



Carer Recognition and Support

State Budget Submission 2005 – 2006

Introduction

The Carers Association of SA Inc. was established in 1989 by a 'grass roots' movement of Carers. The Association is recognised as the peak organisation for family Carers in South Australia.

There is an important distinction between paid care workers who attend care recipients in a professional capacity and the Carers, usually family members or close acquaintances, who provide for their care at all other times. The Carers Association acts as a peak body for the latter group. To avoid confusion this document will refer to them as family Carers

In South Australia there are 235,000 family Carers (Australian Welfare 2003), including 46,126 primary Carers, looking after a parent, child, partner or friend. Family Carers come from all cultural and social backgrounds and range greatly in age. Some provide care twenty-four hours a day, every day; others give care for a few hours a week.

Association submissions and responses are developed utilising documented research, previous submissions prepared by the Association, surveys of members, discussions by the Association Policy Subcommittee and Policy working groups, focus groups of Carers and service providers and miscellaneous input from Association members.

Carer Recognition and Support

The Carers Association of SA acknowledges the Government's release during Carers Week 2004 of the SA Carers Report and the announcement of the development of a Carers Charter and Carer Recognition Bill. These are long awaited initiatives.

The Association notes and welcomes the recognition of the situation and needs of South Australian family Carers, in particular the encouragement of government agencies and non government service providers to adopt a more consistent approach to responding to Carer needs, better coordination between service providers, a strategic and planned approach to funding and resource allocation, participation by Carers at all levels of policy development and service planning and greater recognition and support for family Carers by the wider community.

In order to achieve a consistent approach the Association has called for a strategically driven whole of government approach that recognises the across portfolio nature of the caring role and the need for each government agency to develop its own family Carer policies and programs within a central framework.

The Association is concerned that the good work to date may be dissipated if the resources within government currently devoted to the development of Carers policies are not maintained and strengthened through an across portfolio approach.

The Association has called for, and welcomed, the announcement of the Carer Recognition Bill.

Recommendation

That further funds be set aside for the development of operational policies and the implementation of priorities that arise from the principles enunciated in the SA Carers Report, the proposed Carer Recognition Bill and any associated consultation with Carers, their families and service providers.

Recommendation

That there be a continuation of the Carers Ministerial Advisory Council, or similar body.

The Association recognises the importance of developing policy platforms across individual departments for the operational implementation of the SA Carers Report seven core principles. Nevertheless there are a number of areas in which action should be taking place, even while these platforms are being prepared. These include:

1. Community Recognition

Raising community awareness and acceptance of family Carers' role in society will assist in the validation and self identification for Carers themselves.

Recommendation

That a community education program on family Carers, with appropriate resources, be developed.

2. Carer Assessment

Recognition is but a first step. Each family Carer has his or her own needs separate from the care recipient, for the family Carer is not only providing care but struggling to maintain their own capacity and well being. In particular, family Carers often find it hard to voice their own needs when attempting to secure adequate and appropriate care for the care recipient.

The Association is concerned that current policies and practices appear to be that the care recipient has to be in receipt of services prior to any recognition of the needs of the family Carer. The family Carer not only has the right to be assessed but also the right to have the results of the assessment taken into account when services are provided. This will offer a protection to family Carers when services are provided as their needs will also have to be taken into account. It would also provide for a re-assessment when circumstances change, including receiving greater assistance.

Carer assessment, then, is an important component in determining and in developing appropriate services for the family Carer themselves. Such assessment should cover the family Carer's time commitments, financial impact, training needs, respite needs and social, health and emotional impacts.

A model assessment tool, such as developed by the Carers Association, would be a useful resource in the development of a common Carer Assessment tool for use across services.

Recommendation

That an assessment tool for the assessment of family Carers be introduced for use across government and non government services, with associated training resources for services in the use of such an assessment tool.

3. Cost of Living

Family Carers on a limited income struggle to meet the daily costs with the additional burden of the expenses related to the caring role. State Governments can play a valuable role by maintaining and strengthening a regime of concessions and subsidies.

Whilst acknowledging the concessions and subsidies the Government does provide, nevertheless over the years these have developed in an ad hoc fashion, with an inequitable criteria and decreasing face value.

Recommendation

That a review of all South Australian concessions takes place to ensure that assistance is well targeted and that eligibility criteria ensure concessions are targeted to, and can be easily accessed by, those most in need. Issues for family Carers in such a review include:

- *Recognition of the additional burden on family Carers of the energy costs in meeting the needs of care recipients.*
- *Determination of strategies for the equitable inclusion in government assistance schemes of family Carers who need assistance with household*

expenses, such as electricity, gas and water rates; and housing, transport and education services.

- *Recognition of the Carers Allowance as a basis for eligibility for concessions and subsidies for household costs.*
- *Development of a strategic program of education on entitlements to concessions and subsidies.*
- *Provision of an improved fee waiver system for the Home and Community Care Program.*
- *Provision for subsidised incontinence products across all age groups.*

4. Children and Young People as Carers

The Association acknowledges the recognition of the special needs of young Carers in the SA Carers Report and the efforts of the working group that prepared the Children and Young People as Carers Background Paper which informed it.

Young people from South Australia attending the First National Summit on Young Carers, organised by Carers Australia in August 2004, outlined their priority needs as financial support, promotion of children and young people as Carers, whole of family and age appropriate respite, information about available services and support in schools.

