

Carer Opportunity and Choice

Budget Challenges

State Budget 2010 – 2011 Submission



PO Box 410 Unley SA 5061: Telephone 8291 5600: Fax 8271 6388:
Email info@Carers-sa.asn.au: Website: www.Carers-sa.asn.au

Carers SA

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 and the use of the term 'Carers' in this document refers to them.

Carers SA (The Carers Association of SA Inc.) was established in 1989 by a 'grass roots' movement of Carers to represent the interests of all Carers in South Australia. Carers SA is a non-profit, incorporated, community-based organisation with a membership in the thousands, most of whom are individual Carers. Carers SA is a member of Carers Australia, as are Carers Associations in all states and territories (the National Network of Carers Associations).

Carers SA has a key role in leading change and empowering Carers to participate in a partnership with government and the health and community sectors for the provision of better services, to improve the conditions under which Carers work and to increase the recognition of the contribution of Carers to the South Australian community.

Carers SA submissions and responses are developed through documented research, surveys and other input of members, discussions by Carers SA policy working groups and focus groups of Carers and service providers.

For enquiries about this submission

Rosemary Warmington, CEO

Prepared by

Phil Saunders, Policy Project Officer, Carers SA

Date

December 2009

Contacting Carers SA

58 King William Road Goodwood SA 5034

PO Box 410 Unley SA 5061

Telephone 08 8291 5600

Fax 08 8271 6388

Email info@Carers-sa.asn.au

Website www.Carers-sa.asn.au

Contents

1	Executive Summary	4
2	The Budget Challenge	7
3	Strategic Recognition and Awareness.....	7
3.1	Carers.....	7
3.2	Social Inclusion	8
4	Partners in Care	9
4.1	Carer Partnership and Participation	9
4.2	Carer Partnership in Health.....	9
5	Caring for Carers.....	10
5.1	Assessment	10
5.2	Health and Wellbeing.....	10
5.3	Respite.....	11
5.4	Financial Resilience	12
6	Regional Carer Support.....	13
7	Special Needs Groups	15
7.1	Aboriginal Carers	15
7.2	Culturally and Linguistically Diverse Carers.....	15
7.3	Families of Children with Disabilities	16
7.4	Young Carers.....	16
7.5	Ageing Carers of Adult Children.....	17
7.6	Working Carers	18
7.7	Carers of People with Mental Illness	19
8	Comprehensive Quality Services	19
9	References.....	21

1 Executive Summary

Strategic Recognition and Awareness

Carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail. 1 in 8 South Australians are Carers. About one quarter of the population are affected by government decisions and policies that impact on Carers. Carers are entitled to services in their own right, even though their needs are inextricably linked with those of the care recipients.

Carers are entitled to the same rights, choices and opportunities as other South Australians. Carers require particular measures to be part of this social inclusion vision: flexible and responsive assistance to meet their diverse needs to sustain their caring responsibilities, maintain health and participate in community life.

The Budget Challenge

Carers SA acknowledges the ongoing and increasing support for the work with Carers. This is occurring within a context of increased community recognition and Carer self awareness and the continuing expectation that the majority of care will be met by Carers.

Carers require support through a strategic whole of government approach to positively affect their lives on a day-to-day basis: a significant resource boost into Carer support and the care system.

Partners in Care

Carer Partnership and Participation

Carers are partners in care in community services and health but their knowledge and skills are not well recognised or used. Service providers need to build genuine partnerships with Carers.

A comprehensive program for service providers to address the knowledge and skills necessary for working with Carers is required.

Recommendation 1

Development of a Carer participation and partnership project to facilitate consistency across service provision for Carers, including a Carer participation and partnership template, consultancy assistance in the development of Carer policies by service providers, Carer education and training for service providers and Carer education in managing service system interaction.

Carer Partnership in Health

Carer roles include as health service users, Carer representatives in the consumer participation framework, advocates for the consumer, and partners in the delivery of care. It is critical that these roles are identified and addressed through policy and practice.

Recommendation 2

Development of a strategic Carer participation project for system change across the health sector to enable a true partnership between the health sector and Carers, including development of appropriate Carer participation mechanisms, an education campaign on the role of Carers, guidelines that provide for Carers having access to the health status and treatment information about the care recipient.

Caring for Carers

Assessment

Carers have the right to be assessed in their own right including their time commitments, training and respite needs and the social, health, emotional and financial impacts of the caring role.

Recommendation 3

Development of a common Carer assessment tool from current clinical trials.

Health and Wellbeing

Carers are an at risk population group due to the physical, mental and emotional stresses of the caring role. In putting the needs of the care recipient before their own, Carers are slow to seek treatment for their own health problems. Significantly improving the health and wellbeing of Carers would enable them to fulfil the roles they play within the health system.

Therapeutic counselling plays a vital role in maintaining Carer well-being. Carer counselling services are witnessing more complex calls on top of increasing demand.

After prolonged care giving past Carers need time and ongoing support to recover from the health impacts of caring. Some have ongoing major health problems.

A clinical and population approach that recognizes that Carers have significant health needs that are identifiable, treatable and preventable is required within the primary health care system.

Recommendation 4

Make Carers a 'mainstream' priority for government action with a primary and preventative Carer health program.

Develop a coordinated range of health care monitoring and maintenance programs and complementary social support measures.

Respite

Respite from their caring role is a major factor in enabling Carers to care over the long term and to make 'work/life balance choices. Carers require adequate, appropriate, quality, affordable and flexible respite of all kinds, however in many situations, particularly in rural and remote regions, suitable respite is not available.

Recommendation 5

Provide increased resources and greater flexibility within respite programs to enable greater take up and effectiveness of respite.

Financial Resilience

Many South Australian Carers are living in poverty, struggling to meet the increasing cost of living and rising associated costs of caring. Improving concessions and subsidies to help meet extra costs is a top priority for Carers.

The State Government plays an important role through its regime of concessions and subsidies, however much of this assistance has a decreasing face value and many Carers miss out due to restrictive criteria.

Recommendation 6

Create an effective concessions and subsidies regime for Carers that meets the ongoing rises in the costs of living, including an immediate 25% rise in the rate of concessions, State support for nationally consistent concessions, subsidies and cross border eligibility and a review of state based concessions on their effectiveness in meeting the needs of people on low incomes and those most in need.

Regional Carer Support

Regional Carer support organisations play a vital role in supporting Carers across South Australia, particularly in rural areas, by providing a foundation for connecting Carers and developing innovative support structures in local communities. However limited resources and funding restrictions create barriers to meeting this need across all Carer cohorts. Carers in rural and remote South Australia face particular barriers to engagement and support including isolation, limited transport services and employment options.

Additional assistance in service navigation, transport options and Carer training would enable greater Carer engagement and maintenance of their caring.

Recommendation 7

Provide an increase in resources to maintain and build regional Carer Support programs, including Carer training and service navigation and special provision for rural and remote Carers.

Special Needs Groups

Aboriginal Carers

Providing assistance to Carers from Aboriginal communities relies on recognition of family and cultural considerations, putting into place long term programs that can link with communities. Specific services and communication methods are required to reach out to, and support, Aboriginal Carers.

