

Carer Recognition and Support
State Budget Submission 2006 – 2007
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1. **Introduction**

Carers SA (The Carers Association of SA Inc.) was established in 1989 by a 'grass roots' movement of Carers. Carers SA 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 Carers, usually family members or close acquaintances, who provide for their care at all other times. Carers SA acts as a peak body for the latter group. To avoid confusion this document will refer to them as family Carers

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

2. **Who are family Carers and what are their needs?**

A family Carer is someone who provides care and support for their parent, partner, child or friend who has a disability, is frail aged or who has a chronic mental or physical illness.

Family Carers make many sacrifices to care for a person in need. They come from all cultural and social backgrounds and age groups. Some care for love alone; others provide care from a sense of obligation. Some provide care twenty four hours a day, every day; others a few hours a week.

Regardless of the situation or disability of the person for whom they care, family Carers have many needs in common. These include the need for information; for recognition, in particular as individuals in their own right and as co-providers of care; for physical and emotional support, for respite, for training in the caring role and for financial assistance.

In 2005 over 1 in 8 South Australians (227,700) were estimated to be providing informal care. 41,290 or 18% of this number were in a primary caring role, that is, with major responsibility for another person's well being. (ABS)

As our population ages the need for care in the community will grow. Based on current rates of disability and need for assistance the number of people over 65 needing care is projected to increase by 160% by 2031 but the number of family Carers is expected to rise by only 57% (Carers Australia 2005). Significantly, family Carers themselves will be ageing. Between 2001 and 2031 family Carers aged less than 65 years will grow by 19% while those aged 65 years and over will grow by 110%.

In the push to reduce the costs of services the needs of family Carers cannot be overlooked. South Australian family Carers provide an estimated 5.6 million hours of caring every year. The cost of replacing this 'informal' care with 'formal' paid care is estimated at \$2.66 billion pa (Access Economics 2005). If family Carers did not make this contribution the cost would have to be met by governments.

The huge cost to family Carers of caring cannot be quantified. It includes, for example:

- Many family Carers are harmed physically, mentally, emotionally and socially by their caring responsibilities; attributed to the stress of caring, social isolation, loneliness, changing relationships and loss and grief (Carers Australia 2001).
- Primary Carers' median personal gross income per week in 2003 was \$237 compared with \$407 for non Carers (Carers Australia 2005).
- Loss of earnings by South Australian family Carers not in the paid workforce is estimated at \$424 million (Access Economics 2005).
- Single parent Carers of children with disabilities is one of the most vulnerable groups in our society. Most simply struggle. Their household income is 46% of the Australian average. Nearly 15% of household income is spent on medical costs (Carers Australia, unpublished 2005).
- The average annual electricity bill for family Carers is 14.5% more than the state average (Carers Association of SA 2003).
- Young Carers forego education and employment opportunities to care for family members (Noble-Carr 2001).

Family Carers are filling the growing 'care gap' but should not be taken for granted. Because they play such a vital role in maintaining the fabric of society their health and well being is critical to the community. They need assistance to enable them to sustain their caring responsibilities, maintain their health and wellbeing and participate in family, social and community life, employment and education. They need to be able to exercise choice about their caring responsibilities.

Carers SA acknowledges the government's awareness through Principle 3 of the Carers Charter: 'Carers play a critical role in maintaining the fabric of society.'

The importance of developing a long term approach has once again been highlighted through the AMP/NATSEM report *Who cares? The cost of caring in Australia today 2002 to 2005* which raised two important issues; that care for the elderly is set to join childcare as a major issue in our community and that as our population ages there will not be enough tax paying workers and not enough family Carers.

3. Summary of Recommendations

Recognition and Support for Carers

1. That there be an adequate, appropriate and ongoing provision of funds across government for the elements of the implementation strategy of the Carer Recognition Act and Carers Charter and any associated consultation with family Carers, their families and service providers.
2. That departmental mechanisms be developed to ensure the implementation of the Carers Recognition Act and Carers Charter.

Community Recognition

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

Carer Assessment

4. That a common Carer Assessment Tool for the assessment of family Carers be developed for use across government and non government services.
5. That training resources in the use of a Carer Assessment Tool be developed and provided.
6. That this assessment tool be introduced to HACC services in the first instance.

