



***Caring in the ACT Community –  
Priority Issues for Carers***

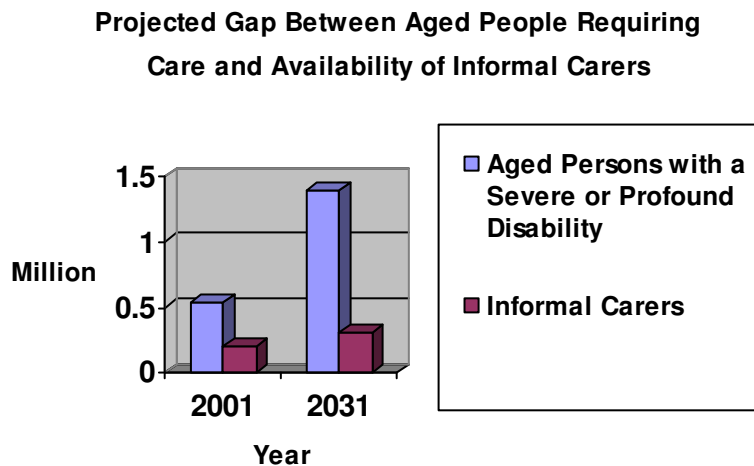
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## ***Meeting the Needs of Australia's Carer Population***

The Rudd Government has recognized that Carers have an essential role in maintaining the health and social welfare system for the benefit of the entire Australian community. It is evident that an urgent review of support to Carers is needed, as the existing model of community-based care is already in crisis from systematic federal neglect over the last decade. Families and service providers throughout Australia are also facing increasing pressures from the changing economy and the impact of the ageing population.

A comprehensive system of support depends upon investment in sustainable programs that meet identified need, improve the training and development of staff, and make an ongoing commitment to providing a better foundation of technology, quality improvement and opportunity for research activities.

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 health system. The number of people available to provide care will greatly reduce in coming decades. With time, current shortfalls in the Carer to care-recipient ratio will widen from a gap to a chasm, as the following chart based on data calculated by NATSEM<sup>1</sup> illustrates:



As greater numbers in the workforce are affected by age-related disability, or called upon to care for family members, it is essential that government, employers and the community sector work together on effective strategies to keep skilled Carers in the workforce, while also supporting and adequately compensating those Carers who undertake full-time caring commitments. Carers must also be provided with appropriate and affordable options for the quality care of their loved ones while they are working or studying.

Research has consistently shown that Carers are already a group more vulnerable to the pressure of external social and economic factors than the majority of non-Carers in

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<sup>1</sup> NATSEM (National Centre for Social and Economic Modelling) (2004) *Who's going to care? Informal care and the ageing population*. Canberra: Carers Australia.

the population<sup>2</sup>. Yet anyone can become a Carer, at any time, as we all have family, friends or neighbours who may need extended care at some time in their lifespan, due to accidents, chronic illness or simply from the increasing frailty of old age.

Carers need support in their own right. Provision of services for people with disabilities and chronic health conditions is an essential need, but it is only half the picture. Ignoring the needs of the Carer is like putting petrol in a car and keeping it clean without paying any attention to maintaining the tyres or engine - sooner or later the vehicle breaks down.

Care needs are not homogenous across the population. Support needs vary with the complexity of issues for the care-recipient, the availability of other forms of informal support, the skills level of the Carer and their individual health factors. Times of transition usually require more support, as does the impact of other 'life events' such as moving house, divorce, death or illness in the extended family.

Regardless of the type of service sought, 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.

### ***Key Issues of Concern for Carers***

The following information is not intended to be a definitive treatise on Carer needs but represents a précis of some critical priorities.

#### **Support for Carers of Children With a Disability**

Caring for a child with a disability is often a 'whole of life commitment'. People with disabilities are living longer as medical technology improves. Coordinated, responsive, long-term support is vital for preventing Carer burnout. Recent research with Carers in the ACT has identified several areas of unmet need, consistent with other evidence collected on a national basis:

##### **1. Need for appropriate respite care**

- Emergency and short term care is insufficient for prevention of Carer burn-out and the national program tends to support Carers aged 65 and over. Existing regular respite programs (where available in Australia) are failing to meet current need due to underfunding, inflexible funding criteria, and an inability to recruit sufficient support workers. Many 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.

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<sup>2</sup> Cummins, R., et al (2007) *The wellbeing of Australians – Carer health and wellbeing*. Melbourne: Australian Centre on Quality of Life, Deakin University.

- 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. 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.
- Sibling care is often needed alongside special needs care. Some parents have discovered that existing respite criteria prohibits care of siblings alongside a child with special needs, even when it is the family preference for siblings to stay together. For these families, getting a break means paying a private babysitter to come in and work alongside a respite support worker or splitting up siblings to put the special needs child into respite care alone, which can often greatly increase separation distress for all siblings.
- After school and holiday care programs are needed for working parents. Few programs have suitable places for children and young people with special needs. Many existing generic out of school care programs are only for children up to age 12, leaving Carers of high-school aged children with no option but to limit or withdraw from workforce participation to care for their children.

