggestions for strategies, solutions or other ideas for improving services to Carers were also recorded.

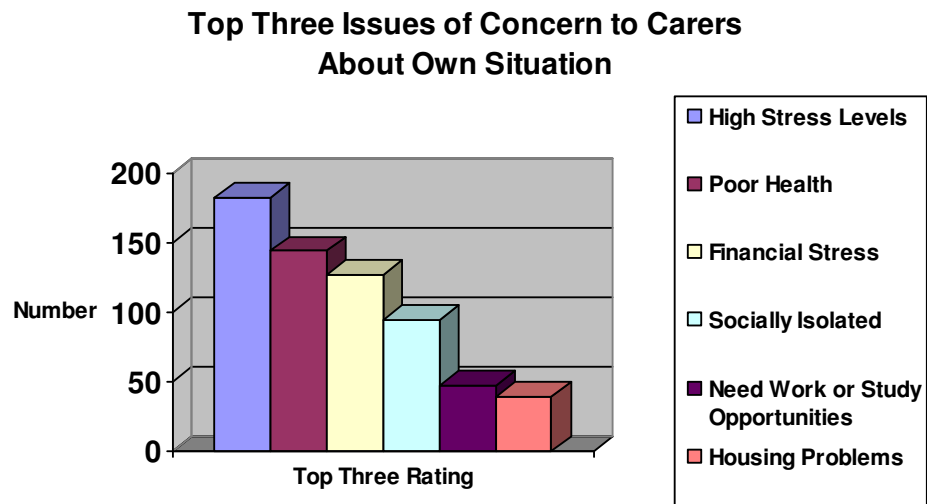
## 4. Results of the Survey

### 4.1 Issues of Most Concern to Carers About Their Own Situation

Participants were asked to indicate issues of most concern to them about their own situation at present. A number of pre-printed options were provided for participants to rank numerically, where 1 = 'Most important' and 6 = 'Least important'. The following table indicates the responses obtained:

Issue of Concern to Carers About Own Situation:	Number of Responses per Rating Group (%)		No response
	1, 2 or 3	4 or less <sup>6</sup>	
Poor health	144 (55%)	58 (22%)	57 (22%)
Financial stress	127 (49%)	72 (27%)	60 (23%)
Housing problems	39 (15%)	129 (49%)	91 (35%)
Socially isolated	95 (36%)	94 (36%)	70 (27%)
High stress levels	183 (70%)	40 (15%)	36 (13%)
Need work or study opportunities	47 (18%)	121 (46%)	91 (35%)

The top three issues of most concern to Carers about their own situation were high stress levels, poor personal health and financial stress.



<sup>6</sup> A small number of participants added extra issues of concern at the section for 'other' and then ranked all items numerically from 1 to 7.

In addition to the pre-printed selections, participants were given the option of nominating other issues of most concern. The items nominated by 62 participants are detailed in the following table:

Issue of Most Concern	Number of Comments
Future care needs if / when Carer is no longer able to provide care	11
Personal impact on Carer's own health and wellbeing (including sleep deprivation)	8
Impact of caring situation on other family members	7
Respite needs	7
Access to support/services/medical care	5
Transport assistance needs	4
Social isolation	3
Coping ability / need for crisis support	2
Costs of providing care	2
Education support available for people with special needs	2
Post-school options for people with special needs	2
Quality of care in existing residential services	2
Time poor	2
Aged care facility places availability	1
Chemist accounts to aged care residents	1
Dealing with bureaucracy	1
Equipment / home modification need	1
Risk of personal injury from providing care	1

#### ***4.2 Issues of Most Concern to Carers About The Care-Recipient***

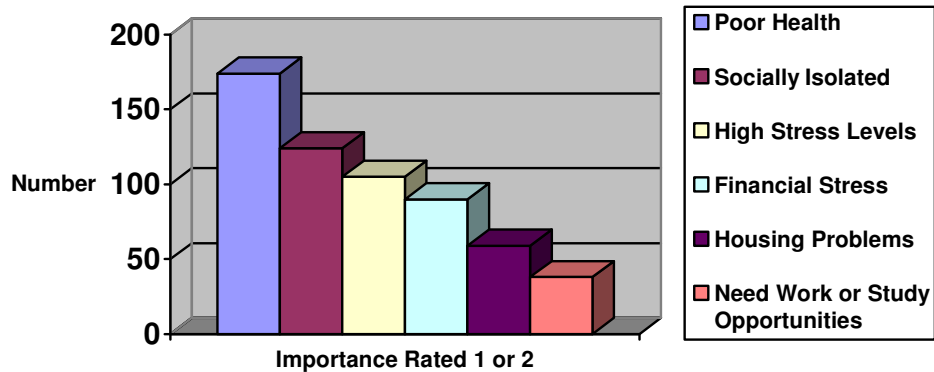
Participants were then asked to indicate issues of most concern to them about (or for) their care-recipient at present. Pre-printed options were again provided for participants to rank numerically, where 1 = 'Most important' and 6 = 'Least important'. The following table indicates the responses obtained:

Issue of Concern to Carers about Care-Recipient:	Number of Responses per Rating Group (%)		No response
	1, 2 or 3	4 or less <sup>7</sup>	
Poor health	174 (67%)	31 (12%)	54 (20%)
Financial stress	90 (34%)	77 (29%)	92 (35%)
Housing problems	59 (23%)	101 (39%)	99 (38%)
Socially isolated	124 (48%)	62 (24%)	73 (28%)
High stress levels	105 (40%)	68 (26%)	86 (33%)
Need work or study opportunities	38 (15%)	111 (43%)	110 (42%)

<sup>7</sup> A small number of participants added extra issues of concern at the section for 'other' and then ranked all items numerically from 1 to 7.

The top three issues of most concern to the Carer about the care-recipient's situation were poor health, social isolation and the care-recipient's own high stress levels.

### Top Three Issues of Most Concern to Carers About Care-Recipient's Situation



In addition to the pre-printed selections, participants were given the option of nominating other issues of most concern to them about the care-recipient. The items nominated by 15 participants are detailed in the following table:

Issue of Most Concern	Number of Comments
Personal impact on care-recipient of having a disability/condition/illness	3
Transport access	3
Socially excluded or isolated	2
Accessibility issues for wheelchairs in public places	1
Equipment / home modification need	1
Motivation for behaviour change	1
Pain management	1
Personal safety	1
Refusal to attend/receive respite	1
Rehabilitation services needed	1

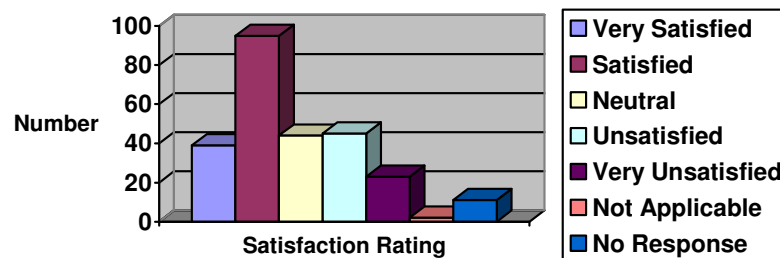
#### 4.3 Satisfaction Level of Access to Support and Services

Participants were asked to nominate the response that most closely met their situation regarding their satisfaction level with their access to support and services. The survey did not differentiate between government and non-government services, as the widest possible response was sought. Participants were invited to make comment on their rating.

Overall results regarding the level of satisfaction with services received are summarized below:

Rating of Satisfaction	Number	Percentage
Very Satisfied	39	15%
Satisfied	95	37%
Neutral	44	17%
Unsatisfied	45	17%
Very Unsatisfied	23	9%
Not Applicable	2	1%
No Response	11	4%

### Rating of Satisfaction with Access to Support and Services



A slight majority (52%) considers services to be satisfactory or higher, comments alongside many positive responses indicated that these respondents were most likely to be in receipt of home help services through HACC<sup>8</sup> funded services. The 26% of respondents who considered services to be unsatisfactory or very unsatisfactory provided some indication that the main problems related to:

- services that did not meet their needs
- poor quality service
- agency support workers not arriving
- high turnover of agency staff
- lack of training for support workers

However, these results should be interpreted with some caution, as many comments indicated that some participants may have interpreted this question to mean only supports and services received through Carers ACT while others had considered broader access to services, both government, for-profit and not-for-profit.

As such, 38 surveys contained explicit comments about Carers ACT services, of which 29 contained positive feedback regarding needs met, and 9 contained critical feedback on needs not met and/or suggestions on ways to improve services.

There were 42 other written comments (11 positive and 31 negative) about services from providers other than Carers ACT. Individual services, agencies and departments are not identified in this report, but comments reached across most areas of the sector: government, not-for-profit and private enterprise. Some Commonwealth departments, agencies and funded services were also the subject of a number of feedback comments. Where appropriate, comments obtained from the

<sup>8</sup> Home and Community Care

Survey will be forwarded directly to such services and/or departments via confidential letter to assist with their service quality assessment processes.

The final 30 comments were all generic, not naming any agency or service. This feedback was all negative. Comments were broadly grouped as follows:

- problems encountered by dealing with bureaucracy and red tape
- waiting lists
- difficulty in finding/accessing services
- lack of trained/quality staff
- ineligibility to qualify for service due to funding criteria or agency rules; and,
- inability/unsuitability of service offered to meet actual need

The general quality of services received from residential care facilities and the amount of care still needed to be provided by Carers were cause for written comment from 5 participants.

#### **4.4 Unmet Need**

Unmet need was indicated by many respondents. Evidence of unmet need, as demonstrated in written comments in the survey, has been summarized into the following table:

Written Comments on Unmet Need	Number of Comments
Safe, accessible, appropriate and affordable respite care	40
Future care	30
Transport assistance	21
Medical care (access to care, costs of care, and dental care)	18
Home help services	17
Workforce participation for adults with disability	15
Supported accommodation services (disability and mental health)	14
Out of school care for children and young people with disability	10
Crisis support services and wellbeing support	8
Post-school options and supports	8
Aged care residential placement needed	7
Access to therapy services (publicly funded)	7
Personal care / In-home nursing assistance	6
School support for children and young people with disability	5
Case management for Carers	4
Equipment purchases/rental	4
Home modification	3
Mental health services (quality and availability)	3
Assessment of needs	2
Episodic care (barriers to support)	2

Written comments from Carers indicated that important issues in unmet need were: safe, accessible, appropriate and affordable respite care, future care supports, and transport assistance. All of the above issues will be examined later in this paper.