Family Caring: The Cost of Caring and Poverty

7. That a review of all South Australian Government concessions, subsidies and rebates 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 and transport costs.
 - Development of a strategic program of education on entitlements to concessions and subsidies.
 - Provision for subsidised incontinence products across all age groups.
8. That a Carers Card be introduced for all family Carers in receipt of the Carers Allowance which would entitle them to a range of concessions and discounts.
9. That strategies be developed and implemented to ensure that fees are not a barrier to seeking support through home and community care programs.
10. That a community education program be implemented to raise the awareness of family Carers and others about the existing fee waiver system for home and community care services.

Children and Young People as Carers

11. That a program be established to provide state wide coordination of information and referral that enables the identification of young Carers, including self identification, which provides young Carers with age appropriate information and connects them with the services that can support them in their caring role.
12. That a policy/program framework is developed as a matter of urgency to ensure ongoing packages of support are available to families of children and young people in a caring role that allow young Carers to develop and fulfil their potential.
13. That a whole of Government (in particular portfolios involving education and training, further education, children's services, families and communities, health and employment) policy framework for young Carers be prepared, including development of appropriate assessment procedures and the identification of whole of family approaches.

14. That a young Carers in schools program be developed and resourced to assist young Carers in the primary and secondary school years, including the introduction of flexible education options such as the use of technology for distance education and other external options; peer support and mentoring; home tutoring, and prior learning recognition of the skills that are learnt through the caring role.

Health Care

Caring is a Public Health Issue

15. That an education campaign be developed within the health system about family Carers as an at risk population group.
16. That education campaigns be developed within the health system and the community about the importance of good nutrition and health for family Carers.
17. That provision be made for adequate quality, affordable and flexible respite of all kinds including in home, out of home, emergency, long term and residential.
18. That appropriate mechanisms be developed for the participation of family Carers, in conjunction with Carers 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 strategies to routinely involve family Carers in care planning, case conferencing and discharge planning in the hospital, general practice and community care settings.
 - 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.

Mental Health

19. That the Mental Health Act be amended to recognise the role of family Carers.
20. 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, as stated in the Mental Health Legislation Review.
 - Development of information, training and support for family Carers.
 - Recognised eligibility for local HACC Community Care programs (respite, home help, personal care, transport).

Employment and Care

21. 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.
 - The development and promotion of family Carer friendly workplace information and training resources that encourage the business and community sectors to develop flexible workplace policies and practices to support family Carers who are combining paid employment with their caring role.
 - The availability to family Carers of affordable quality services and day options that operate at times that fit with paid employment.
22. That amendments to Equal Opportunity legislation outlawing discrimination against family Carers in the workplace be enacted.

Transport

23. That there be greater flexibility in the use of the South Australian Transport Subsidy Scheme, particularly in rural areas, including the allocation of vouchers based on need rather than quotas and the development of secure anti-fraud measures to enable greater flexibility.
24. That measures are taken to further improve the delivery of the Access Cab service in South Australia.

Advocacy

25. That a state wide advocate for family Carers be appointed, either independent to, or placed within, the office of the Health and Community Services Complaints Commissioner.
26. That the government move to have the Equal Opportunity Act amended to include family Carers within the anti-discriminatory ambit.

Education in the Caring Role

Education for Carers

27. That a state wide framework be developed, with associated resources, for the training of family Carers in the skills required to undertake the caring role.

Education for Service Providers

28. That resources be provided for the development of a state wide education and training program for service providers in meeting the needs of family Carers.
29. That resources be provided to enable South Australia's participation in the development and delivery of nationally accredited family Carer education courses and competencies.

4. Recognition and Support for Carers

Carers SA acknowledges the Government's commitment to family Carers as evidenced by the passing of the Carers Recognition Act and Carers Charter; the provisions in the State Budget 2005/2006 for Mental Health funding for family Carers; the release of additional funding provided to the Association in May 2005 to go towards the Carer Retreats Program, 12 education forums for older family Carers of people with a disability and a Carers Week conference and the release of \$6.02 million in February 2005 to provide respite for parents who care for their adult children with disabilities.

Carers SA welcomes the government's 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 the needs of family Carers; 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 Carers SA 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.

Carers SA welcomes the development of an implementation strategy to further the requirements of the Carers Recognition Act and Carers Charter, and the election commitment¹ to put in place such strategies.

Carers SA is concerned that the good work to date may be dissipated if the resources within government currently devoted to the development of family Carer policies and legislation are not maintained and strengthened through an across portfolio approach. Whilst Families and Communities has taken the role of lead agency in the development of family Carer policies, the Association believes that this is a whole of government issue and that an across government approach, as signalled in the Carer Recognition Act 2005, is vital.