Recommendation 8

Development of a state wide Aboriginal Carers program including local Aboriginal Carers project support.

Culturally and Linguistically Diverse Carers

14.2% of Carers in South Australia are from culturally and linguistically diverse backgrounds. Cultural background can act to complicate and compound the issues for CALD Carers. Activities undertaken with CALD Carers must be respectful of the important role of community leaders and the priorities of the individual communities. Specific services and communication methods are required to reach out to, and support, CALD Carers

Recommendation 9

Development of a state wide CALD Carers program including local CALD Carers project support.

Families of Children with Disabilities

Many families of children with disabilities face insufficient and inadequate services due to limited resources and restrictive criteria. These families need early intervention and low level Carer support. Carers would have better capacity to care if they were provided with this support. Disability legislation needs to be updated and reviewed to include Carers.

Recommendation 10

Provision of adequate resources for appropriate services to provide 'all of life' support tailored to the individual family needs to underpin caring.

Young Carers

Young Carers take on the role of caring beyond what could normally be expected of a child, including physical, emotional and intimate care. Young Carers require continuing, flexible support services that are age and culturally appropriate within a family focussed approach to enable them to maintain or reduce their caring role. Schools are a critical point of intervention in building capacity and resilience.

Recommendation 11

Development of an interdepartmental young Carers program that integrates family focussed community and schools based projects including an analysis of current approaches, young Carer impact statements for government programs, early identification and support mechanisms for young Carers at risk and promotion of and involvement in research. Provision of resources to increase young Carer programs.

Ageing Carers of Adult Children

Ageing Carers of adult children may have been caring for many years. Assistance with transition issues is central for them: they are desperately concerned about who will care when they cannot and are keenly aware of the poor availability of housing and support options.

Mechanisms which provide families with options to combine family and formal resources for future support are yet to be developed or considered.

Recommendation 12

Development of a state wide ageing Carers of adult children program including future planning workshops, regional support projects and a register of ageing parent Carers.

Working Carers

Carers may be juggling multiple roles in paid and unpaid work, with a high degree of transition into and out of the caring role. The fulltime employment rate of primary Carers is less than half that of the general population, with many working below their skill and experience levels. Remaining at work relieves financial hardship and social exclusion. Many would prefer to remain in employment. They require support to do so.

Recommendation 13

Development of an integrated Carer workforce participation program including public service workforce participation support policies and practice as a model for business and community sectors, a Carer workforce participation education campaign for employers, an education and labour market scholarship program and suitable quality options for care recipients.

Carers of People with Mental Illness

A very high proportion of people with mental health problems are extremely dependent upon their family for the most basic of everyday tasks. Insufficient state resources for community, social and housing support for people with a mental illness results in considerable burden on their Carers who need a range of services to enable them to continue caring.

Recommendation 14

Provide a priority pathway to social housing and service supports within mental health programs for people with mental illness and their ageing Carers.

Comprehensive Quality Services

The rise in chronic, long-term and life-threatening illnesses and conditions, an emphasis on providing care within the community and the ageing of the population has resulted in greater pressure on family members to provide care.

As this demand for care in the community continues to rise an appropriate resource response to increase and improve services for people with disabilities, chronic illness or who are frail aged will significantly reduce the burden on Carers.

Availability of low cost transport options is central to accessing services.

Recommendation 15

Provision for increased funding including exploring new approaches to fund community care services, a greater balance in funding across disability, chronic illness and ageing sectors, improved regional transport options and the maintenance and strengthening of service collaboration, particularly in rural and remote areas.

2 The Budget Challenge

Carers SA acknowledges the ongoing and increasing support for the work with Carers in South Australia. This is occurring within a context of increased community recognition and Carer self awareness and the continuing expectation that the majority of care will be met by Carers: that there is always somebody in the community to care.

What is required by Carers is the maintenance and further development of this support to positively affect the lives of South Australia's Carers on a day-to-day basis including:

- Addressing the complexity of the issues yet providing the flexibility to cater for individual circumstances.
- Basing programs and services on the principles of early intervention and prevention in practical solutions.
- A sound policy framework in which the role, rights and needs of Carers are recognised as well as the government's responsibility to support them.
- Significant resource boost into the care system across disabilities, chronic illnesses and ageing.

Investment in Carer support provides returns of 7:1 to the government in financial terms, not including the quality of life outcomes for Carers and those they support (Access Economics 2005).

Carers SA acknowledges

- Plan for South Australian Carers 2009
 - Review the SA Carers Recognition Act 2005 (Outcome 1.2.1.).
 - Promote greater recognition and positive images of Carers (2.1.): Carer Recognition Awards (2.1.3.): Continued improvement to Whole of Government implementation and compliance with the Carers Recognition Act 2005 (2.1.4).
 - Develop a profile of South Australian Carers (3.1.): Identify current data that can contribute to building a profile of South Australian Carers (3.1.1.): Develop a report on the profile and trends relating to Carers in South Australia (3.1.2.).
 - Ensure funded non-government organisations comply with the Carers Recognition Act 2005 (3.2): Develop a strategy incorporating information dissemination, data collection strategies and the development of a recording and reporting system (3.2.1.): Carer focus workshops for funding programs (3.2.2.): Contractual requirements for funding include compliance with SA Carers Recognition Act 2005, Carers Charter, and Policy. (3.2.3).
- The ongoing strategic role of the Office for Carers.
- A number of departments are addressing their responsibilities under the SA Carer Recognition Act 2005.

3 Strategic Recognition and Awareness

3.1 Carers

Carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail.

- 1 in 8 South Australians (222,700) provide 'informal care' (ABS 2005): about one quarter of the population are affected by government decisions and policies that impact on Carers
- 30,300 are young Carers under 25, of whom 14,800 are under 18 (ABS 2005).
- 18% (41,290) are primary Carers, with major responsibility for another person's well being (ABS 2005): over 90% of primary Carers are

close family members of the person they care for: 41% are a partner, 26% a son or daughter and 23% a parent (AIHW 2009).

- 71% (29,441) of primary Carers are female (ABS 2005).
- 48% of primary Carers provide at least 40 hours per week support (ABS 2005).
- 44% of primary Carers themselves have a disability (ABS 2005).
- By 2031 Carer numbers will increase by 57% compared with a 160% increase for older people requiring care - a 'Carer crunch' (Percival and Kelly 2004).

- Carers on average are getting older: 56% will be over 65 in 2031, up from 42% in 2001 (Percival and Kelly 2004).
- An estimated 5.6 million hours of caring are provided by South Australian Carers each year, valued at \$2.66 billion (Access Economics 2005).
- An increasing number of Carers are the "sandwich generation", caring for ageing parents as well as a child or spouse with a disability (AIHW 2004).
- The reduction in the number of Carers relative to demand will result in significantly increased demand on disability services; especially accommodation, support and community access (AIHW 2007).
- The prevalence of dementia is projected to increase fourfold from 245,000 in 2009 to around 1.13 million by 2050: people with dementia, their families and Carers must be able

to choose between whether they receive care in the community or in a residential facility. (Alzheimer's Australia 2009).