#### 4.5 *Impact of the Changing Economy*

Participants were asked to consider if the changing economy was affecting their life or impacting on their role as a Carer. An overwhelming 63% of Carers answered 'yes' to this question.

Impacted by Changing Economy	Number	Percentage
Yes	165	63%
No	83	32%
No Response	11	4%

Additional written comments were provided by 102 participants, mainly detailing issues regarding the extra costs incurred through providing care, such as medications, therapy, equipment, home modifications and the cost of specialist appointments. It was clearly evident that inflation of basic staples, such as food, utility costs and the price of petrol is having a significant impact on Carers. Increasing rents and mortgage costs are also increasing financial pressures to unsustainable levels. Unsustainable credit debt and lack of capacity to access emergency funds are also issues of severe concern to many Carers.

Another 44 participants made written comment regarding the need for additional financial support for Carers. Key issues included recognition of the costs of providing care, income loss caused by reducing working hours or leaving the workforce in order to provide care, difficulties created by unrealistic income thresholds and inequitable eligibility requirements for rebates or discount schemes. Suggested schemes for redress included a number of strategies – some suitable for Commonwealth administration and others able to be administered by the ACT Government. Details of suggested assistance will be addressed later in this paper.

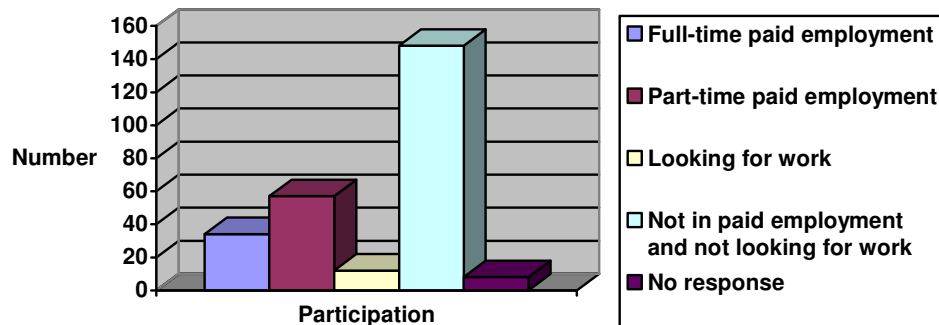
#### 4.6 *Workforce Participation*

Participants were next asked to give an indication of their level of participation in the paid workforce by choosing the most applicable option for their current situation.

Paid Workforce Participation	Number	Percentage
Full-time paid employment	34	13%
Part-time paid employment	57	22%
Looking for work	12	5%
Not in paid employment and not looking for work	148	57%
No Response	8	3%

Over half of the respondents indicated that they were not currently in paid employment and were not presently looking for work. A small number of participants also indicated via written comments that they were presently studying while out of the paid workforce or combining study with part-time work.

### Carer Workforce Participation



Those participants not working (i.e. the 160 participants who indicated they were 'looking for work' or 'not in paid employment and not looking for work') were then asked if they would like to have paid employment. A quarter of this group (i.e. 40 Carers) indicated that they would like to have increased participation in the paid workforce. The 68% of participants who answered 'no' mostly indicated that they were of retirement age or that the time and intensity of their care commitments prevented any kind of potential participation in paid work.

Like to Have Paid Workforce Participation	Number	Percentage
Yes	40	25%
No	110	68%
No Response	10	6%

Participants who were not currently working and interested in rejoining the workforce were then asked to give an indication of the type of supports which would enable them to re-enter the paid workforce. Responses have been divided into barriers and enablers, as perceived by Carers, and summarized below:

Barriers	Number of comments
Time needed to provide care	38
Poor personal health / lack of confidence	11
Lack of recent job references	2
Age	3

Time needed to care is by far the biggest barrier preventing workforce participation, yet while many Carers indicated that access to affordable, quality care alternatives would greatly assist in overcoming this barrier, some noted that in reality the cessation of the care role would be the only way of overcoming the barrier.

Several Carers made written comments noting that care provision in the home was their method of workforce participation, despite it being unpaid and not perceived by government and the wider community as 'work'.

Enablers	Number of comments
Flexible workplace opportunities (e.g. school hours, home-based or part-time)	20
Appropriate and affordable alternative care options	13
Home help services (other than respite)	5
Suitability of available job match (e.g. low stress, matched to skills/qualifications)	4
Transport assistance	2
Help to retrain, re-skill and transition back into workforce	2
Financial support for transition (e.g. to obtain suitable work attire)	1

#### 4.7 Carers Health and Wellbeing

Participants were asked to indicate whether they ever felt at risk of being affected mentally, emotionally or physically because of their caring role.

At risk	Number	Percentage
Yes	218	84%
No	30	12%
No Response	11	4%

Participants were again invited to provide written comments detailing the impact of caring on their health and wellbeing. Overall, 116 participants provided additional information. 35 participants indicated that caring had negatively affected their physical health, conditions discussed included: back or neck injuries, chronic conditions such as fibromyalgia, heart conditions, ulcers, arthritis, high blood pressure and cancer.

In regard to psychological impact, 25 participants stated that they now suffered from depression, anxiety attacks or other stress-related illness at a level requiring medication or other medical care.

Another 56 participants provided information on how caring has impacted upon their general well-being, citing issues such as negative self-esteem, fatigue, anxiety, emotional and physical exhaustion, stress and severe social isolation.

#### 4.8 Other Issues of Concern to Carers

The majority of comments in this section were able to be incorporated into prior data, as they expanded on or reiterated concerns addressed by participants in relation to issues addressed elsewhere in the survey. Many comments also contained messages of thanks and support to Carers ACT for working to improve the supports available to Carers in the Territory.

Overall, 62 completed surveys contained comments which did not fit into any of the above categories:

- 15 Carers expressed concern regarding the level of impact the care situation was having on the wider family, especially on how it affected relationships within the immediate family and/or the extended family. Types

of impact included the demands of the care-situation (particularly the time needed to care); the financial impact of providing care; and the emotional demands of caring. Some respondents referred to other issues regarding wider family relationships, specifically the problems created when other family members were not supportive, when conflict existed between family members, or the additional demands created when other family members also leaned on the Carer (either for emotional support regarding the care-situation or for help with other life issues).

- 11 respondents made comment on the positive benefits of providing care, from keeping relationships going by staying together and reinforcing family ties or marriage vows, to enjoying watching a special needs child achieve, or by feeling that they were contributing to society through providing care.
- 8 participants made reference to the need for improvement in post-school options offering meaningful activity and/or supported accommodation for adults and young people with special needs in the ACT.
- 5 participants detailed issues regarding a need for better support for children and young people with special needs who attend ACT schools. Comments included: concerns about levels of support and available funding; inclusion versus mainstreaming as optimum approach for child's needs; and, the disruption created in the school day by having to attend medical and therapy appointments elsewhere.
- 4 Carers requested help with obtaining advocacy assistance, legal advice or dispute resolution services which were affordable and had the specialist knowledge to effectively assist with the complex needs of the care situation.

Other written comments have been listed in the following table:

Written Comments on Other Issues of Importance to Carers	Number of Comments
Assistance to take a holiday (cost, respite, support for care-recipient)	3
Cross NSW/ACT border services problems	2
More money for community organizations and support services	2
Help in dealing with non-compliant young person with special needs	1
Improvement in home modification service: access, timeliness and funding	1
Isolation of elderly people in community	1
Emergency access into Lanyon Valley, single road to the area is insufficient	1
Better Autism support services (therapy, school support and respite)	1
Need for research into family attitudes and responses to care-situation	1
Support to manage financial matters	1
Income splitting for assessment of joint financial situations	1
Need to make public housing energy efficient by installing insulation and natural gas supply, to help reduce heating costs for tenants	1
Internet/computer training and support for obtaining a computer	1
Increased funding for Home and Community Care (HACC) services	1
Money to be spent on Carer activities support rather than on taxi vouchers	1

## 5. Three Things for the ACT Government to Provide for Carers

Respondents were asked to nominate the three most important things for Carers if they could ask a current or future ACT Government to provide it. Written responses were grouped into common themes for analysis and are listed in order of frequency below.

Top Three Needs Stated by Carers	Number of Comments
Improved financial support, including utilities discounts and help with costs of care (such as equipment and home modification)	118
More appropriate, safe, better quality, accessible, flexible, and/or affordable respite care	114
Better funding and resourcing for services and agencies, including more pay and training for staff, easier access, more flexible delivery and services more appropriate to needs	92
Increased availability of home help, including in-home personal care, nursing and home maintenance services	38
Appropriate/safe/better quality/accessible/flexible/affordable supported accommodation for people with disabilities	24
Future planning, whole of family support, and specialist financial/legal advice	23
Reduce bureaucracy, change government policies on Carers/health, improve government understanding of Carer issues	21
Improved quality and affordability of residential care for aged people	20
Improved transport assistance for people with special needs who are not wheelchair dependent	16
Supported workplace / better post-school options for people with disabilities	13
Improved access/quality/availability/affordability of therapy services	13
Institute public education campaigns on caring	12
Help with medical costs	11
Flexible workplace supports for Carers	11
Carers retreat or Carers support centre offering increased social opportunities and special events, as well as services for Carers	10
Improved school support for children and young people with disabilities	9
Reduced waiting time for medical care and surgery	8
Improved quality and availability of public housing	8
Improved public transport	7
Appropriate/safe/better quality/accessible/flexible/affordable supported accommodation for people with mental health needs	5
Specialist training for Carers (OH&S <sup>9</sup> , personal safety, dealing with crisis, financial planning/credit management)	5
Improved disability access and parking in public places	5
More community centres/public facilities for recreation	4
More out-of-school care for young people with special needs who are 12+ years old	4
Improved wheelchair accessible transport	4
More affordable housing options (\$150k-\$220k range)	2
Dental services	2
Transition support for Carers	2
More help for young Carers	2

<sup>9</sup> Occupational Health and Safety

A number of single comments were also received, including: a request for counselors trained in intellectual disability issues, a Christian-ethos based counseling service, more face-to-face language interpreter services, central register for power of attorneys, planned inclusive communities, more rural services, increased rights for Carers looking after a care-recipient with addiction problems, improved tenant's rights, traffic slowing in residential areas, and improved condition of footpaths to better enable older people to maintain fitness.