Recommendation 1

That there be an adequate, appropriate and ongoing provision of funds across government for the elements of the implementation strategy of the Carer Recognition Act and Carers Charter and any associated consultation with family Carers, their families and service providers.

Recommendation 2

That departmental mechanisms be developed to ensure the implementation of the Carers Recognition Act and Carers Charter.

In seeking appropriate resources for an implementation plan, we believe the focus should go far beyond any initial exercise in bringing the requirements of the Act to the attention of government and non government agencies and the wider

¹ as evidenced through the Government's responses to Carers SA's State Election March 2006 Candidates Questionnaire.

community. Whilst important in bringing these groups into an understanding of the legislative requirements, and in encouraging them to develop appropriate support services, substantial ongoing commitment is required to further the aims of the Carer Recognition Act and Carers Charter.

Whilst recognising the importance of developing policy platforms across individual departments for the operational implementation of the Carers Charter's seven core principles Carers SA believes that there are a number of areas in which action should be taking place, even while these platforms are being prepared. These are:

4.1. Community Recognition

Carers SA acknowledges the government's awareness through Principle 1 of the Carers Charter: 'Carers have choices within their caring role,' and Principle 3 of the Charter: 'Carers play a critical role in maintaining the fabric of society.'

Whilst a valuable welcome development in the recognition of family Carers in South Australia the passing of the Carer Recognition Act, of itself, will not significantly raise community awareness without the provision of adequate funds for an effective community education campaign.

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

Recommendation 3

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

4.2. 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.

Carers SA is concerned that current policies and practices for service access 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 independently of the care recipient but also has the right to have the results of that assessment taken into account when services are provided. This will offer a protection to family Carers as their needs will also have to be taken into account at that time. 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 Carers 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 Carer Assessment Tool, such as developed by Carers SA, would be a useful base in the development of a common Carer Assessment Tool for use across services, either in association with, or as part of, the assessment for care recipients.

Recommendation 4

That a common Carer Assessment Tool for the assessment of family Carers be developed for use across government and non government services.

Recommendation 5

That training resources in the use of a Carer Assessment Tool be developed and provided.

Recommendation 6

That this assessment tool be introduced to HACC services in the first instance.

It is important to note that associated services, such as outlined in this submission, need to be available following the assessment process.

4.3. Family Caring: The Cost of Caring and Poverty

Family Carers on a limited income struggle to meet the daily costs associated 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.

Many family Carers in South Australia are living in poverty. 37% of family Carers in South Australia rely solely on a Government pension for their income. The AMP NATSEM report, *Who cares? The cost of caring in Australia today 2002 to 2005* reported that the annual 'opportunity cost' to family Carers when compared to people with no caring responsibilities was an estimated \$9,300 for a primary Carer and \$2,600 for other family Carers. Carers in the labour force and paying for care spent an average \$162 per week (\$8,400 a year) on elder care and \$118 a week (\$6,100a year) on care for people with disabilities. One third of people who provided primary care for the elderly or people with disabilities lived in the in the poorest fifth of households in Australia.

Carers SA acknowledged the introduction of the Plus One Companion Card allowing family Carers to travel free with the care recipient on public transport. The Association also welcomed the widening of the eligibility criteria for the South Australian Transport Subsidy Scheme and the one off rebate of \$150 towards energy costs in the State Budget 2005/2006.

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

Carers SA encourages the development and introduction of a companion type card or Carers Card for all family Carers receiving the Carers Allowance, which would entitle family Carers to a range of discounts and concessions to assist with the cost of caring, in particular that would be tied to the subsidies and concessions received by Pensioners. An example is the Northern Territory Pensioner and Carer Concession Scheme, introduced on July 1st 2006, which provides for a range of services including electricity/alternate energy, local council property rates, water rates, sewerage rates,

garbage charges, motor vehicle registration, drivers licence, spectacles and public transport.

The Carers Allowance is used as a benchmark in this instance as recognition of the extra costs and burden on family Carers undertaking the highest levels of care.

Recommendation 7

That a review of all South Australian Government concessions, subsidies and rebates 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 and transport costs.
- Development of a strategic program of education on entitlements to concessions and subsidies.
- Provision for subsidised incontinence products across all age groups.