Carers come from all parts of society. Carers come into the caring journey at various stages throughout their life. The condition requiring care can create different demands. People may also be caring for more than one person, or they may care for people across different generations. People vary in their capacity to care, due to age, health, personal resilience, size of social networks or levels of support from extended families.

Carers seek a good quality of life for themselves and the people they care for. Core principles for practical assistance to Carers are health and wellbeing, capacity building for Carers and the care support sectors, and participation and partnership.

3.2 Social Inclusion

Carers are entitled to the same rights, choices and opportunities as other South Australians in order to enjoy health, social and economic wellbeing and to participate in family, social and community life, employment and education.

There is a significant chance that social networks will be affected when people become Carers. 35% of primary Carers lose touch with their circle of friends due to their caring role (ABS 2005): men's social networks are likely to be less extensive than women's, putting them at increased risk of social isolation when taking on a caring role (University of Auckland 2009).

The Premier has spoken of the creation of opportunity for South Australians "wherever they are, whatever they do", ensuring that they thrive and have a "positive focus on the future" (Government of South Australia 2007). These, of course, are things that we all strive for.

So that Carers can be part of this future vision, flexible and responsive assistance is required to meet their diverse needs and to enable them to sustain their caring responsibilities, maintain their own health and participate in family, social and community life, employment and education. They need to be able to exercise choice about their caring responsibilities, yet for many Carers the burden of the caring role and lack of alternative options removes any sense of choice: they cannot leave what they are doing.

The development of the *South Australian Strategic Plan* has highlighted the importance of an across government approach. The iterative nature of the Plan provides ongoing opportunities to further develop targets and accompanying strategies to initiate the measures that we have outlined in this submission for supporting Carers.

Carers SA has welcomed the release of the *Plan for South Australian Carers 2009* as another step in the strategic structural context for the provision of Carer support in South Australia.

There is much to commend in the Plan, which sets out the vision, priorities and actions for the Department for Families and Communities. It continues the SA Carers Policy 2006 dual focus of ensuring that Carers are involved in decisions about those they care for and promoting understanding of Carers' own individual needs. Along with important action by the Department's own agencies, this Plan is a useful template for all other government departments to follow.

Ultimately the success of any policy or plan will be measured in how they affect the lives of South Australia's Carers on a day-to-day basis: substantial ongoing commitment is required through collaboration within the cohesive across government framework.

4 Partners in Care

4.1 Carer Partnership and Participation

Carers play a vital role in community services and health as partners in care undertaking many duties complementary to health and other care professionals. However, their knowledge, skills, experience and expertise in the provision of care are little recognised or utilised by the community services and health industries.

The Australian Institute of Health and Welfare reported in 2009 that over half of all Australians with a disability had a combination of two or more disabilities (about 10% of the population) and that the more disabilities a person had, the more likely they were to need help with 'core' daily activities of self-care, mobility and communication. The report, *Disability in Australia: multiple disabilities and need for assistance*, stated that "the high reliance of formal and informal assistance for people with multiple disabilities highlights the importance of the formal sector working hand-in-hand with primary Carers and families to support people with multiple disabilities" (AIHW 2009).

The AIHW repeated this assertion in its *Australia's Welfare 2009* report suggesting that for support services in the future to meet increased demand they would have to adopt new approaches to service delivery including a stronger shared-care approach between informal Carers and formal support services (AIHW 2009).

Research also shows that Carers can be better judges of the life skills/impairments in social functioning of people with a mental health problem than formal care coordinators and that Carers who participate in the care planning process with professionals have a more positive attitude toward their role and this can assist them with coping (Wooff et al 2003). Partnerships are therefore the key to ensuring that Carers are well supported in their role (Carers SA 2009).

Whilst there is growing awareness and goodwill amongst service providers toward Carers,

nevertheless, effective partnership between service providers and Carers can only be established when the role and functions of a Carer are understood, respected and recognised by the individual professionals and the entire care system.

A comprehensive program for service providers to address the knowledge and skills necessary for working with Carers is required if services are to have the capacity to respond to the requirements being placed on them.

The Budget Challenge

Carers SA acknowledges

- Plan for South Australian Carers 2009
 - Increase awareness of Carers and care related issues via funded services (1.1.2.).
 - Mechanisms exist to ensure active Carer participation (4.1.): Ensure service providers consult and represent Carers in policy and program development, strategic or operational planning. (4.1.1.).
 - Promote Carers in their capacity as Carer and service partner in the provision of caring services (4.2.): Recognise Carers as active partners in the provision of services. (4.2.1.): Formalise the involvement of Carers in the development and delivery of Domiciliary Care SA services (4.2.2.).

Recommendation 1

Development of a Carer participation and partnership project to facilitate consistency across service provision for Carers, including a Carer participation and partnership template, consultancy assistance in the development of Carer policies by service providers, Carer education and training for service providers and Carer education in managing service system interaction.

4.2 Carer Partnership in Health

Of particular importance are the roles Carers play within the health system including as health service users (consumers) themselves, Carer representatives in the consumer participation framework, advocates for the consumer and partners in the delivery of care. It is critical that these roles are addressed by the health care system through policy and practice.

Whilst there has been growing recognition of Carers in health plans and legislation, for example in the Mental Health Act 2009, in order for a partnership to be effective health professionals need to recognise the roles of Carers and, as required by legislation, involve them in the planning and delivery of services which impact on Carers and the people they care for, wherever they occur; for example the early

discharge of people with a mental illness from hospital or older people after an acute episode continues to occur with little if any consideration of family circumstances, capacity or resilience and the formal support they need.

The Budget Challenge

Recommendation 2

Development of a strategic Carer participation project for system change across the health sector to enable a true partnership between the health sector and Carers, including development of appropriate Carer participation mechanisms, an education campaign on the role of Carers, guidelines that provide for Carers having access to the health status and treatment information about the care recipient.

5 Caring for Carers

5.1 Assessment

Carer assessment is important in the development of, and referral to, appropriate services for the Carers themselves.

Carers need to maintain their own well being, but often find it hard to voice their own specific needs when negotiating services for the person they care for. It is too often the frustrating experience of Carers for the different challenges experienced by families not to be taken into account.

Carers SA is concerned at the continuation of practices for service access where the care recipient has to be in receipt of services prior to any recognition of the needs of the Carer. Unless appropriate referrals for the Carer occur they can find themselves waiting for the care recipient to be assessed before they get any care.

Carers not only have the right to be assessed independently of the care recipient but also should have the results of that assessment taken into account for the provision of services. This would offer protection to Carers to have their needs taken into

account and to provide for a reassessment, including receiving greater assistance, when circumstances change, either for the Carer or care recipient.

Assessment for Carer need should cover the Carer's time commitments, training and respite needs; the social, health, emotional and financial impacts; identify Carers most at risk and take into consideration the particular needs of special groups.

