



Submission No. 1000

(Inq into better support for carers)

AOC 30/7/08

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DEPUTY CHIEF MINISTER

MINISTER FOR HEALTH

MINISTER FOR CHILDREN AND YOUNG PEOPLE

MINISTER FOR DISABILITY AND COMMUNITY SERVICES

MINISTER FOR WOMEN

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Inquiry Secretary
Standing Committee on Family, Community, Housing and Youth
House of Representatives (Suite R1-116)
PO Box 6021
Parliament House
Canberra ACT 2600

Dear

Thank you for providing the ACT Government the opportunity to lodge a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's *Inquiry into Better Support for Carers*.

Please find attached the ACT's submission to this inquiry. If you would like to further discuss this submission please do not hesitate to contact Ms Michelle Callen, Manager of Strategic Policy in the Department of Disability, Housing and Community Services on 6207 5938.

I look forward to the findings of this inquiry which I anticipate will assist the ACT Government in better supporting carers in the ACT.

Yours sincerely

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Minister for Disability and Community Services

16 July 2008

ACT LEGISLATIVE ASSEMBLY

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ACT GOVERNMENT SUBMISSION

**TO THE COMMONWEALTH PARLIAMENTARY INQUIRY
INTO BETTER SUPPORT FOR CARERS**

JULY 2008

The ACT Government is pleased to provide a submission to the Commonwealth Parliamentary Inquiry into better support for carers. The ACT Government welcomes the opportunity to have input to this significant review.

The ACT Government is committed to recognising and supporting carers in the Territory. There are over 25,000 carers in the ACT who include children looking after parents, parents caring for children, or people caring for friends or relatives.

The ACT Government has undertaken significant engagement with carers since 2001 in the development and implementation of a Caring for Carers' policy in the Territory and will draw on this knowledge to respond to the terms of reference outlined by the House of Representatives Standing Committee on Family, Community, Housing and Youth.

Background

The ACT Government committed, in 2001, to acknowledging carers and addressing their needs through a comprehensive '*Caring for Carers*' policy and progressing legislative reform.

The *Caring for Carers Policy* (the policy) was developed through extensive community consultation in December 2003, making the ACT one of the first jurisdictions in Australia to develop such a policy. The policy embodies the Government's commitment to better acknowledge and support ACT carers. The policy defines a carer as "*A person who provides, or has provided, unpaid care and support to a person who has needs associated with disability, ageing, ongoing physical or mental illness or substance abuse.*"

The policy aims to provide a basis for improving supports and the health and wellbeing of carers and the people they care for by recognising the social, economic and health risks that confront carers.

The policy is underpinned by seven key principles:

1. Carers have the right to decide whether to take on or continue the role of care and are supported in their choices.
2. The health and well-being of carers is supported through services and programs that are flexible and responsive to individual needs and circumstances.
3. Resources are available to provide timely and adequate assistance to carers.
4. Affordable services of a high standard are available to people who need care, complementing the role of the carer.
5. The critical contribution of carers is recognised, valued and promoted in the community.
6. The carer and the person receiving care are regarded as a partnership, in which each person has rights and responsibilities.

7. Organisations welcome and support carer participation at all levels of decision-making, with respect for the rights and choices of people receiving care.

The ACT Government released *Caring for Carers in the ACT – A Plan for Action 2004-2007* (action plan) in August 2004. The document outlines 34 commitments for action over a three-year period to meet the objectives of the *Caring for the Carers Policy*. There are 13 key strategies under the action plan that enhance recognition of carers in the community and provide practical supports for carers.

Ongoing engagement of carers and key community and government agency partners has been critical to meeting the ACT Government's ongoing commitment to addressing the needs of carers. The action plan is overseen by the Carer Implementation Partnership and is comprised of carers from the community, Carers ACT, the Youth Coalition of the ACT and ACT Government representatives.

To support the objectives of the policy and action plan, the ACT Government committed \$830,000 over four years in its 2004-2005 Budget. This funding has been distributed on an annual basis through the Carer Recognition Grants Program. These grants enable not-for-profit community groups and organisations to pilot initiatives that provide practical support to carers and to undertake research on the emerging needs of carers.

In line with the ACT Government's commitment, in 2005 further work was undertaken to review the legislative needs of carers. A range of ACT legislation was amended to improve support and recognition of carers through the *Carers Recognition Legislative Amendment Act 2006*.

In December 2007, the ACT Government engaged the Allen Consulting Group to conduct a review of the action plan. A new carers' action plan will be developed in consultation with community and government stakeholders that progresses the recommendations of this review.

This submission responds to each individual terms of reference from the House of Representatives Standing Committee on Family, Community, Housing and Youth.