## **2. Post-school support**

- Suitable post-school options are needed for young people with special needs, including opportunities for meaningful training and supported employment.
- Inclusive social programs are urgently required to offer the opportunity to learn and maintain social skills, and build ongoing relationships with peer groups.
- Supports are needed specifically for mid-life Carers to provide advocacy assistance, promote self-care strategies, and assist with stress management, especially during times of transition.
- Barriers to participation identified by families include: no programs or places available, transport problems in getting the care-recipient to programs, and poor understanding of disability in the wider community (which leads to negative experiences due to prejudice and ignorance when in the public domain).

## **3. Supported accommodation**

- Parents who can no longer care for their child, whether due to ill health or old age, often have no real options for alternative care beyond abandoning the child to become a ward of the state. Supported accommodation facilities are limited, overcrowded and often of questionable quality. Accommodation in an aged care facility is patently unsatisfactory for the needs of a young person. 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 to meet the needs of people with disabilities.

- Carers need assistance with placement, transition, and the development of supported accommodation systems which encourage their ongoing involvement in their child's life, even if they cannot continue providing direct care.

## **Support for Carers With Other Complex Needs**

Other emerging groups of Carers also have specific and urgent needs for additional support. For example, someone caring for a person with a chronic illness or condition (such as multiple sclerosis, cancer or early stage dementia) may need diagnosis support or help in accessing a maze of unfamiliar services. Advocacy services are frequently requested, as personal coping resources are limited, especially when the intense emotions experienced while providing care to someone who is terminally ill or who has a degenerative condition.

Early stage dementia is also an area where 'whole of family' support is critical. Rates of diagnosis seem to be increasing, and community understanding of the condition is limited. Imagine the disruption and distress to a family with young children when a mother aged in her early 30s becomes the person needing care. Specialist help is critical for supporting family Carers to enable them to have the maximum potential family time left before the person with dementia is no longer able to comprehend, communicate or even recognize their own family.

## ***Sector Reform***

Reform of the sector funding model is urgently needed to assist service providers to meet surging demand. The following issues are highlighted as needing attention:

- Commonwealth funding formulas to include an operational base enabling service delivery recovery of 'whole of provision' cost, instead of funding based solely on population formulas, which currently disadvantages smaller jurisdictions such as the ACT and Tasmania.
- Commonwealth procurement of community services to focus on evidence-based, local area need, and include an assessment that examines for potential duplication of state-funded services.
- Use of compatible data sets and reporting templates for Commonwealth departments (and also state/territory compatible where possible) to minimize community sector costs in compliance and reporting.
- A clear statement of Commonwealth priorities for investment in services, supported by transparent and accountable procurement processes. Priorities to be reflected in multi-year Service Funding Agreements.
- Improvement in the Commonwealth's timing of allocation for new program funding. Bureaucratic delays result in allocation of new program recurrent

funding to community agencies as late as eleven months into the financial year, with a requirement to fully expend first year's allocation within weeks or days.

- Increased flexibility for new program agreements, as it can take up to two years to fully establish and promote the program to effectively engage with sometimes 'difficult to reach' groups of people in the community, resulting in underspend in years one and two with full expenditure occurring in year three. Requirement for expenditure in equitable proportion to the term of the contract negates capacity to plan, as approval for rollover can take up to nine months in the following year. Accrual accounting practices across a three year framework rather than an annual cash basis model would redress this problem.

### ***Further Information***

Additional information on any of the issues raised in this paper may be obtained by contacting **Dee McGrath**, CEO, Carers ACT on **(02) 6296 9901**.

Relevant submissions which may be of assistance are listed below:

### **Carers ACT Policy Papers and Submissions**

Recent policy papers and submissions are available on the Carers ACT website at <http://www.carersact.asn.au/publications.html>

- The Australian Capital Territory in 2020: A Glimpse of the Future for Carers
- Response to Pricing Principles for Community Services in the ACT: A Discussion Paper (An initiative of the Joint Community Government Reference Group)
- Response to Evaluation of the Adult Disability Assessment Tool (ADAT) and the Child Disability Assessment Tool (CDAT) for the Australian Government Department of Families, Community Services and Indigenous Affairs
- Response to Inquiry into the Early Intervention and Care of Vulnerable Children in the ACT for the Standing Committee on Health and Disability Karin MacDonald (Chair) Legislative Assembly for the Australian Capital Territory

### **Carers Australia Policy Papers and Submissions**

All national papers and research papers relevant to Carer issues may be found on the website of Carers Australia at <http://www.carersaustralia.com>

- Carers' Perspectives on Caring
- 2008-2009 Federal Budget Submission
- Response to Disability Supported Accommodation: A Discussion Paper
- Australian Unity Wellbeing Index 17.1 The Wellbeing of Australians: Carer Health and Wellbeing

Carers Australia is the federal office working on behalf of the National Network of Carers Associations in each State and Territory of Australia.