Trials of a national Carer assessment tool and a Clinical Project in Southern Adelaide investigating health assessment for Carers would provide useful information in the development of a common Carer assessment tool for use across services in South Australia.

The Budget Challenge

Recommendation 3

Development of a common Carer assessment tool from current clinical trials.

5.2 Health and Wellbeing

Carers are an at risk population group due to the physical, mental and emotional stresses of the caring role (Carers Association of Australia 2000).

- Moving into the caring role is associated with anxiety, depression, sleeplessness and stress (Australian Longitudinal Study on Women's Health).
- An epidemiological analysis of health surveys from 1994 to 2004 indicated that Carers report increased chronic illness making them at greater risk of morbidity, disability and mortality than non Carers (Gill et al 2007).
- Severe and sustained fatigue is common: 34% of primary Carers reported they often felt 'weary or lacking in energy' (ABS 2008).
- Carers, in putting their needs last, are slow to recognise, acknowledge and seek treatment for their own health problems. (Carers Australia 2001; NATSEM 2006)
- Carers and their families have significantly worse mental health and vitality and higher rates of depression than the general population: one third are severely depressed and/or stressed (Edwards et al 2008/Cummins et al 2007).

The deterioration of the physical or mental condition of the care recipient can also have significant impact on the Carers' mental wellbeing.

Significantly improving the health and wellbeing of Carers would enable them to fulfil other roles they play within the health system including membership of advisory or reference groups in quality assurance, personal advocacy for the care recipient, and partner in care involved in clinical process and practice.

A clinical and population approach that recognizes that Carers have significant health needs that are identifiable, treatable and preventable is demanded within the primary health care system to reduce the deterioration of South Australia's Carers. It is vital that health professionals can identify them as Carers and address their concerns. The development and use of clinically based Carer health assessment and Carer health check tools within patient profile software would assist this process.

A comprehensive Carer health program across Health would work toward safeguarding and improving the health and wellbeing of Carers; including a GP's education and liaison project; Carer clinical health assessment and monitoring tools; education campaigns on Carers across the health system; post discharge support for patient Carers; a greater research effort; Carer training resources including practical nutrition, health care management and injury minimisation; appropriate provision for counselling to complement Commonwealth funds and resources to regional Carer Support programs to enable support to past Carers.

Past Carers

After prolonged care giving past Carers need time to recover from the health impacts of caring, from the grief, loss and social isolation and to rebuild their lives. Some have ongoing major health problems and in some cases suffer premature death. They require ongoing support. Following recovery, maintenance of

well being can include providing valuable mentoring assistance to current Carers.

Counselling

Therapeutic counselling that addresses stress management, isolation, self-care, grief and loss and transition decision making plays a vital role in maintaining Carer well-being and preventing their complete collapse. Carer counselling services are witnessing more complex calls on top of increasing demand.

The Budget Challenge

Carers SA acknowledges

- South Australian Strategic Plan: Improving wellbeing:
 - Healthy South Australians: increase the life expectancy of South Australians by 5% for males and 3% for females by 2014. (Strategy T2.4.): Psychological wellbeing: equal or lower than the Australian average for psychological distress by 2014. (T2.7.): Work-life balance: improving the quality of life of all South Australians through maintenance of a health work-life balance (T2.12.).
- Plan for South Australian Carers 2009
 - Identify the needs of relinquished Carers. (3.3.1.).

Recommendation 4

Make Carers a 'mainstream' priority for government action with a primary and preventative Carer Health Program.

Develop a coordinated range of health care monitoring and maintenance programs and complementary social support measures.

5.3 Respite

Getting respite from their caring role is a major factor in enabling Carers to care over the long term and to make "work/life balance" choices about participation in work, leisure and community engagement.

At a basic level the respite service replaces the care provided by the Carer with someone else to do the work of caring. However, respite is regarded by Carers as an experience for them, not just as a service for the care recipient: when Carers talk about respite they are saying, "I need a break and want someone to help me"; ie they see respite as a broad range of support and assistance critical in helping them cope with caring.

Carers require adequate, appropriate, quality, affordable and flexible respite of all kinds.

However in many situations respite is not available, suitable, acceptable or possible. Whilst government funds for respite have been increasing, programs are increasingly targeted and provide emergency episodic relief rather than ongoing support. Limited availability of respite, particularly in rural remote locations results in fewer respite options. Many Carers in rural and remote locations have to travel long distances to a regional centre to gain overnight respite care (Pearson Jenny and Associates 2001).

Provision of respite within Carer Support program activity would enable greater Carer engagement. Greater flexibility within funding criteria and appropriate and adequately resourced ongoing respite would provide greater certainty for planning and enable greater uptake of respite options.

The Budget Challenge

Carers SA acknowledges

- State support through HACC and other programs.

- Plan for South Australian Carers
 - Improve the capacity of service providers to increase respite for older Carers. (7.2.2.).
- Ministerial announcement December 2009 of an increase in respite hours.

Recommendation 5

Provide increased resources and greater flexibility within respite programs to enable greater take up and effectiveness of respite.

5.4 Financial Resilience

Many South Australian Carers are living in poverty.

- One third of primary Carers live in the poorest fifth of households, struggling to meet the increasing daily costs of caring: 37% rely solely on a Government pension for their income (AMP.NATSEM 2006).
- Primary Carers' median personal gross income per week is 58% of non Carers for non Carers (Carers Australia 2005).
- If a single person on an average wage were to give up work to become a Carer their weekly income would drop 72% (AMP.NATSEM 2006).
- Over a woman Carer's lifetime she could expect to earn between a quarter and half of the earnings of a woman of a similar age (NATSEM 2008).
- About one fifth of respondents in the Carers SA 2008 Survey of Members reported that they were under housing stress and about one third had had trouble paying energy bills.
- 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 the household income is spent on medical costs. Half of a 2005 sample reported going without food or medication for their children at some time due to their poverty (StollzNow 2005).

Australian studies have consistently found that households that include a person with a disability, mental, illness, long term illness or is frail aged face greater financial hardship than the general population. This is particularly so for Carers in outer regional and remote areas, who face greater financial hardship than Carers living in major cities and non Carers generally.

Carers are more likely to find themselves in mortgage stress than other house purchasers. This is a function of lower household incomes and increased commitment to owning a house to avoid lack of

security and problems in modifying privately rented accommodation (Beer and Faulkner 2009).

The South Australian Council of Social Service *Cost of Living Biannual Update No. 1* showed that for the 31% of South Australians who rely on government benefits as their main source of income the costs associated with housing, utilities and transport were such that even food became difficult to afford. (SACOSS 2009).

Improving concessions and subsidies to help meet the extra costs of providing care was the top priority across all issues of respondents to the Carers SA 2008 Survey of Members.

The State Government plays an important role through its regime of concessions and subsidies, in part to make up for the failures of the federal benefits system. These measures coupled with Federal budget increases in pensions and allowances and the annual bonus have alleviated some of the financial distress.

