



**Response to the Looking Forward,
Informing a New Plan for ACT Women and Girls
2004-2009**

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

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

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Who is Carers ACT?

Carers ACT is a non-profit, community-based, incorporated association and registered charity dedicated to improving the lives of the estimated 43,000 caring families living in the Australian Capital Territory. These families provide ongoing care for people with disabilities, mental illness, chronic conditions, who have palliative care needs, or who are aged and frail. Carers ACT currently provides direct support to over 5,000 families through our counseling, information, respite support, education, social support and case co-ordination services. Our services were assessed in 2009 to meet HACC and NCCP accreditation standards at a level of excellence.

Carers ACT has a constitutional mandate to represent the voices of Carers to government and the wider community. We actively consult with a wide diversity of caring families on an ongoing basis to enable improved understanding of their needs, and enable better inclusion for them and the people they care for. Policy work in consultation, research and representation is kept separate from service delivery to ensure that the privacy of individual service recipients is respected. All Carer participation in policy work is voluntary.

Carers ACT is a member of the National Network of Carers Associations, and works actively with other States and Territories to share knowledge and facilitate improved health and wellbeing outcomes for caring families.

Contents

	<i>Page</i>
List of Recommendations	1
Representation and recognition	2
Good health and wellbeing	4
Responsive housing	5
Safe and inclusive communities	6
Economic security and opportunities	7
Flexible training and education	8

***ACT Women's Plan
List of Recommendations***

1. That the ACT Women's Plan includes campaign to raise awareness of caring and respite needs within the Primary, Secondary and Tertiary Education Levels.
2. That the ACT Women's Plan include additional funding for respite and social Carers programs for the betterment socially, mentally and physically of female Carers in the ACT.
3. The ACT Women's Plan include legislature increasing housing required to be built as universal models up to 30%, to meet the need of female Carers in the future.
4. That the ACT Women's Plan includes additional funding for Carer programs, for the betterment of female Carers.
5. The ACT Women's plan includes retirement equity to those female Carers who have been disadvantaged financially after being or becoming a Carer.
6. The ACT Women's plan include and ACT Government boost to alternative care options to ensure that female Carers have sufficient access to increased workforce and community participation.

1. Representation and recognition

The ACT Government is developing a comprehensive plan that is reflective of the whole health for women and girls in the ACT. Within this framework the Government has recognized that 71 percent of primary Carers nationally are women, and 55.7 percent in the ACT.

Women have always had the role of carer within the family nucleus, and because of this predetermined expectation, they feel obligated to 'do it all', even when it is detrimental to their own health and wellbeing.

Carers have the lowest wellbeing of any group. They are; almost twice as likely to experience chronic pain, are more likely to be obese, 20% have injuries caused by their caring role, and do not receive treatment for themselves because they do not have time, or cannot afford the treatment. Females have a lower wellbeing than male Carers. This can be attributed to physical care of the consumer, social isolation, less respite taken due to cost, and social pressures.¹

Females have a higher need for respite and social inclusion as Carers ACT Composite service data in 2008/2009 indicates:

Access of services provided by Carers ACT	
Percentage of Females	74 %
Percentage of Males	26 %

Without socialization opportunities feelings of isolation and depression develop.² This could be a contributing factor to women and girls making up more than two thirds of hospital attendances for self inflicted harm. To break this cycle women need to be supported as they are role models for young female Carers.³ Currently young female Carers have little support and legislation to protect their rights in the caring role. If we are to break the cycle of poverty for whole families as they care for family members thru generations, then our young Carers now, and in the future need to be educated and supported in the following;

- The definition of caring as a role
- Acceptance and social inclusion of Carers
- Knowledge of pathways to support them in their caring role

They also need to be supported to continue their education through secondary and tertiary levels.⁴ Research indicates that often signs such as unfinished homework, unexplained absences, evidence of poor diet, and tiredness are often miss-read by teachers. The young Carers themselves may not self identify, as for them this is all they have known and it is a part of normal family life. They may hide the fact that they are caring for a family member, as they fear separation from them, and also the stigma attached to the role from peers at school.

¹ The Australian Unity Wellbeing Index Report, April 2008

² Social Inclusion for Carers in Tasmania. Response to the Department of Premier and Cabinet Social Inclusion Unit Consultation Paper: A Social Inclusion Strategy for Tasmania. Jan 2009.

³ Erikson's Theory of Psychosocial Development. http://allpsych.com/psychology101/social_development.html

⁴ Bring it! Young Carers Forum Report. Carers Forum 26-27 November 2008. Release May 2009

They use all their spare time in their caring role and in doing so miss out on afterschool activities such as sport, art and musical interests. These not only consume too much time, but are unaffordable to many of our young Carers.

Carers ACT currently support young Carers in the ACT. Although the numbers of the young Carers accessing services may not be that high, already aforementioned reasons would be a contributing factor. The following is the breakdown by gender of the Young Carer programs accessed in the 2208/2009 financial year.