Carers SA acknowledges the Government's ongoing commitment in the provision of incontinence products' subsidies². Nevertheless concerns remain at age cut off points for such subsidies.

Recommendation 8

That a Carers Card be introduced for all family Carers in receipt of the Carers Allowance which would entitle them to a range of concessions and discounts.

Carers SA continues to receive feedback from its members of their ongoing concern that the need to pay fees for home and community care services impacts on their ability to spend on essentials. This becomes a barrier to accessing services.

Recommendation 9

That strategies be developed and implemented to ensure that fees are not a barrier to seeking support through home and community care programs.

Recommendation 10

That a community education program be implemented to raise the awareness of family Carers and others about the existing fee waiver system for home and community care services.

² as evidenced in response to Carers SA's State Election March 2006 Candidates Survey

4.4. Children and Young People as Carers

Carers SA recognises a young Carer as someone under the age of 25 years who provides significant care and support to a family member within the home who is suffering from chronic physical or mental illness, disability, or who is frail aged, where this care would normally have been provided by an adult in the family.

Carers SA acknowledges the government's recognition of the special needs of young Carers through the Minister for Families and Communities' contribution to a specific number of families in October 2004 and through Principle 6 of the Carers Charter: 'All children and young people have the right to enjoy life and reach their potential'.

Like other family Carers, young Carers take on the role of caring because of natural family responsibilities, but beyond what could normally be expected. It is recognised that young people need to be supported in, or released from, the caring role. Young Carers development as individuals, in education and resilience, and their maintenance of their health and well being is only possible if services are delivered to the whole family.

Carers SA believes that children have the right to participate in education, enabling them to reach their full potential, as well as the right to rest and to be involved in recreation and play. Young Carers, in particular, have the right to have their needs acknowledged, to have access to information on medical conditions and support services available to them, to be provided with practical assistance to maintain their caring role and to a safe and protective environment.

Carers SA acknowledges the United Nations Convention on the Rights of the Child, which emphasises the importance of involving children and young people in decisions affecting their lives.

Young Carers from South Australia have 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.

Carers SA is working together with staff of the Department of Education and Children's Services to provide information to school counsellors and other school professionals about identifying and supporting young Carers within the education system.

Carers SA welcomes the election commitments³ to target improved supports and services for families in which children have taken on a role as a primary Carer, particularly in those families where a parent has a mental illness, disability or addiction and to put into place means to support young Carers as part of the implementation strategies of the Carer Recognition Act.

³ as evidenced by the Labor Platform October 2005 and responses to the Carers SA State Election March 2006 Candidates Questionnaire

Such measures should include:

Recommendation 11

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

Recommendation 12

That a policy/program framework is developed as a matter of urgency to ensure ongoing packages of support are available to families of children and young people in a caring role that allow young Carers to develop and fulfil their potential.

Recommendation 13

That a whole of Government (in particular portfolios involving education and training, further education, children's services, families and communities, health and employment) policy framework for young Carers be prepared, including development of appropriate assessment procedures and the identification of whole of family approaches.

Recommendation 14

That a young Carers in schools program be developed and resourced to assist young Carers in the primary and secondary school years, including the introduction of flexible education options such as the use of technology for distance education and other external options; peer support and mentoring; home tutoring, and prior learning recognition of the skills that are learnt through the caring role.

4.5. Health Care

4.5.1. Caring is a Public Health Issue

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

Carers SA supports a robust and adequately resourced public health system but recognises that family Carers undertake a range of caring roles that are complimentary to the care received through the public health system and without which society's caring responsibilities would not be fulfilled.

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. Two studies are indicative of the trends in research findings:
 - The Australian Longitudinal Study on Women's Health found that moving into the care giving role is associated with increased GP visits, increased use of medication mainly for nerves, depression, sleeplessness and the experience of stress and increased Body Mass Index.

- The Carers Australia 1999 national survey of family Carer health and well being found that only 10% of respondents rated their health as excellent; 46% said it was only fair and getting worse and up to 30% had delayed seeking help for their own health conditions because of their caring role.

Carers SA acknowledges the government's concern through Principle 2 of the Carers Charter: 'Carers health and well being is critical to the community.'

Carers SA welcomes the election commitments of the government⁴ to use the framework of the Carer Recognition Act to continue to acknowledge the particular health requirements of family Carers and the need to ensure Carers have access to a wide range of affordable, accessible and appropriate respite services including home based respite.