However much of the concessionary assistance has had a decreasing face value and many Carers have missed out due to restrictive criteria: the State Government raised services by an average of 4.2% including water, car licence and registration, compulsory third party insurance and public transport in the 2009 – 2010 Budget: the energy concession maximum rate of \$120 per year has not changed since 2004, while fixed charges have risen by over 21% since 2006 alone (SACOSS 2009). Significant price rises are expected in the coming years (The Australian 2009)

In other jurisdictions the Northern Territory Pensioner and Carer Concession Scheme provides an example of a comprehensive program for Carers, covering a range of services using the Carers Allowance as a benchmark as recognition of the extra costs and burdens on Carers and has included recent increases to cover rising costs; the Tasmanian government recently committed to indexing concessions to rising prices rather than to the CPI.

The Budget Challenge

Carers SA acknowledges

- South Australian Strategic Plan: Attaining sustainability
 - Use of public transport: increase the use of public transport (T3.6.).
- South Australian Strategic Plan: Expanding opportunity
 - Economic disadvantage; reduce the number of South Australians receiving government benefits (T6.5.).
- Plan for South Australian Carers 2009
 - Improve Carer awareness of government concessions and benefits available to eligible Carers. (3.3.3.).

- Concessionary measures including the Plus One card, the Residential Energy Efficiency Scheme, free public transport for senior off peak, the national interstate transport concession agreement.

Recommendation 6

Create an effective concessions and subsidies regime for Carers that meets the ongoing rises in the costs of living, including an immediate 25% rise in the rate of concessions, State support for nationally consistent concessions, subsidies and cross border eligibility and a review of state based concessions on their effectiveness in meeting the needs of people on low incomes and those most in need.

6 Regional Carer Support

Regional Carer Support organisations play a vital role in supporting Carers across South Australia, particularly in rural areas. Through a strong peer support approach they provide a foundation for connecting Carers and local services and developing innovative support structures for Carers within local communities.

Caring can be an isolating experience, as a result both of geography and of limited community engagement. Carer Support programs are seen and keenly sought by Carers as a vital back up as they go about their caring role through physical activity such as peer groups, retreats and outings and as community engagement through meeting with other Carers in similar situations and events in public spaces. Underpinning all of this is community recognition and encouragement of the Carer for their caring role.

Peer support, being able to talk to others in a similar situation, is of significant assistance to Carers in maintaining their caring role, because Carers best understand other Carers' feelings, concerns, and needs. Carers are then able to offer support to others in similar situations.

There is an important need for Carer support programs to be able to offer and deliver a range of services to all Carer cohorts across the Carer life journey, with no thought to the individual Carer's age, ethnicity or ability and at a variety of times to suit individual needs. However limited resources and funding restrictions geared mainly to the over 65s create barriers to meeting this need.

In addition these agencies are seeking to widen their services to include:

- Regular checks on Carers whether by phone or home visits.
- In home support for Carers through one on one visits.
- Appropriate services for Aboriginal and CALD Carers.
- Carers in transition support for 6 to 12 months after formal care or death of the care recipient.
- Improved communication technology in remote regions.

Service Navigation

Carers require assistance in knowing what services are available for themselves and for their care recipients, in linking with them and in using them and in juggling the demands of, and access to, support programs across portfolios in particular health and ageing and across different jurisdictions within the state and between state and commonwealth.

Transport

Carer engagement with services is dependent on reliable low cost transport options.

Carer Training

Carers take on the caring role with little or no training. Carer training is essential to build Carer capacity.

However, the appropriate training available across South Australia is very limited in scope with a small

number of courses and workshops across various topics. Development of a comprehensive Carer training program in South Australia to build on existing programs includes Carer roles and responsibilities; manual handling; Carer health and wellbeing; advocacy; gaining service system support and managing paid care workers.

The training framework needs to include flexible approaches to allow for the time pressure on Carers, their physical and emotional status and the changing needs of care recipients as well as provision for transport and respite to enable Carers attendance.

Carers in Rural and Remote Regions

Carers across rural and remote South Australia face long distances, limited or no public or community based transport options, a limited number of services with many either clustered in regional centres or based in Adelaide, service provision limited by the impact of low population bases on unit costs of service delivery, lack of care workers, limited employment opportunities, the isolation of dispersed populations and an often absence of nearby family or support services to care for them or their family in their absence.

The Tyranny of Distance? Carers in regional and remote Australia, the first report to examine the geographic spread, age profile and social, health and economic wellbeing of Carers in regional and remote Australia indicated that:

- The major difficulty in accessing services in outer regional and remote areas was found to be because of distance, inadequate services or lack of services.
- A higher percentage of Carers living in outer regional and remote areas reported affordability of services to be a difficulty.
- Carers in remote and regional Australia were more likely to be Indigenous largely as a result of the distinctive geographic distribution of the Indigenous population and the high level of care required for many of them.
- Carers in outer regional and remote areas experienced higher rates of disability or a long-term health condition themselves and lower rates of employment than non-Carers living in the same areas and Carers in major cities.

Measures are required to meet the challenges faced by rural and remote Carers including funding levels, transport and service collaboration.

Building on the strong foundation of regional Carer Support would enable the ongoing development of

innovative local and state-wide projects, in particular for special needs groups such as those outlined below.

Carers SA encourages ongoing investigation into other potential sources of funds, eg Health, Regional Development, Primary Industries and Disabilities.

Additional funding is required so that regional Carer Support programs can:

- Provide for their particular region.
- Provide for all Carer cohorts across the life journey.
- Offer Carers a range of activity.
- Provide for transport and respite within program activity.
- Assist with service navigation.
- Assist in the development of a state wide Carer training program.

The Budget Challenge

Carers SA acknowledges

- State Budget 2009 – 2010 commitment to Remote Communities of \$7.1 million to improve government coordination and services in remote communities.
- The continuing support for regional Carer Support programs across South Australia by the Home and Community Care program through the Office for the Ageing.
- Plan for South Australian Carers 2009
 - Establish skills training programs for Carers (2.2.): Ensure the safe provision of services by Carers for the person being cared for (2.2.1.).
 - Develop and implement evidence informed service models for Carers. (7.1.): Progress national developments relating to improving outcomes for Carers. (7.1.1.): Assist to develop a tool to capture information on Carer needs and support services. (7.1.2.): Establish Home and Community Care funded Carer support services state-wide. (7.2.3.).

Recommendation 7

Provide an increase in resources to maintain and build regional Carer Support programs for services across all Carer cohorts including those outside of the HACC target group, including Carer training and service navigation and special provision for rural and remote Carers.

7 Special Needs Groups

7.1 Aboriginal Carers

Providing assistance to Carers from Aboriginal communities relies on recognition of family and cultural considerations. Within Aboriginal communities sharing and mutual support in the context of kinship ties play a vital role. In many cases family members such as grandparents and children are providing unacceptable levels of care without support.

A long term strategy needs to be put into place to offer a state wide network of Carer support for Carers from Aboriginal communities to provide for liaison with communities; a coordinating role; advocacy and education both for Carers in the caring role and for service providers in the needs of Aboriginal Carers.