Access of services provided by Young Carers ACT	
Percentage of Females	64 %
Percentage of Males	36 %

Female and young female Carers have the right to be socially productive and to actively participate and contribute to our society.⁵

Recommendation 1

That the ACT Women's Plan includes campaign to raise awareness of caring and respite needs within the Primary, Secondary and Tertiary Education Levels.

⁵<http://www.socialinclusion.gov.au/Pages/default.aspx>

2. Good Health and wellbeing

The timeframe from retirement at 65 to death has also been extended from advance in medical knowledge, cures for diseases which once caused earlier death, and preventative medicine advance techniques. Population projections indicate that ratios of available Carers to people with care needs aged 65+ will drop from 57:100 in 2001 to 35:100 IN 2031.⁶ This will increase pressure on our society to make available more care alternatives that are flexible and consumer centered if we are to be inclusive of women in their caring role. The Australian Institute of health and Welfare⁷ has stated the “the aging 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”. In recent decades the Government has fostered a huge growth for care to be administered at home by Carers who are unpaid. The lack of sufficient residential facilities and limited hospital beds are reinforcing our society’s dependence on the work of unpaid carers. This reliance on Carers has created a gap in the health services as Carers become unhealthy mentally, socially and physically. They need support from peers who understand their situation, and to be able to vent about their problems, and know that they are not alone, but supported. This is where Carers ACT is helping those female Carers today, both young and older, as evidenced in both tables above.

As Carers reach retirement age, whereas a person employed full time can now look forward to leisure time, the stress and burdens are increased for the Carers, as the consumer needs in old age increase, along with the Carers age increase and health declines from time spent in the caring role. Respite can aid in the Carer having a physical, mental and social break.⁸ This can prolong the well being of the Carers and the care is of a higher standard when given this opportunity to take time away from their role.

*I feel very isolated at times and it is often difficult to be tolerant at home.*⁹

If we are to expect our Carers to continue in their role, it is imperative that they receive the ‘care’ to support them in their role.

Recommendation 2

That the ACT Women’s Plan include additional funding for respite and social Carer programs for the betterment socially, mentally and physically of female Carers in the ACT.

⁶ NATSEM (2004) Who’s going to care? Informal care and the ageing population. Canberra: National Centre for Economic Modelling, University of Canberra.

⁷ Noble-Carr, D., Moore, T., McArthur, M. (2008) Who cares? Experiences of young people living with a family member who has an alcohol or other drug issue. Canberra: Institute of Child Protection Studies, ACU National

⁸ Social Inclusion for Carers in Tasmania. Response to the Department of Premier and Cabinet Social Inclusion Unit Consultation Paper: A Social Inclusion Strategy for Tasmania. Jan 2009

⁹ ‘Have your say’ ACT Election survey report. July 2008

3. Responsive housing

The timeframe from becoming a Carer until final caring duties cease due to recovery or death of the consumer vastly varies. When disability occurs families are ill prepared for this life changing event. Whilst they must cope emotionally, they must also strategize for further care, special equipment needs for daily life, financial aspects of care, and a range of diverse scenarios due to different cultural values and views.¹⁰

Many times the current residence is not suitable to accommodate the consumer, and so modifications must be made to the existing home. This is usually at full cost to the Carer and care recipient. Although some modifications may be small, such as new locks on doors for dementia cases, others may require extensive changes to the family home. Renovating a house is a costly exercise, with prices increasing daily and final costs far exceeding the original quote. Changes to make bathrooms, and toilets wheelchair accessible may not be a viable solution, when consideration must be made for the value of the current home versus the cost of the renovation. It in some cases is cheaper to sell the family home and find more suitable accommodation that has already been modified. To find a home that is already modified for wheelchair access is no easy task.

Houses that are being built today are not built to a standard for ease of access to wheelchair bound persons. The extra cost for this to a builder is not viable, so therefore the families who request such a plan are going to have more costs from day one. Yet the initial cost of having a house made wheelchair accessible, versus having to modify a home, is over time more fiscally efficient. To assist female Carers in the future consideration and changes in the building of universal modeled houses needs to happen on a greater scale and consistently.¹¹ The Master Builders Association has advised that the additional cost of a universal design is only approximately 6% more, which over time would financially be beneficial.

Recommendation 3

The ACT Women's Plan include legislature increasing housing required to be built as universal models up to 30%, to meet the need of female Carers in the future.