Term of Reference 1: The role and contribution of carers in society and how this should be recognised

Carers make a substantial contribution to the economic and social welfare of our community. It is estimated that ACT carers provide over 70% of the support to people who need assistance with self care, communication, housework, and meal preparation. Carers also provide highly valued support to other carers such as information about services, practical advice, skills development and emotional support.

Despite the significance of the contribution made by carers, the caring role remains largely invisible and unrecognised. Many people do not identify as a 'carer' or seek support because of values, beliefs and attitudes that downplay the importance of the role. Within some cultural groups in our community, there is a perception that seeking assistance may be seen as neglecting family responsibilities or duty. Those that do identify as carers often feel that their contributions and support needs are not well understood.

The public recognition of carers is fundamental to removing the social and attitudinal barriers to accessing support from services and the community. It is important that the recognition of the valuable role and contribution of carers is respectful to carers and people who receive their care and acknowledges the interdependency in caring relationships.

Feeling acknowledged and respected can contribute to leading to experiences of improved self-esteem, coping resources, health and well being; as well as reductions in stress, depression, feelings of isolation and pressure.

It is important that carers are recognised as a collective group and not just as a family member who performs caring duties, as recognition of the carer role will increase self-identification of carers, and therefore increase the likelihood that carers will seek support; and recognition of the role of carers in the broader community will improve carers ability to support the person they are caring for. These two issues are explored in further detail below.

Self Identification

Recent research indicates that if a person does not see themselves as a 'carer', they are unlikely to search for, or easily find, government services that meet their needs as a carer. They will remain in the parlance of the literature, 'hidden'. Government efforts to support carers will be less effective if they are not able to improve self-recognition of carers, about their role and the associated needs.

The ACT Government has resourced various initiatives that aim to assist carers to identify themselves as carers. For example, a communications audit identified available information and resources for carers in the ACT as well as key gaps. A support kit was developed for children, young people and families where a parent has a mental illness or dual diagnosis, providing opportunities for young carers to develop skills to articulate their support needs and access the services they require. Further the ACT Government has resourced a range of online information sources for carers through Carers ACT, Canberra Connect, ACT Communities Online, CONTACT Canberra, FaBRIC and other community agencies.

Public/Community Recognition

Recent research indicates that carers usually have an important role in the medical treatment of the person which they are caring for, for two key reasons. Firstly, recognition is likely to result in improved health outcomes for the person they are caring for. Carers provide a number of key supports, ranging from general observations about daily health to basic medical care.

The more service providers take the needs and abilities of carers into account, the better carers will be able to perform such duties. Secondly, greater recognition by service providers that carers are part of the 'treatment team' will assist in the ability of carers to exercise some choice about their role, where appropriate. For instance, enhanced information provision about a person's condition may give a carer greater confidence to continue performing their role, or lead them to decide that they can no longer cope with the demands of a caring relationship.

The ACT Government has enacted legislation giving greater recognition of carers. The *Health Records (Privacy and Access) Amendment Act 2005* included amendments about the disclosure of personal health information for a consumer to a person responsible for the consumer's care in circumstances where the consumer cannot give or withhold consent particularly if the information is necessary to enable the carer to provide safe and appropriate care. The *Carers Recognition Legislative Amendment Act 2006* introduced a new definition of 'carer' for the *Discrimination Act 2001*, amended the *Human Rights Commission Act 2005* to allow carers under legal disability, such as children and young people to lodge a complaint as an agent of an aggrieved person; and amendments to the *Guardianship and Management of Property Act 1991* introduced a requirement that multiple carers be consulted as part of any decision-making process.

The ACT Government has resourced projects aimed at increasing the recognition of carers in the broader community. For example, a Carer Information Kit, supported by training sessions, was developed for service providers and professionals to enhance information dissemination for key transition points for carers in the ACT. Further, training has been provided to ACT school counsellors on the issue *Children of Parents with a Mental Illness* in early 2008 and a similar model of training and presentation to be used to train all ACT teachers on the issue of *Young Carers* in 2009. The development of theatre works about young carers needs has also been supported.

While these initiatives have been effective at improving information available to carers and increasing community understanding of caring, there is a need to improve the distribution of information on available supports and services to carers, particularly those who do not have linkages with the community sector. The recent review of the action plan indicates where carers are aware of the information and services, many find it confusing and difficult to navigate. This could be improved by a more active approach to information dissemination, such as one on one counselling to guide carers through relevant information and services and a more dynamic information provision at gateways. The review also highlights the ongoing need for Governments to focus on raising awareness about carer roles and issues across Government agencies.

Term of Reference 2: The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment

The ACT Government recognises the importance of supporting carers through key transitions, including returning to or maintaining employment.

Carers who work or want to work often need flexibility in the workplace. This includes arrangements regarding work hours, and family friendly practices. The need for flexibility is also important in relation to education and training. Carers, including young carers who study, may benefit from the flexibility to complete education at home, have their caring skills recognised as part of their education, take periodic leave from study commitments, and have extended timeframes for completing courses.