Recommendation 15

That an education campaign be developed within the health system about family Carers as an at risk population group.

Recommendation 16

That education campaigns be developed within the health system and the community about the importance of good nutrition and health for family Carers.

Recommendation 17

That provision be made for adequate quality, affordable and flexible respite of all kinds including in home, out of home, emergency, long term and residential.

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.

Carers SA welcomes the election commitments of the government⁵, to continue to recognise the important role of family Carers; to ensure the recognition by health professionals of family Carers as stakeholders who should be involved in the planning of home based care or discharge from hospital, health or residential facilities of their friend or relative; and for other health service providers to consult with family Carers or their representatives when developing policy, planning and programs which impact on family Carers and the people they care for.

Recommendation 18

That appropriate mechanisms be developed for the participation of family Carers, in conjunction with Carers 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.

⁴ as evidenced in the ALP Platform State of Confidence and in its responses to Carers SA's State Election March 2006 Candidates Questionnaire

⁵ as evidenced in the ALP Platform State of Confidence and in its responses to Carers SA's State Election March 2006 Candidates Questionnaire

- Development of strategies to routinely involve family Carers in care planning, case conferencing and discharge planning in the hospital, general practice and community care settings.
- 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.

4.5.2. Mental Health

Carers SA acknowledged the announcement of funding for Mental Health Services in South Australia in the State Budget 2005/2006 including the one off budget commitment of \$25 million across the mental health sector, including additional monies for respite.

Carers SA remains concerned at the paucity of recurrent state resources for community based care of the mentally ill in South Australia. This has grave impacts on family Carers. Improved recurrent services for people with mental illnesses would serve to lighten to load on family Carers.

Unmet need requires the one-off \$25 million to be converted to recurrent expenditure, with a long term plan to increase this amount to an annual commitment of \$50 million, as proposed by the Mental Health Coalition.

Family Carers of people with a mental illness and their needs continue to be largely unrecognised and ignored by the mental health system and its practitioners. The Mental Health Act needs to be amended in keeping with 2006 state election commitments.⁶

Carers SA welcomes the election commitments⁷ to ensure that the Carers Recognition Act and Carers Charter are implemented in public mental health services and to introduce reform amendments to mental health legislation that recognises the important role that family Carers play and to better recognise their needs and rights.

The National Women's Health Study indicated high levels of anxiety and depression amongst family Carers as a result of their caring for people with a mental illness.

Due to continuing concerns with supported residential facilities, supported accommodation and boarding houses, family Carers continue to provide care at home as an alternative, rather than see the care recipient live in such places.

The greatest challenge facing family Carers of people with a mental illness is that mental health services are not family Carer sensitive and do not achieve the

⁶ as evidenced by responses to the Carers SA State Election March 2006 Candidates Questionnaire

⁷ as evidenced by responses to the Carers SA State Election March 2006 Candidates Questionnaire

objectives of family Carer engagement embodied in the National Mental Health Standards.

As a consequence of family Carers' disengagement in mental health service delivery decision making, the pressures on family Carers are enormously exacerbated as are the demands placed on the infrastructure and resources of the service networks which support family Carers (Networks for Carers of People with a Mental Illness Project 2003).

Recommendation 19

That the Mental Health Act be amended to recognise the role of family Carers.

Recommendation 20

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, as stated in the Mental Health Legislation Review.
- Development of information, training and support for family Carers.
- Recognised eligibility for local HACC Community Care programs (respite, home help, personal care, transport).

4.6. Employment and Care

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.

The 2003 Australian Bureau of Statistics Survey of Disability, Ageing and Carers indicated that in South Australia only 53% of all family Carers aged 15 and over were employed, with 34% employed fulltime. Only 46% of primary Carers were employed fulltime.

The TOCC February 2005 Creating Choice: Employment and the Cost of Care report indicated that 26% of people providing elder care and 29% of people providing disability care had reduced their working hours due to the cost of care, whilst 40% of people providing elder care and 33% of people providing disability care were likely to consider leaving the workforce due to the cost of care.

Young Carers in particular find it difficult, due to missed education opportunities and lack of time, to pursue part time work and gain permanent employment.

Many family Carers who are not in the workforce would prefer to be if affordable, alternative care was available. The limited services and day options available mostly offer limited hours that do not match the hours of people in paid employment.

The government has a responsibility to provide leadership by ensuring that its own practices are family Carer friendly.