## 6. Key Issues for Carers in the ACT

The overwhelming and immediate response from Carers to the Carers ACT 'Have Your Say' ACT Election Survey was unexpected. Receiving 259 completed questionnaires for a written survey, with no 'added incentive' to participate beyond the provision of a reply paid envelope, was impressive. The amount of written comment and depth of considered response to questions in the survey was almost overwhelming. It was clear that despite being extremely time-challenged, often in poor personal health, and mostly very stressed, it really does matter to Carers in the ACT that their voices are heard on issues of concern to them.

### 6.1 Health and Wellbeing

Carer health and wellbeing has been of concern to Carers ACT for some time. The Australian Unity Wellbeing Index is a measure of health and wellbeing across all sections of the Australian population. A national study conducted by Cummins<sup>10</sup> in 2007 revealed 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; having much lower wellbeing scores than any other group in Australia previously studied.

As Australia's population is now ageing in unprecedented numbers, it is ever more important that Carers' and care-recipients' needs and wellbeing are safe-guarded. A system of more effective and sustainable health and social support services needs to be urgently developed, as greater numbers of people will either need care provided or need to provide care in the near future.

The ACT Election Survey results indicated that high stress, poor personal health and financial pressure are the top three issues that most concern Carers in the ACT about their own situation. An overwhelming 70% of respondents considered high stress levels to be of most concern to them. The role of a Carer may involve significant personal and physical demands. A Carer may provide organizational, financial and emotional support on a daily basis. A caring role is never devoid of emotional challenge. Many Carers experience very high stress as a result of juggling the emotional, physical and organizational demands placed on them by the caring role. Contributors to high stress levels vary according to individual situations, as can be seen in the respondent quotes listed below:

#### Carers have their say on stress

*Stress levels are overwhelming at times, though always high. Grief is a constant issue. I also have fibromyalgia which is largely affected and possibly caused by the stress of caring.*

*Balancing family, work and supporting a 93 year old who will not accept 'outside' help is stressful. I sometimes think I'll have to give up work but can't afford to. My situation will not last forever, unlike many others' situations as my relative is 93.*

*Overwhelming stress and high work demands mean that I am always 'running on empty'.*

*It stresses me out that I am no longer capable of hiding from my mother the fact that I get stressed. Rearranging medical and other appointments can be exhausting, as is negotiating with other family members.*

It is vital that Carers are properly supported to reduce unreasonable amounts of stress, as high and long-lasting stress levels are proven to have a negative impact on

<sup>10</sup> Cummins, R., et al (2007) *The wellbeing of Australians – Carer health and wellbeing*. Melbourne: Australian Centre on Quality of Life, Deakin University.

personal health. While many Carers do gain personal satisfaction from providing care, it is clear that it usually requires a significant investment of time and energy. Caring is truly a 24 hour a day, seven day a week, and 365 day a year job. It often requires Carers to multi-task, do heavy lifting, be an expert organizer, and deal with personally confronting situations which engender a significant amount of stress.

**A staggering 84% of all respondents agreed that they had felt at risk of being affected mentally, emotionally or physically because of their caring role.**

A caring role fundamentally impacts upon the Carer's own life, yet each care situation depends upon there being a pre-existing relationship, whether partnership, kinship or friendship. This situation may create a tension in roles, as providing care and needing care may require established patterns of interrelation to change. Taking on a caring role fundamentally changes the relationship between two people, in ways that may both enhance and challenge the pre-existing connection. Without appropriate support during transition, such tensions may have a negative impact on the relationship, creating more distress for both Carer and care-recipient and further lowering well-being.

Cummins found that lowered wellbeing also meant that Carers were more vulnerable to other stresses in their lives. Issues such as self-esteem, isolation, lack of recognition, emotional strain, and loss of control over their own lives were all included as being of concern to Carers. A big stress for many Carers is concern about their own ability to continue to provide care, and what would happen if they were ill or incapacitated.

#### Carers have their say on wellbeing

*We are both getting very tired as our two mothers increasingly need us. We notice the emotional strain lately more and more. I am medically retired and my husband assists me, my 82 year old mother and his 91 year old mother.*

*Juggling the care duties for a person whose condition is deteriorating continuously and work requirements is impacting significantly on my wellbeing. Yet I can't afford to give up working.*

*I am daunted that this is for the rest of our lives, and what happens to our son when we are not here? I am always tired and I feel I never have time to truly revive myself.*

*Self-esteem is poor due to other people looking down on me. Carers are not supported, only those who are fit and strong get society's approval. Carers and those in need of care are nobodies.*

*I don't know how I keep going. I am basically a single mum as my husband is very ill, as well as the kids being sick/disabled. Don't really qualify for any Carer's benefit as my kids are over 16.*

*I am 70 and caring for my mother who is 92, [which] puts various physical strains on me. Watching her decline affects me emotionally. Inability to control my own social activities, feeling trapped, affects me mentally.*

Cummins<sup>11</sup> has also found that many Carers have high levels of pain, and are very likely to have suffered a physical injury from their caring role. Over half the respondents to the survey were concerned about their own poor health, and 35 respondents provided written comments on personal health issues. Comments indicated that the amount of time needed to provide care, the intensity of the care role, and the demands of work and other family life were all contributors to Carers' feeling exhausted and rundown. Injury from caring activity and lack of time and money for preventative care were also significant factors leading to health difficulties for many Carers.

<sup>11</sup> Cummins, R., et al (2007) *The wellbeing of Australians – Carer health and wellbeing*. Melbourne: Australian Centre on Quality of Life, Deakin University.

### Carers have their say on personal health

*Physically sick because of exertion required. Mentally/emotionally sick because of constant battle for services.*

*I have depression and anxiety. I experienced an anxiety attack at school (1<sup>st</sup> time ever) and I have developed a heart condition which is brought on by stress. My medication costs \$25 per month and I am not on a health care card.*

*As I am now approaching 70 years old, I have increasing emotional and physical limits in my caring role.*

*My back is now in need of constant osteopathy or physiotherapy, which we can't afford, from lifting my child. Lack of sleep is a killer.*

*Caring for a drug-addicted, drunk, severely depressed adult child who can be violent, and who threatens suicide ... panic attacks are always there ... when you are in your 60s trying to cope with this, any help would be deeply appreciated.*

*Very stressed all the time, depressed at times. Now have high blood pressure (which I didn't have before).*

*I have progressive vision and hearing loss and find it increasingly difficult to manage my Alzheimer's mother.*

*It is 24/7, fortunately I am mentally strong but the stress is affecting my heart and I don't get time between work and home to visit the doctor.*

Time and cost seem to be key issues in Carers not accessing primary health care services. Yet basic preventative health care is critical in the long term for them to continue in their caring role, and in preventing them from becoming a care-recipient themselves.

Lack of necessary self-care soon leads to problems. 25 Carers provided written comment expressing their concerns about having experienced severe depression requiring medical intervention or experiencing what many described as a 'nervous breakdown'. These comments are clear examples of the toll of unsupported caring. Stress and poor health becomes overwhelming leading to an inability to function effectively. All of the Carers quoted in the following table are still providing care to at least one other person. The question remains who is there to care for the Carer, and what happens to the care-recipient if they can no longer provide that care?

### Carers have their say on depression

*I already have been affected. The anger, resentment and loss of control of your own life over 20 years of caring, without cooperation or appreciation, has led to depression and an inability to function.*

*I have had one nervous breakdown already, and I need to be careful that I don't take on so much that I put myself at risk of another one ... I have to work, but my caring role means I can only work part-time. The cost of living means I need to work outside the home.*

*It's very stressful for me as I am also a Vietnam Vet with PTSD<sup>12</sup> and I am getting older. I believe my wife's condition is progressive – she is slowly deteriorating.*

*I am starting to question my own mental health and am considering seeking help. There just seems to be too much for me to cope with.*

*I am on anti-depressants and I thought I was doing okay but I seem to have hit a bit of a pot-hole.*

*Have already suffered depression from the constant strain and isolation. Strain on marriage. Lack of sleep.*

<sup>12</sup> Post-Traumatic Stress Disorder

## 6.2 Economic Participation and the Costs of Providing Care

There was clear evidence from respondents that inflation of basic staples, such as food, utility costs and the price of petrol are having a significant impact on Carers; with over 63% of respondents agreeing that the changing economy was impacting on their life. Accelerating rents and mortgage costs are also increasing financial pressures to unsustainable levels. The median house price in September 2007 was \$460,000<sup>13</sup> making Canberra the third most expensive city behind Sydney and Perth. Inability to pay debts and lack of capacity to meet costs for medical needs are already issues of severe concern to many Carers.