The ACT Government has progressed a range of actions to support carers to maintain or return to work. Workshops on discrimination and equal employment opportunity to private sector employers are delivered by the ACT Human Rights Commission and include information on the importance of accommodating carers' needs in the workplace and compliance with the law. The Human Rights Commission also developed and published a brochure entitled 'Parent or Carer Discrimination', which explains the operation and effect of the *Discrimination Act 1991* as it relates to parents and carers and the role of the Commission in investigating and resolving complaints of such discrimination.

The ACT Government's 2007-2010 Collective Agreement includes measures to recognise the demands on carers and to provide them with sufficient flexibility to allow individuals to continue to contribute to the workplace while also meeting their carer responsibilities.

Access to respite is a key support enabling carers to access work opportunities. The ACT Government is committed to improving access to flexible and timely respite care and other forms of short-term care that provide carers with opportunities for other activities and breaks and has invested significantly in the provision of respite services and programs. The ACT Government, through Disability ACT and the Home and Community Care (HACC) program, provides and funds centre based respite care and flexible respite care. The ACT Government has further supported targeted research to better address carers respite needs, particularly for young carers and Aboriginal and Torres Strait Islander carers.

In supporting carers to access employment, it is critical that carers' access to education is also supported. The ACT Government has supported training for carers to assist them in returning to work, and provided individual support for young carers at schools and colleges to manage their responsibilities and continue their studies.

There is an ongoing need to support young carers to access education and employment. A study supported by the ACT Government indicated that young

carers often experience high levels of financial stress, live in families experiencing financial hardship and often do not have access to Centrelink Carers Allowance or a Carers Payment.

Term of Reference 3: The practical measures required to better support carers, including key priorities for action

It is important that carers have access to practical assistance that minimises the level of care required or the impact of caregiving on the carers. This includes access to home help, respite care or in-home care, equipment and technology, home and vehicle modifications, counselling and family support, opportunities to develop skills and knowledge, financial support, mutual supports and advocacy support when dealing with organisations.

Carers have diverse types of needs. Some needs relate to the activities of care such as how to safely lift someone into the shower or how to respond to a medical event. Other needs relate to taking care of their own health and well being, this includes participating in economic, social and community life. In general, one type of support on its own will provide some support but a combination of supports can have a substantial impact on the quality of life. There are many specific issues for young carers, mature carers, primary carers, Indigenous carers and carers from diverse cultural backgrounds.

Informal networks between carers are important sources of social and psychological supports. The ACT Government has resourced a number of projects that provide opportunities for socialising, a buddy support system for families in crisis, mutual support and inclusive recreational activities. Some of these projects were targeted at specific groups of carers including young carers, Aboriginal and Torres Strait Islander carers, carers from culturally and linguistically diverse backgrounds and carers who live in a particular region. For example, Carers ACT is funded to provide 14 culturally and linguistically diverse carer support groups which identifies socially isolated carers from multi-cultural and linguistically diverse backgrounds and assists their participation in community groups and activities.

It is important that carers have opportunities to develop skills and knowledge to assist them in their caring role. The ACT Government has supported a number of projects in this area. For example, Friends of the Brain Injured Children (ACT) received funding to undertake their project *Bad Backs: Carers Lifting and Massage Training* where an Occupational Therapist visited families in their home to assess and provide training in lifting and carrying techniques. Parents of children with cerebral palsy were trained in massaging techniques for their children. A further example is training provided for young carers in Senior First Aid and practical caring skills.

There are further practical measures jointly funded by the ACT and Commonwealth Governments. These are primarily carer support services funded under the Home and Community Care (HACC) program. HACC also provides assistance to carers through home help support. A further joint ACT-Commonwealth Government service is the *Respite for Older Carers* program.

More respite opportunities, home care support, and one-on-one counselling and guidance for carers at transition points are priority areas of continuing, and growing need, in the future. It is important that future practical measures respond to the diversity of carers needs. The diversity within the carer population means that a 'one size fits all approach' to services will disadvantage those groups in the community who do not have strong linkages to government agencies or the community sector. In particular, young carers, Aboriginal and Torres Strait Islander carers and carers from culturally and linguistically diverse backgrounds are less likely to seek support through a generic service delivery response. Appropriate respite services are a key area of continuing need for carers from these groups. Adequate financial support that recognises the role of carers is also a key area of need among carers.

Term of Reference 4: Strategies to assist carers to access the same range of opportunities as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future

There is a community expectation that families will provide support to people who need care, but there is also an understanding that care is not only the responsibility of families. While caring can be a positive and rewarding experience for many, it can have a negative impact on individual health and wellbeing if the demands of caring exceed the carers' economic, physical or psychological capacity to provide care. A broad range of services and supports are funded through government and non-government agencies to provide care and support to individuals and families.