Carers SA acknowledges the assistance that current workforce re-entry programs provide. These programs, however, are limited in scope and eligibility. Family Carers need a special workforce program that complements existing programs.

Carers SA acknowledges the ALP election platform's support for the right of family Carers to continue to work if they choose through more flexible in house, day care respite.

Recommendation 21

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.
- The development and promotion of family Carer friendly workplace information and training resources that encourage the business and community sectors to develop flexible workplace policies and practices to support family Carers who are combining paid employment with their caring role.
- The availability to family Carers of affordable quality services and day options that operate at times that fit with paid employment.

Carers SA is concerned that Carers will continue to experience difficulties in the workplace in juggling their work and family commitments, particularly in light of recent changes to national industrial relations regimes.

Carers SA welcomes the election commitment of the government⁸ to amend the Equal opportunity Act to better recognise the needs and rights of family Carers.

Recommendation 22

That amendments to Equal Opportunity legislation outlawing discrimination against family Carers in the workplace be enacted.

4.7. 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 recipients and family Carers 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.

Carers SA acknowledges the work of the Office of Public Transport in pursuing public transport options, particularly in rural areas, and in the rolling out of accessible buses. The Association believes that there is scope for greater promotion of routes and times of accessible buses given the current random nature of the availability of accessible buses on routes and timetables.

⁸ as evidenced by responses to the Carers SA State Election March 2006 Candidates Questionnaire

Carers SA also believes that further consideration of ways of supporting alternative transport options in areas where, or at times when, accessible transport is not available is required. Access Cabs in South Australia continue to receive comment about unsatisfactory delays and the lack of availability when required.

Carers SA acknowledges the changes to the South Australian Transport Subsidy Scheme and welcomes the widening of the eligibility criteria for the scheme, particularly as it relates to functionality. The introduction of the Plus One Companion Card was also welcomed by the Association as a measure of the recognition of the cost of caring.

Carers SA also welcomed the government's state election 2006 commitment to spend an extra \$5m over the next four years on the South Australian Transport Subsidy Scheme to increase to 80 from 60 the number of vouchers people would receive over six months and to increase the maximum level of subsidy to \$40 from \$30; and to consider flexibility for regional South Australians using the SATSS, for example allowing them to use multiple vouchers for a single trip.

Recommendation 23

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

Recommendation 24

That measures are taken to further improve the delivery of the Access Cab service in South Australia.

4.8. Advocacy

Carers SA welcomes the election commitment of the government⁹ to ensure that family Carers have access to support and advocacy in their role as a family Carer.

Carers SA welcomed the appointment of the Health and Community Services Complaints Commissioner and the establishment of her office. However, the Association remains concerned that the limited resources of the H&CSC Commissioner, coupled with those of existing aged and disability advocacy services, will be insufficient to adequately support the advocacy needs of family Carers. This is a situation that requires monitoring, with a view to providing additional resources for a state wide advocate for family Carers that is independent to, or placed within, the office of the Health and Community Services Complaints Commissioner.

Recommendation 25

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

⁹ as evidenced by the ALP Platform

Carers SA is disappointed that efforts to amend the Equal Opportunity Act to include family Carers within the anti-discriminatory ambit and that seek to provide for adequate and appropriate resourcing of complainants have languished.

Carers SA is encouraged by the election commitment of the government¹⁰ to amend the Equal Opportunity Act to better recognise the needs and rights of family Carers.

Recommendation 26

That the government move to have the Equal Opportunity Act amended to include family Carers within the anti-discriminatory ambit.

4.9. Education in the Caring Role

4.9.1. Education for Carers

It is well acknowledged that the bulk of care is provided as unpaid care by family Carers in the care recipient's home. The changing mode of community and health delivery relies heavily on the expectation that family Carers will continue to be available when needed and that they will be able to maintain their caring role including coping with the increasing pressures of supporting people with high support needs who have been discharged into community settings.

Yet family Carers take on the caring role with little or no training. The training in the skills necessary for undertaking the caring role that is available across South Australia is largely informal, remains ad hoc, uncoordinated and is very limited in scope.

Once again, a whole of government approach is required, since training is required across a range of issue such as the family Carer's role, disabilities and illnesses, manual handling, family Carer health and well being, personal care, negotiation and advocacy and the health and community services system where it provides support to family Carers and the care recipients. Innovative training strategies could include for example family Carer training within the home as part of care packages.

Recommendation 27

That a state wide framework be developed, with associated resources, for the training of family Carers in the skills required to undertake the caring role.