### Carers have their say on costs of living

*High interest rates mean I must return to work, but the stress of also carrying out my caring role is enormous. I don't want my daughter's/family's health to suffer due to my need to work.*

*Cost of medicine, cost of petrol, not able to use public transport. Even to buy food at present – having to use a credit card just to buy food.*

*Had to quit my job to fulfill Carer role – falling further and further behind in mortgage.*

*I do worry about the increasing cost of everything ... I will have to work more hours and I really don't think that is the best thing for my family. I am tired enough already.*

*I have to be more mindful of the cost of living, costs which then impact on my ability to provide therapy and medical care for my children.*

*To pay for the basics (housing, electricity etc.) we have to cut down on food.*

*Cost of housing is ridiculous – have to get a lodger to help cover incredibly high rent. Very stressful! Also can't get a new pet (our dog died earlier this year) because of renting, even though having a pet helped us all to cope a bit better and be happier.*

*We can barely survive on one income. The stress this creates can be quite unbearable.*

*No more 'luxuries' even if they are essentials.*

*We can't afford to buy our own place to live, even something quite basic ... am a Commonwealth public servant so have access to flexible work arrangements, but you can't exactly have a career being part-time.*

*There appears to be no way to prevent a pensioner falling into poverty when care and medical expenses become overwhelming.*

*Can't pay my bills and need to work. Who's going to look after my daughter if I have to work?*

*We now have to sell our house and move interstate. We can't afford to live in Canberra, where our extended family lives.*

*My husband can't drive or catch buses. It's cheaper for me to drive him than use taxis but I only have \$100 per fortnight for petrol. I always need more than that, and the only place I can take it from is the food money. With three children as well, that makes things pretty tight ... two of the kids are on the Autism Spectrum so they need a lot of work too.*

Whether on Commonwealth income support or on a modest income from employment or superannuation, it is clear that many people are unable to meet the immediate, basic costs of living. Many Carers already struggle with debt and have greatly increased expenditure due to the costs of providing care. The cost of care can be divided into direct costs and indirect costs. Direct costs include consumables (such as medicines, continence aids, tube-feeding formula) utility costs,

<sup>13</sup> Australian Bureau of Statistics (2008) *House prices index: Eight capital cities* ABS Cat. No. 6416.0

and capital costs (such as equipment and home modifications). Indirect costs can include additional wear and tear on items used more because of care needs (such as vehicles and washing machines) and lost opportunity costs (e.g. working part-time instead of full-time not only loses immediate income but reduces superannuation savings and ability to pay off mortgage incurring higher overall interest costs).

#### Carers have their say on costs of care

*It is becoming more stressful since I have to buy medication for my son on a monthly basis.*

*Non-PBS items cost over \$150 per month. Increased specialists' fees too.*

*Petrol is an issue. I require a bigger car in order to ferry my relative about. The model I have is the one he can get into easily (and out of).*

*Costs of medication, physio care, equipment costs, food costs – all add to stress!*

*Struggling to meet the costs of acquiring services as well as pay the home loan ... interest on the mortgage and fuel prices are impacting significantly on ability to manage financially.*

*We need to move house or make substantial modifications and I will have to reduce paid work over time, with mortgage still considerable.*

*Fuel costs are impacting because we have to go to Canberra Hospital 4 times a week for dialysis and there is no subsidy or tax break for the costs.*

*Increasing costs of food, fuel and medical products contribute to financial and health stress. These items are necessities not luxuries.*

*Higher prices of food and supplements means that I can't keep up the standard of care.*

*High mortgage – we remortgaged and renovated to suit son's needs. Unable to give up work to consider caring for him when schooling's finished.*

Funding for equipment is a particular problem for many Carers, as items are very expensive. Families of children with disabilities face particular issues as many items are quickly outgrown, and being custom-made for the child's specific needs so are not easily used in a second-hand system. Families are often faced with long delays in accessing approval for even partial funding for items such as wheelchairs. Currently a year long process in the ACT is not uncommon. By the time many families have got approval, their child has grown and needs remeasuring which changes the cost of the item. The ACT disability equipment subsidy scheme administered through Disability ACT only meets a percentage of total cost.

Many Carers consider that having to beg for money for essential equipment is demeaning and highly stressful. Hoists and wheelchairs are essential for enabling mobility and preventing injury to Carers and care-recipients. It is inequitable that medical and care facilities would not allow staff to move patients without the availability of proper equipment or training in occupational health and safety procedures, but in their own homes we expect Carers to do just that. People with complex care needs (such as quadriplegia or who need tube-feeding) rely on an essential minimum level of equipment to physically survive, and this equipment must be maintained to a high standard of medical hygiene to avoid complications for the care-recipient.

### 6.3 Social Inclusion

Across the ACT, the weave of our social fabric is changing. Family composition has been decreasing in size and cohesiveness for some time. People are becoming more at risk of social isolation due to changes in community interaction patterns. In 2006, 32% of ACT residents did not live within any kind of family unit, an increase from only 28% in 1996. The number of siblings available to share the care of

elderly and disabled parents is declining, as most baby boomers have commonly only had one or two children compared to the average of 4+ children per family born in preceding generations. As longevity increases, many ACT residents are now providing care for ageing parents, and even grandparents, while also trying to raise a child with special needs. The emergence of the term ‘sandwich generation’ aptly describes how some Carers feel caught in the middle of competing family care needs.

It is clear that the demand for care will continue to increase in the future. Medical care advances are improving longevity for people with disabilities and increasing post-trauma survival rates, which also contributes to an increasing number of people with disabilities in the population. The Australian Institute of Health and Welfare<sup>14</sup> has stated that “the ageing of the Australian population and the greater longevity of individuals, including those with a disability, are leading to increasing numbers of people with a disability and a severe or profound limitation, especially at older ages”.

Carers are also very likely to be at higher risk of social isolation due to the demands of providing care for others. The three most significant barriers in the way of social participation are time, cost and appropriate respite care alternatives for the care-recipient.

#### Carers have their say on isolation

*Carers have a life as well as family – you tend to be invisible and lose contacts leading to isolation.*

*We gave up any social life, holidays, entertainments and such to keep costs down. We have out-lived old friends so have limited few younger ones, and have no relatives near Canberra.*

*Not only am I left to care and problem-solve but because it is seen as ‘my problem’ or that ‘I’m good at it’ family and friends assume I am coping.*

*I would like to do volunteer work, to get out and see people.*

*I feel very isolated at times and it is often difficult to be tolerant at home.*

*Social isolation of the siblings is the issue of most concern.*

A vital part of Carers ACT’s role is to keep finding ways of effectively reaching completely isolated people; the hidden Carers who are often most at risk. Cummins<sup>15</sup> found that Carers “have an average rating on the depression scale that is classified as moderate depression”. As social isolation is a significant contributor to depression, it is vital that Carers enjoy the opportunity to maintain relationships with other family members, friends and the wider community.

Social activities and support groups also assist to link Carers together, which has the potential to improve their health and wellbeing. Carers can have access to safe and welcoming environments where there are others who understand their situation, or they may prefer to join with mainstream activities, subject to access (or respite support) being possible for the care-recipient.

#### 6.4 Transport

Many elderly Carers also find that lack of affordable and accessible transport is a significant barrier to participating in social activities. The Australian Capital Territory has a lack of sufficient numbers of wheelchair accessible taxis or other suitable public transport options for people with mobility assistance needs.

<sup>14</sup> Australian Institute of Health and Welfare (2007) *Australia’s welfare 2007*. Canberra: AIHW Cat No AUS 93.

<sup>15</sup> Cummins, R. et. al. (2007) *The wellbeing of Australians – Carer health and wellbeing*. Melbourne: Australian Centre on Quality of Life, Deakin University

### Carers have their say on transport

*My husband is virtually a prisoner in our house due to little help with his transportation other than paying heaps for wheelchair cabs, even with coupons. It's punitive.*

*Community transport is supplied by [Name deleted] which we have used for 7 years. They need at least one more driver and another car ... they can't get the extra funding.*

*We can't drive a car and we can't cope with buses – even if there were any nearby.*

*Would like to see taxi vouchers for full cost not 50% ... we have vouchers unused because of the 50% costs.*

*Transport can be a problem for appointments, if you don't have two full days notice to book through the local community centres.*

*Lack of disabled parking spaces is a problem.*

Many care-recipients in the ACT are eligible and receive Taxi Subsidy Scheme Vouchers. The ACT Scheme has not increased its subsidy for many years and yet taxi fares have increased quite significantly over the same period. These taxis are expensive and are relatively unaffordable for any long distances. As a comparison, Seniors can have unlimited travel for \$1.40 between 9.30am and 3.30pm daily on Action buses, but the lack of disability-accessible buses means this public transport option is not a viable alternative for older people with mobility problems. Community transport systems work well, but demand far outstrips supply, and services are struggling to find additional funding for expansion of existing programs.

## 6.5 Respite

Respite is an essential need to enable Carers to provide sustainable and quality care. The survey did not ask any direct questions about respite, but over 40 respondents made written comments regarding unmet need for respite. Responses indicated four main issues: availability, cost, suitability for need, and quality of service. Carers need affordable respite which suits the needs of the care-recipient, which provides good quality care in a safe environment, and which is easy to arrange and access.

### Carers have their say on respite

*Respite has only one staff member for overnight [care].*

*The respite worker we had moved ... yet the service has not even contacted us to let us know she could not continue, or try and find another suitable person.*

*Respite too expensive, but need more.*

*Suitable respite facilities – low level respite care is only available at institutions which also cater for people with dementia. This environment is very distressing for a frail aged person who is mentally alert and capable of looking after herself with some support.*

*Have difficulty getting support workers for respite or personal care, and the capability/quality of those you get is decreasing.*

*As the person I care for cannot be on her own, I am completely housebound other than for work. I have no option other than to work. My biggest need is weekend respite – this is not available.*

*Respite care costs too much.*

*Respite services are unreliable. Support workers are transient and do not provide nursing care, so nurses need to be arranged separately.*

*In-house respite services for a 40 year old daughter (very disabled) are almost non-existent.*

Flexibility to meet needs is critical, but there are significant gaps in respite service for the ACT. Night care is a problem, as is getting respite for people with high need or who also need nursing care. Some Carers would like siblings and care-recipients to be cared for together, but agencies can require that a regular babysitter be obtained for sibling care, alongside the respite worker. The cost of extra workers puts respite out of reach for parents who may just want some time alone together to maintain their own relationship. Carers ACT is advocating with the Commonwealth Government to reduce limitations on guidelines to include siblings, particularly in high care cases. Transience of support workers is also a problem, as the low pay for respite work does not encourage people to embrace it as a long term option.

## 6.6 Home help

Home help and home modification services are critical for allowing people to remain living in their own homes with a maximum degree of independence. A large number of Carers and people with disabilities access the services funded under the Home and Community Care program. It is vital that these services are adequately funded to ensure that need is met at a suitable level. Increased access to periodic cleans and ongoing maintenance work is needed by many older Carers and care-recipients, as they simply cannot cope with heavy work.