To have real choice, carers need to have options and information about support. Many carers currently feel that they do not have choices because of difficulties accessing services. Carers can also experience other difficulties when making decisions, for example a decision to end or reduce care is difficult. Some carers believe that if they stop or reduce care they will be criticised, or that this might lead to the person they care for being forced into an unsatisfactory care arrangement. These concerns may prevent them from seeking help or delay help seeking until they are in a crisis. Positive promotion of carer support services will encourage earlier help seeking and planning.

It is important that a decision to access services or alternative care arrangements is not seen as a decision to withdraw from the relationship or stop being involved in the way that care is provided. The contribution of the carer should be acknowledged and their ongoing involvement encouraged. It is important that services continue to recognise and support the natural relationships between family members and friends.

Changes that can lead to a reduction in caring responsibilities or the end of a caring relationship include: changing family structure; a death or illness; changing needs; or the opportunity to access services. These changes can have a significant impact on carers who might require assistance to adjust to

new circumstances. Types of assistance include help to return to work or study, grief counselling, housing and financial advice, support to build social activities and networks. In particular, young carers may need help to catch-up with their peers if their education, work prospects or independent living options have been affected while they have provided care.

The ACT Government's *Caring for Carers Policy* is supported by the principle that carers have the right to decide whether to take on or continue the role of care and are supported in their choices.

There is growing recognition that policy measures responsive to the diversity of caring roles, and geared around key transitions, are likely to be most effective in supporting carers through changing circumstances. Some of the key transitions include:

- At the onset of disability, illness or dependence (birth or later in life).
- Transitions to school.
- Moving from children's to adult services.
- On discharge from hospital.
- At the end of care (when the person cared for dies or moves into institutional care or overcomes their illness/disability to the extent of no longer needing a carer).

The ACT Government has resourced a number of projects and programs to assist carers at key transition points to make choices about their caring role. For example, UnitingCare Kippax was recently funded to provide the *Carers in Transition Project* which will target activities and strategies to support people who have ceased their caring role, usually due to the death of the person they have been caring for. Community Connections was funded for *Developing Circles of Support for Mature Carers and Others, Including Those from Different Cultural Backgrounds* to create support networks for families to consider solutions to problems they experience in everyday life and plan and develop directions for a safe and secure future. Further, assisting families to plan for their future is incorporated in all support services provided by Disability ACT.

The ACT Government has also resourced a range of research to better understand the support needs of carers at key transition points, including:

- The Mental Health Foundation received funding for *Hospital Care – Mental Health Carers Experience* which researched the experiences of mental health carers, when the person they care for has contact with a mental health in-patient facility.
- The Australian Catholic University received funding for *A Research Project - Supporting Children and Families affected by Alcohol or Other Drug Use* to explore the nature of care responsibilities, support needs and services to be able to respond to children, young people and families affected by alcohol and drug use. Preliminary research findings from this study indicate young carers are less likely to receive support from agencies and are more likely to have their education affected due to caring responsibilities.

- The Youth Coalition of the ACT received funding for *Supporting our Family Kit* and developed a support kit for children, young people and families where a parent has a mental illness or dual diagnosis. This research found that young people need more support for their relatives and families including more personal support, respite, in-home care, assistance with employment, family-based rehabilitation, family counselling and mediation, advocacy and financial support; and more support for themselves including help with education, community awareness, recognition and respect, training of professionals, information on their relative's condition, information on available services, respite and personal support.

There is a continuing need for support at key transition periods, in addition to regular on-going support. The episodic nature of carer needs, which tend to peak at crisis and transition points, is not well addressed by current support services. While some new pilot studies have been trailed in this area, more effective services and supports are needed to address these transitional or crisis periods of need.

Conclusion

In responding to the terms of reference for this inquiry the key areas of future need were identified by the ACT Government.

Areas of ongoing need which the recent review and this submission have identified include the need to improve the distribution of information to carers on services available as well as raising awareness about carer roles and needs across Government agencies and service providers. To overcome the barriers to social and economic participation for carers there is a continuing need to support carers to access to both education and employment.

The needs of carers are diverse. Opportunities to access respite need to be tailored, particularly for young carers, Aboriginal and Torres Strait Islander carers, and carers from culturally and linguistically diverse backgrounds.

The support requirements of carers may vary during different stages of the provision of care. This may either be related to transition in their caring role or due to personal choices to access differing levels of support. The ACT Government recognises the need for continued support that is modified during the different stages of carers' responsibilities.

The ACT Government is committed to improving the lives of carers and providing a level of support that will enable them to participate in the wider community. The *Caring for Carers Policy* and the action plan demonstrate the ACT Government's commitment to acknowledge and support ACT carers.