For effective service delivery at local level a mix of ongoing support and one off special projects in conjunction with regional Carer support programs that are flexible to respond to changing local circumstances in disability programs, elder programs, training, information, health and wellbeing would complement a state wide program by meeting regional needs.

The Budget Challenge

Carers SA acknowledges

- Support, particularly through HACC, for projects across South Australia with Aboriginal Carers.
- Plan for South Australian Carers 2009
 - Identify opportunities to improve self recognition of Aboriginal staff within the Department for Families and Communities who are in caring roles (2.1.2.)
 - Community benefit SA workshops focus on Aboriginal Carers (3.3.2.).
 - Provide culturally appropriate service responses to Aboriginal Carers (5.1.): State-wide Aboriginal Carer needs analysis and service model development (5.1.1.): Consult with Aboriginal and Torres Strait Islander Carers on Disability SA policy and service development (5.1.2.): Housing SA staff are sensitive to aboriginal Carers' cultural needs and requirements (5.1.3.): All Office for Carers information and promotional materials are provided in formats that are culturally appropriate (5.1.4.).

Recommendation 8

Development of a state wide Aboriginal Carers program including local Aboriginal Carers project support.

7.2 Culturally and Linguistically Diverse Carers

There are 31,720 Carers (14.2% of all Carers) in South Australia from culturally and linguistically diverse backgrounds, of whom 7,000 are primary Carers (16.2% of primary Carers) (ABS 2005).

Cultural background can act to complicate and compound the issues for CALD Carers: different cultures with different requirements related to English language proficiency, low literacy, low educational levels, the concept of a 'Carer' as challenging cultural beliefs and migration status all play a part.

Any activity undertaken with regard to CALD Carers needs to be respectful of the important role of community leaders and the need to work at an acceptable pace and within the priorities of the individual communities.

Resources for culturally appropriate programs would create linkages within CALD communities and with mainstream services for CALD Carers.

The Budget Challenge

Carers SA acknowledges

- Plan for South Australian Carers 2009
 - Implement the recommendations of the DFC commissioned report: Responding to Culturally and Linguistically diverse Carers: Carers Voices (7.2.1.).

Recommendation 9

Development of a state wide CALD Carers program including local CALD Carers project support.

7.3 Families of Children with Disabilities

The insufficient services for families of children with disabilities creates enormous burdens on the Carer faced with limited, if any, choices for their children and providing a lifetime of care: particularly for "whole of life" sole parents.

Carers SA is receiving repeated feedback on the need for better general Carer support for Carers of young children with a disability. Many of these families are younger, have not experienced institutional care and are struggling to provide care for their children. Many are receiving limited if any services through Disability SA, nor are they eligible for HACC services, since HACC is focused on frail elderly people and their Carers as a priority.

These families need early intervention and some low level Carer support similar to that provided for mainly

ageing Carers through the HACC funded Carer support programs. This would have the benefit of building on existing infrastructure. Carers would have better capacity to care if they were provided with this support and would feel included and supported in the community.

Disability legislation needs to be updated and reviewed to include Carers.

The Budget Challenge

Recommendation 10

Provision of adequate resources for appropriate services to provide 'all of life' support tailored to the individual family needs to underpin caring.

7.4 Young Carers

Young Carers take on the role of caring because of natural family responsibilities, but beyond what could normally be expected of a child; including physical, emotional and intimate care and childcare of siblings. In taking on a caring role they put their own lives and futures on hold.

- Carers aged between 5 and 17 are usually caring for a parent or sibling but those aged 18 to 25 may be caring for a close friend, relationship partner or their own child.
- Significant numbers of young Carers are carrying out caring duties over 50 hours per week, with children as young as five becoming Carers and remaining Carers for over a decade (Becker 2008).
- Young Carers forgo education and employment opportunities to care for family members: only 4% of young primary Carers 15-25 were still in school or higher education compared with 23% of the general population (Noble-Carr 2001).
- 45% of young primary Carers live in a sole parent household (Noble-Carr 2001).
- 25-30% of young Carers care for a person with a mental illness.

Many young Carers appreciate and value the contribution they make in their caring role, yet they often face significant barriers when accessing services. Many struggle to obtain recognition of their caring role from schools, medical practitioners or service providers. Some families fear that disclosure of support needs may lead to the children being placed under child protection services. Some fear community stigma, especially where mental illness or alcohol and drug dependence are a factor.

The *Bring it! Report* showed that young Carers need continuing, flexible support and services, equal access to these, as well as services that are age and culturally appropriate and based on best practice. It highlighted the need for a family focussed approach, where the whole family's needs are assessed regardless of which member first contacts an agency. (Carers Australia 2009). Early intervention can have long term benefits.

Schools are a critical point of intervention in building capacity and resilience in these young people who otherwise are at risk of underachievement. Young Carers who leave school place themselves at risk of not being able to undertake further education or of entering the workforce. Transition support into further education and the workforce is complementary to school based intervention.

Young Carers require an interdepartmental program, underpinned by the understanding of their needs and an acknowledgement of their contribution within a family focussed approach that seeks reduce their caring role: a program that integrates community and schools based programs to facilitate young Carers' development as individuals, with educational participation, resilience and the maintenance of their health and well being.

The Budget Challenge

Carers SA acknowledges

- South Australian Strategic Plan Expanding Opportunity
 - SACE or equivalent: increase the proportion of 15-19 year olds who achieve the SACE or comparable senior secondary qualification (T6.16).
- State Budget measures: targets: DECS improving pathways for all young South Australians to engage in further education, training and of employment.
- Department for Education and Childrens services support for a small project to work with schools and staff support in joint projects for young Carers.
- Government commitments to young Carer programs such as Raw Energy and breakthrough.

- Plan for South Australian Carers 2009
 - Raise awareness of young Carers and their needs at identified key access points to services and support. (Outcome 6.1.): Develop young Carer information and publications that are age appropriate, easy to understand and helpful to young Carers. 6.1.1.): Participate in the Australian Research Council funded three year study, exploring the impact of the caring role on young people. (6.1.2.): Identify opportunities to minimise caring responsibilities of young people who provide care (6.1.3.).

Recommendation 11

Development of an interdepartmental young Carers program that integrates family focussed community and schools based projects including an analysis of current approaches, young Carer impact statements for government programs, early identification and support mechanisms for young Carers at risk and promotion of and involvement in research.

Provision of resources to increase young Carer programs.

7.5 Ageing Carers of Adult Children

Ageing Carers of adult children who are getting older themselves may have been caring for many years and are concerned about who will care when they cannot. Assisting with transition of care is central for ageing Carers. These people are desperately concerned about the end for ongoing care for their son or daughter and aware of the poor availability of housing and support options. They often feel abandoned by the state and distrustful of formal services. They need information about options for, and the legal and financial requirements of, permanent care arrangements as well as ongoing respite and other support.

Many ageing parents do not have a fall back Carer. Many will need to be engaged in planning housing and other support for their son or daughter prior to their own frailty or death. There is currently no mechanism to register a future need for housing and support. Mechanisms which provide families with options to combine family and formal resources for future support are yet to be considered or developed.