### Carers have their say on home help

*My wife is a stroke victim. We're over 80. We'd like to stay in our home, but getting help with the regular maintenance is a big problem.*

*I wish to have my 85 year old husband, who is a veteran of WW2, live out his days in our home not a nursing home. Surely this is not too much to ask for. Help the Carers achieve this goal.*

*My partner is not so cooperative sometimes. He needs a lot of emotional support for his physical problems, incontinence and daily routine.*

*Home care packages do not cover all essential needs and are not available on weekends ... I need help to undress her and get her to bed at night.*

*Need real assistance with endless jobs – social services mainly write reports, draw a steady salary and make plans and policy – but they do not do the washing up, the house cleaning, shopping, or 1000 other jobs.*

*Help [needed] in provision of special jobs which cleaners won't do and help in garden work.*

*We badly need a bathroom renovation. Can we afford it? No! This would take the wear and tear off my back.*

## 6.7 Workforce Participation

The biggest barrier to workforce participation for the majority of non-working Carers is quite simply the time demanded by the provision of care. In real terms, many Carers are aware that they are presently of more economic value to the government to be providing unpaid care in the home than they would be in the workforce. Yet, this view is short-sighted, as many Carers would greatly benefit from the reduced social isolation and improved economic circumstances gained from increased workforce participation.

As the available workforce shrinks with the ageing population, the ACT Government needs to adopt a long-term view by investing in Carer skills and encouraging the business community to adopt work practices which enable a better work-life balance. In the survey, 160 of 259 respondents indicated that they were not currently in the workforce due to retirement or caring commitments, 25% of these

Carers said they would like to return to the workforce on a part-time or full-time basis if they could be supported to overcome barriers preventing participation.

The need for appropriate and affordable care alternatives is paramount to Carers. Increasing availability and use of day care programs for frail aged people (both dementia-suitable and non-dementia programs) is a key strategy, as is improving alternative care options for adults with disabilities. In-home respite is expensive, and Carers anecdotally report that agency respite workers are unreliable and very transient due to poor pay and conditions in the sector.

Flexible work options are also needed to enable a better work-life balance for all families in the ACT. Employers need to be more innovative; looking at where they can offer positions that fit in with school hours, or considering where home-based work, compressed or annualized hours may be possible to implement.

The Commonwealth Employed Carer Innovative Pilot is invaluable in supporting Carers to continue in work or in helping them to return to work. The strength of the program delivered by Carers ACT lies in its ability to offer flexible support options and to work with the employer as well as the employee. Eligibility for this program is currently restricted to a small selection of Carers who must fit into highly specific criteria, and Carers ACT is advocating for expansion of eligibility criteria to all Carers, and a commitment to long-term funding.

#### Carers have their say on workforce participation

*I have chosen to change jobs to reduce stress levels and enable me to provide better care for my mother. Financially this has been horrendous.*

*I have a public servant job with good security and Carer's leave provisions ... it's important to me financially and socially.*

*I have recently negotiated to work 1 day per week from home ... there are still misperceptions about how hard I work at home simply because I am not in the workplace.*

*I retired to undertake caring for my sibling after my mother's death.*

*Having 2 disabled children under 10, we worry about the cost in the future. We are both holding down professional jobs but realize to survive emotionally one of us will need to stop, then how do we afford to live?*

*Supposed skills shortage doesn't translate into flexible work opportunities for Carers ... 6 months of looking and not being competitive is disheartening.*

*When my daughter gets suspended from school and school holidays, it is a nightmare trying to find care for her. Have to rely on my mum at time to travel interstate and look after her.*

*When son finishes school will have to leave work in 2010.*

*Contract work leaves you worried, as you don't know if contracts are going to be reassigned.*

*I struggle to keep employed so that I will have a career to return to when my time as a Carer is completed. Being a Carer means my own career, and therefore financial stability, in my senior years is severely compromised.*

## 6.8 Quality of Support and Services Provision

Fair and equitable assessment of care situations needs to be developed around a matrix tool which examines the impact and intensity of care on a 'whole of family' basis, as well as traditional measures such as type of care provided and time spent caring.

Carers need support for the initial access process, including clear pathways for referral, and to be offered respite support for interviews or assessments, so they do not necessarily have to discuss care situations in front of the care recipient. Bureaucracy is an issue for all Carers, and few have the ability to remain on hold on

a telephone or in a queue for an hour or so. Alternative pathways are needed for maintaining information and permanent disabilities need to be recognised as such, across the lifespan.

#### Carers have their say on accessing services

*I find it extremely difficult to work out the pathways I need to take to access the help I am seeking. I am frustrated at the lack of referral from government agencies to other support systems.*

*Their organization seems to operate haphazardly and not with client's interest as focus.*

*Print fewer glossy brochures and put more people at the coal-face.*

*Cease the need for constant form-filling-out for those with life-long disabilities.*

*Often brushed off by many organizations. Often sent around in circles when trying to find out information about specific issues relating to both aged care and aged care & health issues.*

*There are long delays before the [Name deleted] starts and completes the assessment process.*

*I'm aware of the services available to me, but I couldn't be bothered – too many meetings which causes stress for my mother.*

*Carers are treated like criminals, like we are getting money for nothing. We get no respect and no support.*

*Being a Carer is a breeze, dealing with governments is stressful!*

Responsiveness in the system also needs to be increased. Care needs change over time, but it is often difficult for Carers to get services to respond to changed needs in a timely manner. Episodic conditions seem particularly difficult to manage administratively, despite the proven success of 'step up step down' models of care in the mental health system, which could be applied to other episodic care situations.

Carers also need clear and supportive pathways for appeals and/or dispute resolution. They may hesitate to complain because they fear losing services, or worry that changing service providers may create further distress for the care-recipient. Some Carers feel it is ungrateful or rude to complain, especially when services are free or subsidised. Carers also indicated that they were unsure of their rights in many cases, and found it difficult to get information on exactly what they were entitled to, and what choices they were able to exercise. Yet, in many cases, it remains that there may simply be no alternative service to consider due to lack of available places or lack of funded service providers in the ACT.

Negotiating a maze of services can be confusing and stressful, especially to older Carers. One to one support is needed in many cases, with some Carers needing access to case-management support when living with complex situations. Ongoing general information on services available assists many Carers, but it must also be remembered that many Carers are hesitant to make contact. They worry they may not qualify, they may not self-identify as being in need, and they can often fear they are taking the places of someone more in need.

All services need to be welcoming and encouraging, which can be challenging when short-staffed and under-funded. Carers who are refused services because they don't meet funding criteria or because there are no service workers available are unlikely to voluntarily reach out again. It is also vitally important that community services and health workers are well trained and empathetic in their customer service approach as some Carers may be in an extremely vulnerable position, despite seemingly good coping skills on the surface.

### Carers have their say on service quality problems

*I feel one has to 'fight' to gain access to services and be grateful for what you get, regardless of quality.*

*We receive no respite – on a waiting list. Minimal speech and occupational therapy; hardly seems worth it. No social worker. Basically nothing!*

*[Name deleted] seems to have a brief to limit services to school-aged children. They offer appointments once a term and generally spend the time telling busy, stressed parents what else they should be doing for their children's development. A sure way of limiting the repeat visits, I think.*

*Service providers often add unnecessarily to stress levels – hold-ups, lack of service, by being bureaucratic, unsympathetic etc.*

*Many services for my mother-in-law in Melbourne are very satisfactory, but we do not have the same level of satisfaction for my mother in the ACT where service provision has been erratic and of dubious quality ... private contractors on [Name deleted] are not consistent in delivery or quality – this needs to be looked at closely.*

*Inappropriate services from both [Name deleted] and funded organizations (community) have been our biggest problems ... most community organizations are insensitive to the needs of both consumers and Carers. Govt agencies are similar.*

*Older people should be able to stay at home if they choose. It shouldn't get to the point where people make the decision re nursing home only because support (physical, emotional, financial) isn't adequate.*

*The confidentiality guards that the doctors apply need to be revised, too stringent.*

*Services very much depend on the people giving them, and for the most part they are very short-staffed and ill-equipped to devote the time necessary.*

*Very unsatisfied with financial support and [Name deleted] housing availability.*

*We have had some very distressing incidents in our lives because of well-meaning organizations – who thought they knew about disability.*

*Not enough support from [Name deleted] – long waiting lists and no follow-up.*

*Agency Carers [paid support workers] need to be more qualified and trained so that fulltime family members can actually take time out to recharge batteries.*

*More hands-on therapy and a change of attitude by [Name deleted].*

*Training of psychiatrists in particular, to recognize and respect Carers and the impact on them of their role.*

*There is a chronic shortage of paid care givers – organizations such as [Name deleted] and [Name deleted] are always short-staffed. Perhaps better funding would allow them to pay staff higher rates.*

*Support and services do not appear to provide for Carers that are in full-time employment and on their own.*

*It takes up to two days of my time to arrange respite care in a government facility, and it is too time consuming for a couple of days respite.*

*Another stressful project, filling out the paperwork, obtaining receipts for this and that. You then begin to resent the person you loved all your life for the burden not asked for.*

Waiting lists for all services are a disincentive for many Carers. Anecdotal evidence received by Carers ACT often indicates that Carers may be told there is a waiting list and give up without gaining a place on the list. Some Carers are not told that the waiting list may be prioritized; and that they will never reach a high-enough priority to actually receive services. Community services need to be encouraged and resourced to gather data on unmet need, including waiting lists and waiting times in their minimum data set reporting, without fear that it will be perceived as evidence of service inefficiency.

### Carers have their say on waiting lists

*I have been on a waiting list for over 15 months. I am desperate for speech and OT for my son.*

*We have been waiting for a wheelchair for over a year now.*

*I have been on a waiting list for respite since last year.*

*I have been waiting for 7 months to have my mother reassessed.*

*It seems we will have to wait for a long time for an ACAT assessment.*

*My severely disabled son has been granted accommodation with a disability house (residential) however he has been delayed due to others not receiving the grant.*

*A GP visit usually means waiting 8 days for an appointment.*

*Waiting lists to see a specialist is 4 months, both private and at hospital.*

The role of a Carer changes if a care-recipient achieves a placement in a residential facility, but it does not cease. Carers often spend a significant amount of time and money providing quality care for their loved ones. A number of issues and problems for Carers were identified from responses received in the survey.