Recommendation

That a policy framework for young Carers be prepared, including development of appropriate assessment procedures and the identification of whole of family approaches.

Recommendation

That a special program for young Carers be developed within the Department for Education to assist young Carers in the primary and secondary school years including the introduction of flexible education options including use of technology for distance education and other external options, peer support, mentoring and home tutoring that support the young Carers and their families, and recognition of the skills that are learnt through the caring role.

Recommendation

That a program be established to provide state wide coordination of information and referral that enables the identification of young Carers, including self identification and that provides young Carers with age appropriate information and connects them with the services that can support them in their caring role.

The Association acknowledges the announcement during Carers Week 2004 by the Minister for Families and Communities of special packages of assistance to specific families in which there is a child with a disability and an identified young person in a caring role.

Recommendation

That there be further development of special packages of assistance for families of children and young people in a caring role.

5. Health Care

5a. Caring is a Public Health Issue

The Association acknowledges the progress of the health reform agenda in South Australia. In particular the Association notes the intent of greater consumer participation in the processes of health care in this state.

Participation and partnership are at the core of the family Carers' interface with the health system. This interface occurs in two significant ways.

1. Family Carers continue to be a high risk population group due to the physical, mental and emotional stresses of the caring role.
2. Family Carers are partners in the delivery of health care as they accompany the care recipient to medical appointments and take responsibility for the health care needs of the care recipient at all other times.

Recommendation

That appropriate mechanisms be developed for the participation of family Carers, in conjunction with the Carers Association of SA as peak body, in the health care of those they care for. Such mechanisms would include:

- *Development of strategies, including education campaigns, within the health system on the role of family Carers and the part that they can play in care programs.*
- *Development of guidelines that provide for family Carers having access to necessary information about the health status and treatment of the person cared for.*
- *Development of guidelines for the development of clear service delivery agreements between family Carers, care recipients and service providers.*
- *Development of injury minimisation programs for family Carers including training resources and priority of access to back care treatment within the health system.*
- *More quality, affordable and flexible respite of all kinds including in home, out of home, emergency, long term and residential, with an emphasis on family Carers having access to adequate planned respite through the year.*

5b. Mental Health

The Association remains concerned at the paucity of state resources to community based care of the mentally ill in South Australia. This has grave impacts on family Carers whose needs are still largely unrecognised and ignored by the mental health system and its practitioners.

Recommendation

That a support and development program for family Carers of people with a mental illness be established. Such a program would include:

- *The implementation of the National Mental Health Strategy as it relates to family Carers.*
- *Recognition of the needs of family Carers by the mental health system.*
- *Development of information, training and support for family Carers.*
- *Recognised eligibility for local HACC Community Care programs (respite, home help, personal care, transport).*
- *Greater psychiatric disability support services including housing and provision of medication to lighten the load on family Carers.*

6. Employment and Care

Research indicates that whilst family Carers move in and out of the workforce they are less likely than others in the community to be in the workforce, they are less likely to be in fulltime employment and they need special assistance to return to paid jobs after a period of caring.

Recommendation

That a special workforce assistance program for family Carers be developed including:

- *A scholarship program to enable attendance at secondary and tertiary institutions for family Carers, particularly young Carers, including provision for respite.*
- *The development and utilisation of Public Service Employment and Care policies and practice as a model for the business and community sectors, accompanied by training resources to assist them.*

7. Transport

The provision of low cost accessible transport options has a vital role to play in the accessing of services and reduced social isolation for care recipient and Carer alike, particularly in the case of young Carers. It provides significant relief to the family Carer who otherwise would be responsible for providing the transport needs for the care recipient.

The Association acknowledges the work of the former Public Transport Board, now the Office of Public Transport, in pursuing public transport options, particularly in rural areas. The Association believes that there is scope for greater promotion of routes and times of wheelchair accessible buses, as well as further consideration of

ways of supporting alternative transport options in areas where, or at times when, accessible transport is not available.

The Association acknowledges that some consideration has been given to changes to the South Australian Transport Subsidy Scheme.

Recommendation

That there be greater flexibility in the use of the South Australian Transport Subsidy Scheme, particularly in rural areas, including the widening of the eligibility criteria using a definition based on the DDA; the allocation of vouchers based on need rather than quotas and the development of secure anti-fraud measures to enable greater flexibility.

8. Advocacy

The Association welcomes the passing of the Health and Community Services Complaints Bill. However, the Association remains concerned that there will continue to be limited resources to adequately support the advocacy needs of family Carers, currently not being met through existing aged and disability advocacy services.

Recommendation

That a state wide advocate for family Carers be appointed, either independent to, or placed within, the office of the Health and Community Services Commissioner.

This would serve to underpin the proposed changes to the Equal Opportunity Act that seek to include family Carers within the anti-discriminatory ambit and that seek to provide for adequate and appropriate resourcing of complainants.

9. Education in the Caring Role

Whilst there is some education and training for family Carers in the skills necessary for undertaking the caring role this remains ad hoc and uncoordinated and very limited in scope. Issues include the family Carer's role, disabilities and illnesses, personal care, negotiation and advocacy and the health and community services system where it provides support to family Carers and the care recipients.

Recommendation

That a state wide framework be developed, with associated resources, for the training of Carers through innovative training strategies, for example family Carer training within the home to be included as part of care packages.

Development of training at state level needs to be linked with a nationally recognised curriculum, including accreditation for other study.