4.9.2. Education for Service Providers

As stated, there is a real risk to community care and health sectors if family Carers are not able to provide or sustain the level of support and care needed. Without the recognition and support from within the community care and health industries, through appropriate industry training, many family Carers are at risk of relinquishing the care they currently or might expect to provide in the future. This in turn will place even more pressure on existing services.

In addition, there is limited training for service providers about family Carers and the provision of support services that would meet their needs. A comprehensive education and training program for service providers on family Carers and the caring

¹⁰ as evidenced in its response to the Carers SA State Election March 2006 Candidates Questionnaire

role is required if services are to have the capacity to respond to developments arising from the state government's Carers Recognition Act and Carers Charter.

Carers SA acknowledges government awareness through Principle 4 of the Carers Charter: 'Service providers work in partnership with Carers.'

At a national level training modules have been developed, particularly through Carers Australia, for and about family Carers and in family Carer competencies. Carers Australia is seeking the inclusion of family Carer specific competencies in Community Services and Health training packages.

Family Carers play a vital role in the community services and health industry, yet in the majority of circumstances their knowledge, skills, experience and expertise in provision of care is not recognised or utilised by the community services and health industries.

Family Carer specific competencies address the knowledge and skills necessary for working with family Carers across all chronic illnesses, conditions and disabilities. They address the major issues that have been identified for family Carers, including family Carer health and well being, lack of family Carer inclusion by service providers in the care relationship, lack of information, service quality and coordination issues.

The inclusion of family Carer specific competencies in education and training for service providers would ensure that the knowledge, the contribution and the role of family Carers as integral members of caring teams is recognised, utilised and planned for.

The inclusion of family Carer specific competencies in their education and training will assist service providers to improve the effectiveness, efficiency, quality and sustainability of their services by planning for, developing and including family Carer inclusive work practices within service delivery.

Recommendation 28

That resources be provided for the development of a state wide education and training program for service providers in meeting the needs of family Carers.

Recommendation 29

That resources be provided to enable South Australia's participation in the development and delivery of nationally accredited family Carer education courses and competencies.

4.10. Comprehensive Quality Services

Carers SA acknowledges current government commitments to services, in particular in the provision of respite.

Carers SA acknowledges the government's awareness through Principle 7 of the Carers Charter: 'Resources are available to provide timely, appropriate and adequate assistance to Carers.'

Carers SA welcomes the government's acknowledgement, through the ALP Election Platform, that family Carers cope best with their roles when appropriate and accessible supports and services are in place for those in their care.

Carers SA also welcomes the government's election commitments¹¹ to ensure that the implementation strategy of the Carers Recognition Act includes service providers taking into account the views, needs and best interests of people receiving care when decisions are made that impact on family Carers and the role of family Carers; and to continue to work with the non government sector on a Workforce Development Strategy to address issues in the training, recruitment and retention of staff.

Family Carers and the people they care for require:

- Clear information and guidelines available about services.
- Resources to provide timely, appropriate and adequate assistance to family Carers.
- Access to timely, affordable and quality equipment.
- Adequate, qualified and credentialed staff in the community care sector.
- Clear service delivery agreements between Carers, care recipients and service providers.
- More quality, affordable and flexible respite of all kinds for all family Carers including in home, out of home, emergency, long term and residential.

4.11. Special Needs Groups

In the preceding sections we have acknowledged support being provided; welcomed commitments; and outlined priority measures which we consider need to be appropriately resourced even whilst government agencies are developing individual family Carer policy platforms for the implementation of the Carer Recognition Act and Carers Charter.

Whilst these measures are for Carers across disability, chronic illness and aged care, there are specific special needs groups for whom special consideration needs to be given within any measures developed. These groups include young Carers (see above), Aboriginal and Torres Strait Islanders, family Carers from Culturally and Linguistically Diverse communities, sole parent Carers, ageing Carers and those living in rural and remote regions of the state.

Carers SA welcomes the election commitments¹² to include such groups in the implementation strategies of the Carer Recognition Act and looks forward to such measures being outlined.

¹¹ as evidenced in its responses to the Carers SA State Election March 2006 Candidates Questionnaire

¹² as evidenced in the government's responses to the Carers SA State Election March 2006 Candidates Questionnaire, and in the ALP Platform

5. References

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- Australia's Welfare 2001 Australian Institute of Health and Welfare Canberra 2001
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