### Carers have their say on residential care

*Costs and quality of care in high level nursing homes are appalling and cause spouses/Carers extreme worry and stress.*

*There are some concerns regarding the quality of administration and some [paid workers] behaviour towards her ... not enough trained staff.*

*I was advised by Mental Health professionals and the police that it was time for her to try to cope in a group house, under the 'supervision' of a case manager. Unfortunately in the 2 years since this happened, there has been little or no improvement in my daughter's condition and I continue to be concerned for her. She continues to neglect her health, living in dreadful conditions and mostly staying in bed.*

*[The nursing home is] taking away all drugs when patient goes to hospital and then re-supplying and re-invoicing for the same drugs when they return again.*

*Can't get a dentist to visit a nursing home, unless you are a pensioner.*

*Biggest problem is chemist accounts – it is always incorrect and oversupplied when invoicing for drugs. It is a nightmare to sort out for the Carer, every month.*

*I work full-time, but I spend most of the weekend with my mother who is in a hostel. The hostel provides limited care during weekends and public holidays. It costs me in time, money, lifestyle, health, emotional wellbeing and sense of empowerment over my own life.*

*Even though my husband and brother-in-law are both in residential care, it does not mean I no longer have great responsibility for them. There is no recognition for this type of care, which in my case has been for 4 years ... who would do the 'caring' things I do for both of them if I was out of the equation? In the case of my husband I am constantly an emotional seesaw – guilt at having to place him in care, the dreadful confrontations on each visit as I cannot take him home. The physical side for me is relieved as I no longer have to assist him, but I am deteriorating rapidly.*

All Carers struggle with bureaucracy and gaining access to information. A clear system of standards for minimum levels of service delivery and expected timeframes would greatly assist in resolving many issues. Increasing capacity for staff training across the sector would also assist in redressing many issues of poor communication. Carers are often aware that services are already at capacity, and feedback via the survey indicates that this can create barriers to receiving quality

service, as staff cannot offer sufficient time or services to effectively meet Carer need.

However, when things go well, Carers really do appreciate the difference that appropriate support makes to their lives, and the lives of the people they care for. Simple things, like a single point of trusted contact, a well-planned program of assistance, or a needed service received from a well-trained and empathetic support worker can make all the difference to a busy, stressed and overloaded Carer.

#### Carers have their say on good service quality received

*IName deletedI has improved my life no end, offering regular respite.*

*The 8 weeks support we received when my wife came home from hospital (following a stroke which left her hemiplegic) were excellent.*

*Compared to where I was on the Central Coast, Canberra is far in advance for services. Am very satisfied.*

*Thankfully have not had need to use a large amount of services, but what we have used we have been satisfied with the level of support and access to services.*

*Satisfied with services I am currently receiving, however there has been a long wait and difficulty in accessing these services.*

*It was so difficult at first to find where to start, but I now know – call Carers ACT!*

*I am thankful to receive hydrotherapy, a supportive GP, and the support and services of the pain management unit at IName deletedI.*

*I found the transport for my wife valuable whilst I was on respite leave.*

*I am very proactive in seeking assistance for my mother. I wonder if we would do so well otherwise.*

*ISP 2-3 hours per week day is invaluable (especially for the social isolation).*

*The professionals that I have had most contact with are brilliant in their work and impeccable in the support they give me, at the same time respecting my relative's independence.*

## 6.9 Medical and Dental Care

Medical care is often difficult for Carers to access, as they struggle with the amount of time and cost needed to effectively access services for their personal needs. Many Carers spend so much time and cost assisting the care-recipient to manage medical needs that they simply forget or fail to prioritize their own health care. Yet good health is essential for providing effective care in the long term.

A number of respondents indicated that dental care and preventative care are the biggest unmet needs in regard to health care. Dental care is expensive and publicly funded services have unreasonably long waiting lists. Preventative care is almost non-existent for both Carers and care-recipients. Again, the everyday demands of medical care for the care-recipient can overshadow all other concerns, making preventative care an ideal rather than a base level for actual practice.

Investing in better preventative care is critical for preventing further increase in demand on an already overloaded health system. Future ACT governments need to support initiatives to provide a comprehensive primary care programs for Carers, as Carers already have unreasonably high rates of chronic illness and injury in comparison to the rest of the Australian population.

#### Carers have their say on medical need

*Pensioners, like my son, need a proper comprehensive dental service that would restore decayed teeth not just remove them.*

*Our doctor is often too busy to see us.*

*We suffer a lot of stress from doctors misdiagnosing our son when he is sick.*

*Follow-up mechanisms to improve Carer stress and health are non-existent.*

*Dental surgery is a problem ... our dental health is poor.*

*In 18 months I have not been able to get a case manager for son with mental health problems nor a public psychologist, so currently pay \$150 a fortnight for him to see a private psychologist and I have no private cover*

*No time or money to get teeth fixed, have new glasses, or have long overdue 'girlie' operation. Care-recipient's needs make mine fade into insignificance.*

*Reinstate community nurses to visit [Name deleted] clients in their homes and assess their medical condition before seeing a GP.*

*[Name deleted] should have more integrated records – it's ridiculous the way we have to endlessly repeat our medical histories every few hours when in hospital or seeing specialists.*

#### 6.10 Advocacy for Carers

Advocacy and advice for Carers is essential to help them manage in their role. Most requests for assistance relate to problems in accessing services, support in dealing with difficult or complex tasks (such as Guardianship hearings) or help in negotiating cross-border issues of eligibility. The stress and time demands on a Carer often requires specialist, supportive assistance to negotiate difficulties and achieve a satisfactory outcome. As Carer and care-recipient needs differ, it can be a conflict of interest for disability advocacy services to try to represent both parties, and their funding restrictions necessitate that priority is given to care-recipients over Carers.

#### Carers have their say on advocacy needs

*Need recognition that individual family situations ... need responses tailored to their particular needs.*

*Carers ACT and [Name deleted] are excellent, but I have to extrapolate from ACT conditions/infrastructure to assess how they apply in NSW where my mother lives.*

*Even though our son is under 18, we have no say in whether he goes to school or not, where he lives, or whether he takes his medication or not. How do we help him?*

*[I need] better advocacy services in the ACT.*

*[I need] legal advice and help for family in dispute, for welfare of Carers and patients.*

*More staff in advocacy role to represent Carers when difficult or new situations arise with government or other bodies.*

#### 6.11 Future Care

The majority of Carers are so focused on issues of day-to-day survival that they have little time or energy to devote to future planning. The fear of what will happen if they can no longer provide care lurks in the corner of most Carers' minds, becoming an overwhelming problem as they age and have insufficient financial resources in place to give them any hope of realistic choices for their own care and that of the care-recipient.

### Carers have their say on future care

*We are in desperate need of facilities for young disabled people. Where will my daughter go if anything happens to me? There is nowhere for these people to be cared for – please help!*

*How our son will fit into the community after we are gone is our biggest worry.*

*My daughter with Down Syndrome is 28. I am 63 and have serious health problems. Before long, she will be my Carer. Is that all the future she has to look forward to?*

*There needs to be much more age-appropriate services etc. for teenagers and to prepare the family for the future.*

*Realize that older Carers have been caring for a long time and should be a priority – or the effects of caring will add cost to the govt's health care finances.*

*My husband has terminal cancer and mild dementia. While he is mainly independent and functioning quite well now, his future needs could well be a heavy burden. He is 77, I am 73.*

*The stress of not knowing what will happen to my son is enormous. There are few services, they are not well funded and they are not always appropriate.*

*As the young disabled leave school and face uncertain futures, the stress on families/Carers increases.*

*I want a future for my child that doesn't involve babysitting in front of a TV.*

*While living at home with family, no need to worry about expenses. Cared-for person will always need support – this is expensive. Without family, how will they survive with little money?*

Future planning is needed by all Carers. From the development of emergency care plans (e.g. if the Carer needs to go to hospital) to permanent care options, wills and special disability trusts should the Carer die. Many Carers need specialist support to develop care plans, and access to free legal and financial advice.

The emotional issues of succession caring also need to be addressed with suitable support. Carers often feel intense emotions about seeming to expect siblings or other family members to provide care, especially when they are a single parent. More than anything, Carers need options for their own future care as well as the surety that their loved one will be suitably cared for in the future.

### 6.12 Burnout, Breakdown and Suicide

A number of surveys were received with very distressing comments indicating that the respondent was in severe crisis, some to the point of being suicidal. These comments have not been included as quotations, in the interests of protecting privacy and in preventing the risk of comments being quoted out of context in a detrimental manner.

It is consistently evident that unsupported caring may put Carers at risk of burnout, breakdown and/or suicide. Counsellors working with the Carers ACT Carer support services closely monitor Carers for indications of suicidal ideation and other evidence of inability to cope. This data is reported back to the ACT and Commonwealth under existing contractual reporting requirements.

**Carers ACT wishes to greatly encourage any Carer who feels that they are not coping well, who has thoughts of suicide, or who feels they may be at risk of harming themselves, to make immediate contact with our counseling service on 1800 242 636 or (02) 6296 9900 or to contact Lifeline's 24 hour telephone counseling service on 131114. Help is available.**

## ***7. Solutions and Strategies***

### **7.1 Whole of family assessment and support models**

There needs to be a change in our perception of care relationships, to develop a model of care which is the shared and equitable responsibility of families, community and government. Ongoing education on the role of the Carer as an equal partner in the care relationship is needed across government and non-government areas of the community service, health and disability sectors. A holistic model is needed to address issues for Carers across their life-span, without sectioning people with special needs into little boxes of 'early intervention', 'adolescence' or 'aged care' and leaving yawning gaps in service provision in between. Most of all, the model of care needs to change from a polemic system of all-institutionalized care or all-community care, to become a seamless 'whole of life' model which is responsive to the changing needs of both Carers and care-recipients, offering real choice of quality supports.

The ACT Government needs to work with the Commonwealth to develop smarter ways of providing care for the community on a limited budget, through the effective support of Carers and care-recipients, to better meet the anticipated demand of an ageing population. A responsible approach which complements Commonwealth funding strategies is vital, as strategic application of funding is needed to meet shortfalls and gaps in service delivery. Reductions in bureaucracy and red-tape are urgently needed to ensure that more money is available for direct service provision. A focus on preventative care is essential for reducing long-term costs and maximizing the potential of both paid and unpaid workforces to ensure continued economic viability for the Territory.