¹⁰ Have your say/ ACT Election survey report. July 2008

¹¹ http://www.architectureweek.com/2001/0620/building_1-1.html

4. Safe and inclusive communities

People are becoming more isolated within our community as the family units become smaller. The average baby boomer has only conceived one or two children, as compared to the 4+ children per family born in preceding generations. With fewer siblings to share the caring role, the burden becomes greater to the siblings. They often find themselves being the 'sandwich generation' with caring for their ageing family and children. These roles are becoming a greater reality for many families, and the majority falls to the female carers. ¹²By the year 2013 it is predicted that 56% of all carers in Australia will be over the age of 65, the bulk of which will be female.¹³ Social inclusion of our female Carers is of utmost importance if we are to expect that they will continue in the caring role. The respite breaks are invaluable to allow time for the female carers to socialize and regain the mental capacity to deal with the continued care, which can be very demanding and require much patience.¹⁴ Carers ACT strives to find ways of effectively reaching completely isolated people; hidden Carers who are often most at risk. Cummins¹⁵ found that Carers "have an average rating on the depression scale that is classified as moderate depression". Social isolation is a significant contributor to depression, and because of this it is vital that service providers continue to be able to provide support to those female carers who are in danger of falling victim to their circumstances. This could be a contributing factor to women and girls making up more than two thirds of hospital attendances for self inflicted harm as sighted in the Women's ACT Plan.

¹² Exploring the needs of older women in the Canberra Community. A YMCA of Canberra community study.2009

¹³ J Austin, op.cit, p.15.

¹⁴ Social Inclusion for Carers in Tasmania. Response to the Department of Premier and Cabinet Social Inclusion Unit Consultation Paper: A Social Inclusion Strategy for Tasmania. Jan 2009

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

Recommendation 4

That the ACT Women's Plan includes additional funding for Carer programs for the betterment of female Carers.

5. Economic security and opportunities

Whilst the Government is supporting Australians during the economic down turn could the same support be extended to female carers who have lost their jobs due to the caring role?

"We've learnt from past downturns that if they lose their foothold in the labour market, for some people, they will never work again. And so having learned those lessons from past economic downturns, in this economic downturn we have struck our Compact with Retrenched Australians to provide immediate assistance to Australians who lose their jobs in the hope of not replicating in this economic downturn those statistics from the past."¹⁶

With additional security of being able to return to their job when the caring role is completed, and having additional financial assistance during the caring time, more females would have the confidence in their caring role, knowing that it is a change, but not necessarily a permanent negative one. Along with flexible respite, and educational opportunities, female Carers would not feel the need to give up all their life's work when undertaking the caring role. The positive on flow to society would be a larger workforce that has valuable work skills.

With the ability to integrate back to the workforce the long term benefits to female carers are significant. They not only would be increasing the workforce numbers, and knowledge, but also ensuring their financial income in retirement. The Australian Institute

Of Health and Welfare¹⁷ notes that "primary carers have a lower labour force Participation rate (39%) that people who were not carers (68%)".¹⁷

The broken pattern of work, or ongoing part time and casual work which is often the only work flexible enough to meet the needs of the Carer's care recipient results in a lower wage earned, and less superannuation accumulated.¹⁸

To take advantage of respite opportunities the women Carers who are of retirement age need to be financially secure in their own right. Planning for retirement is a right of all Australians, though women Carers have been denied this right by the disadvantage of being and becoming a Carer.¹⁹

¹⁶ Interview transcript Radio National Breakfast (2009) 7:40am 18 September.

¹⁷ NATSEM (2008) Women carers in financial stress report: Lifetime health and economic consequences of caring: Modelling health and economic prospects of female carers in Australia. Canberra: Carers Australia / Commonwealth Financial Planning

¹⁸ Commonwealth Financial Planning Women Carers in Financial Stress Report¹⁶ completed by the National Centre for Social and Economic Modelling (NATSEM)

¹⁹ Social Inclusion for Carers in Tasmania. Response to the Department of Premier and Cabinet Social Inclusion Unit Consultation Paper: A Social Inclusion Strategy for Tasmania. Jan 2009

Recommendation 5

The ACT Women's Plan to include retirement equity to those female Carers, who have been disadvantaged financially after being or becoming a Carer.

6. Flexible education and training

There has been focus on expanding the number of women on boards and committees, and women as Chairs or Duty Chairs. What statistical data has been collected on those women who are in a caring role, who either have the potential to increase the numbers of women already having success in the aforementioned areas? Women who have given up much of their work time have been left behind in the workplace and workforce generally. Even short absences can cause a woman to fall behind in technological advances, computer system and program changes, Occupational Health and Safety changes, policy and procedure changes. Often work places make these changes daily. The employer, government and educational institutions need to recognize and support women Carers in their efforts to up-skill and re-skill. More flexible strategies such as short courses, and partial courses with full certificate or other recognition given to help keep these women in the workforce, and assist them in having the skills to be more marketable in the workforce. Keeping women Carers in the workforce greatly enhances their wellbeing, by feeling more connected to the community.²⁰

Consideration of other barriers such as;

- Lack of respite in working hours to gain employment.
- Cost of daily respite, in relation to income being earned.
- Respite availability after work hours for night education courses
- Costs of after hours care

Social isolation is a double barrier for many older Carers as they are in a caring role, and also aging themselves. Carers ACT hopes to assist these women in engaging them at the new Holt facility.

²⁰ Australian Government Department of Families, housing, Community Services and Indigenous Affairs Social Policy Research paper No 34. parenting and families in Australia

Recommendation 6

The ACT Women's Plan include a ACT Government boost to alternative care to increased options to ensure that female Carers have sufficient access workforce and community participation.