Many are whole of life sole parent Carers with their own health issues.

The Budget Challenge

Carers SA acknowledges

- Plan for South Australian Carers 2009
 - Support older Carers of children with disabilities experiencing ageing issues (1.1.1).
 - Develop a framework of service delivery for ageing Carers. (4.3.1.).
 - Provide services for a targeted group of ageing Carers of people with a disability. (7.1.3.).
 - Monitor unmet need for targeted ageing Carers. (7.3.2.).

Recommendation 12

Development of a state wide ageing Carers of adult children program including future planning workshops, regional support projects and a register of ageing parent Carers.

7.6 Working Carers

Many Carers are juggling multiple roles in paid and unpaid work, with a high degree of transition into and out of the caring role:

- Many Carers withdraw from employment when they become Carers (Gray et al 2008): only 46% of primary Carers were employed fulltime (ABS 2005).
- 44% work below their skill and experience levels (TOCC 2007).
- 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 (TOCC 2005).
- The ability to participate in paid work on limited, part time or fulltime basis is the expressed preference of many Carers of workforce age (Access Economics 2005, Edwards et al 2009): many Carers working part-time would increase their hours if care were more affordable (TOCC 2006).
- Remaining at work relieves financial hardship and social exclusion (TOCC 2005): Carers were less likely to suffer from stress if they combined their caring role with paid employment (University of Melbourne 2006).
- Carers may need help in order to enter or re-enter the workforce after a period of caring.
- 53.6% of unemployed women who receive the Carer payment want to work. Of this group 47.4% have been employed just prior to commencing caring (Gray et al 2008).

Caring must be seen as compatible with paid work. Those who care need support to continue in the paid workforce to mitigate against financial hardship and social exclusion and to contribute to the maintenance of a viable workforce in Australia.

The 2009 *State of Ageing in South Australia* report (Hugo et al 2009) indicated that the proportion of Carers balancing paid employment and caring roles would increase and recommended that issues related to work and providing care must be considered in terms of intervention strategies.

The Budget Challenge

Carers SA acknowledges

- SASP Growing prosperity
 - Employment participation: increasing the employment to population ratio (T1.12.).
- The ongoing work of the Work Life balance Strategy of Safework SA: Carers in the workforce: a new age? forum held during Carers Awareness Week 2009.
- The enactment of the Equal Opportunity (Miscellaneous) Amendment Act 2009 which includes recognition of caring responsibilities within the ambit of anti-discrimination measures.
- Plan for South Australian Carers 2009
 - Carers and work will be a "particular focus" for the Department for Families and Communities.
 - Develop recruitment strategies for Carers entering or returning to the Department for Families and Communities (1.3.): Promote the Department of Families and Communities as an employer of choice for Carers (1.3.1.): Develop a Discussion Paper on Issues and Options for back to work programs for Carers who have been out of the workforce for over twelve months (1.3.2).
 - Develop a best practice model of workplace flexibility for workers with caring responsibilities. (2.3.): Improve working arrangements for Department for Families and Communities employees with caring responsibilities. (2.3.1.): Improve mechanisms for monitoring and evaluating employee awareness and understanding of the SA Carers Charter. (2.3.2).

Recommendation 13

Development of an integrated Carer workforce participation program including public service workforce participation support policies and practice as a model for business and community sectors, a Carer workforce participation education campaign for employers, an education and labour market scholarship program and suitable quality options for care recipients.

7.7 Carers of People with Mental Illness

The insufficient ongoing resources for community based care, social support and housing options for people with a mental illness results in considerable burden on Carers. Carers require a range of services are required that focus on the Carers including peer support; specialised information, advice, training and education in self care and supporting organisations; respite; counselling and advocacy.

The Housing and Support Needs of Ageing Carers of Adult Children With Mental Illness survey conducted by Carers SA in conjunction with the Mental Health Carers Housing Group in July 2009 revealed that a very high proportion of people with mental health problems are extremely dependent upon their family for the most basic of everyday tasks. They face a bleak future in the absence of this support.

- The average age of the Carers was 64 with that of the care recipients 38.
- 93% of the care recipients were either living "at home" with the Carer or independently but with a great deal of support from the Carer/family.
- 86% of the care recipients would require supported accommodation when the Carer was no longer able to undertake the caring role: but that accommodation had not been arranged in 92% of cases.
- An average of only 28% of services, across a range of living, health and social services required by, and provided to, the care recipients were provided by someone other than the Carer.
- A gap exists between the advice of healthcare professionals and the services Carers actually receive.

Creating suitable and appropriate social housing options with ongoing service support to enable people with serious mental illness and associated disabilities to live well in the community would significantly reduce the overwhelming burdens on their Carers, particularly ageing Carers.

8 Comprehensive Quality Services

The rise in chronic, long-term and life-threatening illnesses and conditions, an emphasis on providing care within the community, and the ageing of the population is placing greater pressure on family members to provide care.

Carers' primary concern is the wellbeing of the people they care for and the services that provide support for them. Carers' first thoughts are for the needs of the person for whom they care. The more

Carers require the Government to recognise and include the reduced capacity of ageing Carers to continue to provide housing and associated living, social and health supports to their adult children in the assessment and provision of social housing and social supports to people with mental illness and establish a priority pathway to social housing and service supports within mental health programs for them.

Continuation and further support for mental health education and liaison program for Carers to provide tools and links for their caring over the long term.

The Budget Challenge

Carers SA acknowledges

- Enactment of the Mental Health Act 2009 including recognition of the role of Carers.
- Support from Australian governments for regional program for Carers of people with mental illness.
- State Budget 2009 – 2010 measures
 - Mental Health: Commence construction of 20 aged acute mental health beds and rehabilitation and allied health treatment facility at The Queen Elizabeth Hospital: Implement the new Mental Health Act 2009: Commence development of supported accommodation on the Glenside site and in the outer metropolitan area.
- Minister informed Carers SA 6 October 2009 that 420 new houses had gone to mental health to allocate; and for them to take into account the needs of ageing Carers in the assessment of housing for adult children with mental illness.

Recommendation 14

Provide a priority pathway to social housing and service supports within mental health programs for people with mental illness and their ageing Carers.

support provided to the care recipient, the more the burden is taken from Carers, the greater the capacity of the Carer to undertake the caring role over the longer term.

Carers require a more responsive, less confusing care service system that meets the needs of the care recipients in both quantity and quality.

The Way Forward A New Disability Framework For Australia, released in December 2009, cites government services for people with disabilities "a national disgrace" and called for structural reform (Disability Investment Group 2009).

This report underscores Carer stories that services for their care recipients continue to fall short of what is required:

- There are large gaps in services particularly for adolescents and adults with a disability.
- The current situation is unsustainable due to inadequate resources to meet growing demand: hours being provided per client are being reduced; service providers are unable to maintain a quality workforce or pay workers appropriately.
- There is an over reliance on a growing number of ageing Carers who have limited resources to buy or otherwise gain alternative care arrangements.