Fair and equitable assessment of care situations needs to be developed around a matrix tool which examines the impact of care as well as traditional measures such as type of care provided and time spent caring. Assessment needs to be conducted by trained interviewers, and needs to include a fair and equitable assessment of the costs of providing care. Centralised assessment and improved data sharing across the sector will assist in reducing the need for duplication and inconsistency of assessment, while also reducing the demands on Carers and care-recipients to continually repeat their story and/or medical history. Carers ACT recognises that protection of privacy is essential, and supports the development of 'smart card' systems where the data is held by the Carer and the consumer, and read by the agency of their choosing when appropriate, rather than potentially less secure multi-access internet-based systems.

Regardless of the shape, form or funding mechanism of any model for care provision, all Carers need support which is:

- Responsive to individual need
- Understanding of the demands of a caring situation
- Flexible in delivery
- Easy to access
- Consistently of good quality.

### **7.2 Health and Wellbeing Support**

It is essential that Carers are provided with sufficient support to assist them to maintain their own health and wellbeing, alongside the work they do to maintain the health and wellbeing of the care-recipient. Limited options for free treatment complicate timely access to medical care, as does the availability of affordable and

accessible respite options. The ACT Government needs to recognise Carers as an 'at-risk' population group, commit to appropriate health promotion programs, and support the implementation of a primary health care program from the Commonwealth.

Counselling services continue to be a critical need for many Carers. The ACT Government needs to support greater access to specialist counselling by extending the recent and much-needed new initiatives in mental health support to benefit Carers across the community. Carers ACT currently offers low and no-cost counselling services to Carers through the National Carer Counselling Program, but increased demand (especially from Carers with complex needs) means that there are many gaps where complementary services can be implemented with the support of the ACT Government to better address unmet need.

Additional unmet health need includes access to dental services. Carers noted specific difficulty in waiting periods and costs of private care. Many also found that they simply had no time to attend for preventative care, and only went in an emergency by which time more costly treatment was usually needed. Affordable alternatives to private care or a system of subsidization for Carers is urgently needed in the ACT.

Program development is also recommended in the following areas:

- to manage sleep deprivation experienced by Carers
- to ensure personal safety and manage challenging behaviours
- to implement occupational health and safety training for Carers

Services already received are important to Carers in maintaining their own health and wellbeing, and they strongly express their desire for those services to continue.

### **7.3 Financial Support for Carers**

Key priorities for action have to ensure that basic needs for survival are met before 'added value' or quality of life issues can be addressed. Carers cannot even think of future planning or arranging respite when they are struggling to pay bills and put food on the table. Long-term solutions are needed to redress financial inequity for all ACT Carers and care-recipients to improve their long term health and wellbeing.

Current and future ACT Governments need to commit to working with the Commonwealth to develop inclusive strategies which recognize and address the costs of providing care, by:

- increasing the level of subsidy available for essential equipment and home modifications
- offering a low or no-interest loan scheme to help Carers on low incomes to get out of debt and/or to pay for unfunded portions of equipment or home modification costs
- extending the existing pensioner discount on utilities to all Carers where the care-recipient is co-resident (subject to reasonable income thresholds)
- introducing a Carer Card offering discounts on public transport and other ACT government services, and coordinating and promoting a discount scheme for Carers across the business community
- contributing to emergency assistance programs for Carers in need, to assist with essential items such as whitegoods replacement, car repairs and compassionate support after bereavement

- establishing a medical supplies service administered through a department or agency, such as ACT Health, where consumable medical supplies (including continence aids and tube-feeding formula) are available for registered purchasers to obtain on behalf of people with disabilities and chronic health conditions at minimum possible cost

#### **7.4 Respite Services**

Emergency and short term care is insufficient for prevention of Carer burn-out and the Commonwealth funded program tends to support Carers aged 65 and over. Existing regular respite programs are failing to meet current need, mainly due to underfunding, inflexible funding criteria and an inability to recruit sufficient support workers. This means that many agencies have long waiting lists, and respite is only offered on a critical needs basis. Some families in the ACT, with genuine and immediate need for respite, may never reach the top of the queue.

Additionally, some families report that they can get some funding but can't find anyone to do the job. Paid support workers need training and sufficient salary to enable them to provide quality respite. The low pay offered to respite workers makes it is hard to attract and retain quality workers. Much of the workforce is made up of students and other transient workers. The transience of the support sector means that families often have a parade of new and inexperienced workers coming through their home, which may also create distress for the care-recipient.

The current system needs improvement in flexibility of respite delivery to meet a diversity of respite needs. It also needs to be a safe, quality experience for care-recipients and affordable enough for Carers to make reasonable use of the service. Some parents never get the chance to have a break and stay at home in peace and quiet. In-home respite care means that parents must leave the home to get a real break, which is problematic if they don't have funds to pay for a motel room or travel costs.

Out of home respite facilities are needed which offer a safe, harmonious and healthy environment where parents can be sure that their children are cared for at an equivalent standard to home care. Non-suitable respite creates great stress in the care-recipient and effectively removes any benefit the Carer may have received from getting a break.

#### **7.5 Community Services Sector Capacity Building**

There is a desperate need for services to be funded at a level which enables them to attract and keep good staff. Continuity of care is important. Carers find that having a parade of strangers through their home is intrusive and disruptive to them, and that continual transition of personal care and respite workers is distressing for the care-recipient. Many Carers also have to invest significant amounts of time in training new support workers to enable them to appropriately and safely provide care for the care-recipient. Respondents to the survey also indicated that it was hard to get people of good quality and skill levels to assist with supporting care.

Quicker release of HACC<sup>16</sup> growth funding with strategic criteria to meet evidenced short-falls in service delivery is paramount for more effective services to be delivered to Carers and care-recipients across the ACT. HACC and other services also need support and encouragement to identify ways in which they can make services more flexible in delivery. Carers need additional flexibility as to when and how they access services. Support services should be provided when most needed by the Carer and care-recipient, not when best suited to the agency or service

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<sup>16</sup> Home and Community Care

worker. Help is often most needed with before or after hours care and on weekends. Respondents to the survey highlighted that inability or unsuitability of service offered to meet need was often a factor in unsatisfactory performance.

## **7.6 Transport Assistance**

Innovative schemes are needed to provide long term, sustainable solutions to current transport difficulties faced by Carers, people with disabilities, chronic illnesses or who are frail aged. Increases in fuel costs are putting an inequitable demand on Carers who need to provide transport to care-recipients for medical appointments, treatments and therapies. The ACT Government may wish to consider offering a fuel voucher system to Carers who are required to make regular trips for essential medical needs such as dialysis or chemotherapy, where the need is medically unsuitable for delivery via in-home services.

Increased home visit systems, such as those already being implemented in some areas by the ACT Government, are often more cost effective and efficient, and are well-supported by many Carers, as detailed previously in this report. Extension of existing community transport programs is critical, as many Carers and care-recipients are facing increased barriers as a result of the increased transport charges and reduced availability of services due to rising fuel costs. Patient transport systems for hospital appointments are highly regarded and well-utilised by Carers, so recent extensions to this program through the ACT Ambulance Service have been warmly welcomed by Carers. The new ACT Regional Community Bus Service designed to improve the social inclusion and community participation of people who find it difficult to use regular bus services (e.g. seniors and other people with mobility limitations) was not announced at the time of the Survey, but will assist to address some of the unmet need evidenced by respondents. Disability access and parking continues to be an issue of concern for many Carers and people with mobility challenges.

## **7.7 Supported Accommodation**

There is an urgent, identified need to develop a range of options which offer a real quality of life, with meaningful activities and appropriate care levels to better meet the needs of people with disabilities in the ACT. Greater engagement is needed between government, providers and families to develop inclusive accommodation options which offer sustainable, quality care and security of tenure for residents.

Developing options for special needs facilities which allow ageing in place for both Carer and care-recipient is considered a highly desirable option by many people. Flexible facilities which can accommodate graduated support needs and allow for a real quality of life are already being developed in Victoria. The ACT Government needs to work with the Commonwealth to support the development of new models of care which better meet the current and future needs of the Territory's aged and disabled populations.

Carers also need assistance with placement, transition into care and ongoing involvement in their loved one's life, even if they cannot continue providing direct care. The adjustment to post-caring, whether caused by bereavement or transition into residential care, requires a rehabilitative approach for many Carers, as they can struggle to reconnect to community after years of focus solely on a caring role.

## **7.8 Post-school support**

Around 30 young people with moderate to severe disabilities leave the school system in the ACT each year at present. Respondents in the survey requested the development of more suitable post-school options for young people and adults with

special needs. Additional opportunities for meaningful training, supported employment, and inclusive social programs are urgently required; to enable the learning and maintenance of social skills and to encourage the building of ongoing relationships with peer groups and the wider community.

Even though some post-school programs are currently available in the ACT, families report they have difficulty in finding available places and may have transport problems in getting the care-recipient to attend. There is also a poor understanding of disability in the wider community (which leads to negative experiences due to prejudice and ignorance when in the public domain) creating additional stress for families. Two respondents in the survey specifically requested that the ACT Government initiate a public education program to promote inclusive attitudes and behaviours; a suggestion which may receive broader support from other Carers given a consistency in anecdotal reporting of barriers to community acceptance.

ISP (Individual Support Packages) funding has been of assistance to many families in the ACT, but there is also anecdotal evidence that these funds may be somewhat under-utilized because families may need additional support in accessing and implementing them. Carers report that in some cases the level of funding is insufficient to meet need, especially where complex or multiple disabilities are involved. In other cases, families report they have had difficulty in spending funding due to a lack of available support workers or suitable facilities/programs with available places in the ACT.

Lack of adequate support for post-school age people with disabilities inevitably requires the withdrawal or reduction in workforce participation for their Carer. Parents/Carers in this age group are often aged between 40-65 years and can be one of their employer's most productive and skilled employees. With the current ACT skills shortage and the impact of the ageing population set to reduce workforce participation rates, it is even more important that the ACT finds cost-effective ways to better utilize its population and remain economically productive.

## **7.9 Advocacy Services**

Specialist advocacy services for Carers would help to create a 'mesh' or 'web' of support, linking Carers to existing services in more effective ways, helping to identify better ways of meeting community need and building cooperative networks of liaison between government, agencies and services in the ACT. Independent advocacy is urgently needed, especially for Guardianship Hearings, Mental Health Tribunal matters, general service complaints and appeals against assessment decisions.

Specialist advocacy assistance is vital for Carers, as they can sometimes struggle to articulate the reasons why they may have different needs to non-Carers. Some Carers simply need their advocacy service to be one-to-one support to assist in managing information and to provide assistance for filling out forms, and other Carers need more intensive support to resolve more complex issues. Complaints and problems with service provision can be an issue also requiring advocacy support from people who understand issues faced by Carers. Querying support providers when not happy with services can often be difficult. Many Carers and care-recipients do not complain because they fear a loss or reduction in services.

Development of self-advocacy education programs and kits would be a viable support to the implementation of a Carer advocacy program. Self-advocacy is highly cost-effective and also builds Carer capacity and confidence for self-management of other issues. Existing advocacy services for people with disabilities are already overburdened, and often have a conflict of interest when trying to assist Carers, as they are ethically orientated to place the interests of the care-recipient before that of the Carer in all issues.

Carers may also need support to access dispute resolution services. It is critical that both government and services recognise that not all families are harmonious and in accord on care decisions. There is evidence that early access to counselling, mediation support or dispute resolution is often beneficial, as tension can arise regarding care responsibilities in families, and this can cause a breakdown in relationships if left unresolved, to the detriment of both Carer and care-recipient.

### **7.10 Future Planning**

Carers ACT has been working to address the needs of mature age Carers and encouraging people to engage in structured future planning by running a series of well-attended and informative workshops which brought together guest speakers from a number of government departments and other services. Providing useful information and support for making future care plans is an effective way of helping families to reduce stress and develop practical, workable plans.

Permanent changes to care situations also need very careful planning. The availability of specialized, empathetic support is crucial for the wellbeing of the Carer. It is inequitable that Carers are the only group of people in society who are never allowed to achieve and enjoy a full and comfortable retirement. Lack of suitable supports for in-home care or alternatives to in-home care mean that many Carers remain as full-time unpaid workers with demanding jobs that continue without reprieve until their own death.

Emergency care planning is essential for all Carers. While kits are available through Carers ACT, a promotion/education program is needed to help Carers become aware of the kits and start using them. Some Carers may need additional help to identify alternative care strategies if they should be hospitalized or otherwise incapacitated. They may also need support to plan for respite and funding options. Assistance to list all of the ways in which daily care is provided, such as current medications, appointment diaries, or small comforts in routine and preference (which may make life easier for the care-recipient during any period of disruption) are also essential for development of successful alternative care plans.

Consultation with Carers has also made it apparent that many Carers need access to free or low-cost legal and financial advice, which can provide advice and assistance on issues such as rights and responsibilities for Carer, wills, guardianship, and contracts. Costs of care and limited resources make it difficult to access appropriate professional advice, which creates an unnecessary level of risk, especially when Carers are required to take on the management of the care-recipient's financial affairs.

## ***8. Conclusion***

Carers in the ACT have clearly demonstrated their wish to be heard on issues of concern to them. While the health and wellbeing of the care-recipient remains the primary concern of most Carers, many are now recognizing that they need support in their own right to keep providing care in the long-term. Responses to the Carers ACT 'Have Your Say' Election Survey once again confirm national research findings that caring has a significant impact on the health and wellbeing of the Carers. The top three issues of concern to Carers about their own situation were high stress levels, poor personal health and financial stress.

Services for care-recipients do help Carers, but they also have needs in their own right, created by the demands of providing care. Unsupported Carers are more likely than average to experience isolation and depression from the impact of their care role. A staggering 84% of respondents to the Survey indicated that they had felt at risk of being affected mentally, emotionally or physically because of their caring role. The physical, emotional, organizational and financial demands of providing care make many Carers more vulnerable to external pressures, such as the rising cost of living. Carers are also more at risk of poverty because the time needed to care often limits or removes their ability to participate in the workforce, while the cost of providing care simultaneously creates an additional drain on financial resources.

Carers need improved financial supports, access to flexible, affordable, quality respite, and services which better meet both their own needs and the needs of the care-recipient. Carers have diverse needs which can change over the lifespan. They need flexible services which are responsive, easily accessible and delivered by well-trained, empathetic support workers. Smarter ways of providing services in the ACT are needed to address the challenges faced by the ageing population and the reduced availability of people who are able to provide unpaid care. An increased emphasis on preventative care, early intervention, and targeted, specialist services, based on evidence of unmet need, will all help to improve long-term outcomes for Carers.

Realistic and positive action by the ACT Government in consultation with the Community Services sector, and working alongside the Commonwealth Government, would help to deliver a range of sustainable and practical supports to improve life for both Carers and care-recipients. Strategies to assist in meeting the costs of care may include an increased subsidy for disability/medical equipment, low or no-interest loan schemes for Carers, extension of ACT Government senior/pensioner discount schemes to include Carers, the introduction of a Carer Card scheme, an emergency assistance program for Carers, a medical supplies service, and a fuel voucher system for regular therapy or hospital visits. Key needs for the ACT also include improvement in post-school options and an urgent need for quality supported accommodation for people with disabilities or mental illness.

Changes in family structures mean fewer people have extended family to rely on, and greater economic pressures make it essential that people now need to work to maintain even a basic standard of living. Workforce participation support schemes are vital to enable better utilization of underemployed people, and to ensure the retention of skilled workers currently in employment. Many Carers would like to increase their level of participation, but need appropriate and specialized assistance to do so. Balancing work and care responsibilities is vital for maintaining Carer health and wellbeing. Current programs in workplace support are limited by funding restrictions to a small group of eligible Carers in the ACT. There is strong evidence that a comprehensive program of workplace support would be of significant long term economic benefit to the ACT.

Carers make a significant social and economic contribution to the ACT. Priority development of smarter services for Carers must include: a change to a model of shared care which does not place an inequitable load on families, a charter of rights to drive reform of the care support system, and the development of long-term sustainable support systems with a greater emphasis on recurrent funding strategies to build a skilled workforce. Carers would greatly benefit from programs which support the development and maintenance of higher levels of social and community connection, programs that support accessibility (such as home help and transport), targeted reductions in waiting lists for support services, and clearer standards for expected service response. Carers would also greatly benefit from reforms to assessment methods for care situations, including fair and equitable assessment of the costs incurred by providing care. Centralized assessment and better data sharing across the Community Services sector would also help to improve service efficiency, leading to better long term outcomes for Carers.

Future planning and advocacy support services are both critical needs for Carers in the ACT. Carers need to plan for short-term emergency alternative care if they become unwell or incapacitated, and they also need to make advance plans for permanent replacement care systems if they should cease to be able to provide care. Effective future planning also depends upon access to appropriate professional advice, especially for financial and legal matters. Advocacy services which solely represent the Carer in their own right are not currently available in the ACT, and there is clear evidence of unmet need in this area.

The 'Have Your Say' Election Survey was designed and conducted by Carers ACT to give a greater insight into current issues of concern and needs of Carers across all sections of the ACT. Candidates for the ACT Legislative Assembly are urged to take note that there are an estimated 43,000 Carers in the Territory who, alongside their families and friends, will take keen interest in the statements and actions of all parties and independent candidates when addressing issues of concern to Carers. Future care in the ACT is dependent upon careful planning, real consultation, and appropriate, timely action. The Territory needs to move forward and build a world-class system of inclusive care, where every person needing support truly becomes the shared responsibility of families, government and the whole of community.

## Appendix A



# Have Your Say

## ACT Election Survey

### 1. What are the issues of most concern to you at present?

Please rank each column in order of importance: 1 = Most Important .... 6 = Least Important

	For You	For the Person You Care For
Poor health	<input type="checkbox"/>	<input type="checkbox"/>
Financial stress	<input type="checkbox"/>	<input type="checkbox"/>
Housing problems	<input type="checkbox"/>	<input type="checkbox"/>
Socially isolated	<input type="checkbox"/>	<input type="checkbox"/>
High stress levels	<input type="checkbox"/>	<input type="checkbox"/>
Need work or study opportunities	<input type="checkbox"/>	<input type="checkbox"/>
Other (specify)	<input type="checkbox"/>	<input type="checkbox"/>
_____		
Your comments	_____	
	_____	
	_____	

### 2. How satisfied are you with your level of access to support and services?

Please circle the response that most closely meets your situation

Very Satisfied	Satisfied	Neutral	Unsatisfied	Very Unsatisfied	Not Applicable
Your comments _____					
_____					
_____					

### 3. Is the changing economy affecting your life or impacting on your role as a Carer?

Please circle the response that most closely meets your situation **Yes** **No**

Your comments \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**4. Are you in the paid workforce at present?**

*Please circle the response that most closely meets your situation*

<b>Full-time paid employment</b>	<b>Part-time paid employment</b>	<b>Looking for work</b>	<b>Not in paid work and not looking for work</b>
----------------------------------	----------------------------------	-------------------------	--

Your comments \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**5. If you are not working, would you like to have paid employment?**

*Please circle the response that most closely meets your situation*      **Yes**      **No**

**6. If you would like to re-enter the paid workforce, what do you need to enable you to do this?**

Your comments \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**7. Do you ever feel that you are at risk of being affected mentally, emotionally or physically because of your caring role?**

*Please circle the response that most closely meets your situation*      **Yes**      **No**

Your comments \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**8. If you could ask a current or future ACT government to provide three things for Carers, then what would they be?**

- a) \_\_\_\_\_
- b) \_\_\_\_\_
- c) \_\_\_\_\_

**9. Are there any other issues you would like us to address on your behalf?**

Your comments \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Your comments and experiences are essential for us to properly help the voices of Carers reach the ear of governments. Thank you for your time in completing this survey.**

**Please return completed surveys in the reply paid envelope to Carers ACT by 31/05/08**