Specific service requirements for Carers include a much larger range of respite, day care, social, advocacy, transport and accommodation options to better provide for individual needs rather than a "one size fits all" approach; follow up visits to ensure service quality and the support of increases in, for example, equipment and personal care goods subsidies.

Carers SA has welcomed the recent announcements of inquiries into new approaches to funding services:

- The South Australian trial of self directed care. The Productivity Commission's investigation into the feasibility, costs and benefits of a national care and support scheme for people with a disability, including a "no fault social, insurance approach".
- The Social Inclusion Commissioner's inquiry into South Australian disability services.

Nevertheless, any new approaches to funding disability services must include be sustainable and reliable to provide for lifetime care and take into account the needs of Carers.

Transport

The provision of transport plays a central role in accessing services and reducing social isolation for care recipients and Carers alike, particularly for rural, ageing and young Carers. Providing transport for the care recipient can provide significant relief to the Carer who otherwise would be responsible for providing the transport needs for the care recipient.

A greatly expanded innovative community based transport service would enable Carers to get themselves and their care recipients to services and engage with the wider community: including greater use of existing community transport resources, provision for greater inclusion in service budgets for transport to and from services and further expansion of PATS for regular trips.

The Budget Challenge

Carers SA acknowledges

- South Australian Strategic Plan Expanding opportunity
 - Housing for people with disabilities: double the number of people with disabilities appropriately housed and supported in community based accommodation (T6.10): Participation by people with disabilities: increase the number of people with disability involved in day options (T6.11).
- State Budget 2009 – 2010 measures
 - Disability: Additional \$23.3 million to support disability services.
 - Health: \$40 million to improve and increase sub-acute care in the community including developing regional aged care teams, increasing in-home rehabilitation services and a community pharmacy network: \$114 million for increased levels of health services.
- State Budget 2009 – 2010 Targets
 - Families and Communities: Continue to expand basic HACC maintenance and support for frail older people and their Carers: Develop sustainable policy options to improve service choices for people with disabilities: Develop the Strategic Plan for South Australian Carers 2009-2012.
- Announcements December 2009 of a review of disability services by the Social Inclusion Commissioner and additional \$31 million for disability services.

Recommendation 15

Provision for increased funding including exploring new approaches to fund community care services, a greater balance in funding across disability, chronic illness and ageing sectors, improved regional transport options and the maintenance and strengthening of service collaboration, particularly in rural and remote areas.

9 References

- ABS 2009, Australian Social Trends Carers and Employment, Canberra
- ABS, 2008, A Profile of Carers in Australia, Canberra
- Access Economics, 2005, The Economic Value of Informal Care, for Carers Australia, Canberra
- Access Economics, 2009, Keeping dementia front of mind: incidence and prevalence 2009-2050, Alzheimer's Australia, Canberra
- AIHW 2009 Australia's Welfare 2009, Canberra
- AMP NATSEM, 2006, Who cares? the cost of caring in Australia today 2002 to 2005, University of Canberra, Canberra
- Australian Bureau of Statistics (ABS), 2005, 2003 Survey of Disability Ageing and Carers, Australian Bureau of Statistics, Canberra
- Australian Institute of Health and Welfare (AIHW) 2009, Disability in Australia: multiple disabilities and need for assistance Canberra
- Becker S, 2008, Global perspectives on young carers: findings and messages from research, presentation to Carers SA
- Beer A and Faulkner D, 2009, the housing careers of people with a disability and Carers of people with a disability AHURI Research paper cited in Carers Victoria: pre budget submission 2010-2011 Melbourne 2009
- Carers Association of Australia, 2000, warning – caring is a health hazard, Carers Association of Australia, Canberra
- Carers Australia, 2009, The Bring it! Report 2009, Canberra
- Carers SA, 2009, Carer Participation Position Statement update July 2009, Adelaide
- Cummins RA, Hughes J, Tomy A, Gibson A, Woerner J and Lai L, 2007, The Wellbeing of Australians – Carer Health and Wellbeing, Deakin University, Melbourne
- Disability Investment Group, 2009, The Way Forward A New Disability Framework For Australia, Commonwealth of Australia, Canberra
- Edwards B, Gray M, Baxter J and Hunter B, 2009, The Tyranny of Distance? Carers in regional and remote Australia, the Australian Institute of Family Studies for Carers Australia Canberra
- Edwards B, Higgins D, Gray M, Zmijewski N and Kingston M, 2008, the nature and impact of caring for family members with a disability in Australia, Research report number 16, Australian Institute of Family Studies, Melbourne
- Gill T, Jury H, Avery J, Warmington R, Stacey A, Taylor A, 2007, The Health and Wellbeing of Adult Family Carers in South Australia: an epidemiological analysis 1994 – 2004, Government of South Australia, Adelaide
- Government of South Australia, 2005, Carers Recognition Act 2005, Adelaide
- Government of South Australia, 2006, SA Carers Policy: Supporting Carers, Government of South Australia, Adelaide
- Government of South Australia, 2007, Creating Opportunity: South Australia Strategic Plan, Government of South Australia, Adelaide
- Gray M, Edwards B and Zmijewski N, 2008, Caring and women's labour market participation, Family Matters issue No. 78, 2008
- Hugo G, Luszcz M, Carson E, Hinsliff J, Edwards P, Barton C and King P, 2009, State of Ageing in South Australia, Department for Families and Communities, Government of South Australia, Adelaide
- National Centre for Social and Economic Modelling (NATSEM), 2008, Women Carers in Financial Stress Report, Carers Australia, Canberra
- Office for Carers 2009, Plan for South Australian Carers 2009, Department for Families and Communities Government of South Australia
- Pearson Jenny and Associates, 2009, Research in Respite Care: the views of Carers of young people with severe and profound disabilities in selected rural remote and Indigenous communities of Australia: final report prepared for the Commonwealth Department of Family and Community Services 2001 cited in Carers Australia Submission to the Senate Inquiry into Men's Health 2009

Percival R & Kelly S, 2004, Who's going to Care, Informal Care and an Ageing Population Report, Prepared for Carers Australia by the NATSEM, University of Canberra

South Australian Council of Social Service, 2009, Cost of Living Biannual Update No. 1, July 2009

StollzNow, 2005, A Crisis in Caring or a system that Works?, prepared for Carers Australia, Canberra

Taskforce on Care Costs, 2005, Creating Choice: Employment and the Cost of Care, TOCC, Sydney

Taskforce on Care Costs, 2006, Where to now? 2006 TOCC Final Report, Taskforce on Care Costs, from www.tocc.org.au

The Australian 1 December 2009, 'Consumers face 50pc power bill rises'

University of Auckland, 2009, Experiences of Informal Caregivers in New Zealand, Auckland)

University of Melbourne, 2006, Mixing paid work and disability care – no longer a recipe for stress, University of Melbourne, Melbourne, unpublished

Wooff, D., Schneider, J., Carpenter, J. & Brandon, T., 2003, Correlates of stress in Carers. Journal of Mental Health: Feb 2003.