

Carer Opportunity and Choice Challenges for Candidates

Carer Awareness Campaign State Election 2010

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.

Carers 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 give care for a few hours each week.

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. Carers have diverse needs, which can change over a lifespan, requiring specialised assistance through flexible and responsive supports to maintain their family, workforce and community connections.

Strategic Recognition and Awareness

Carers have indicated the importance of legislative and policy recognition in driving culture change to highlight the impact of caring, the acknowledgement of Carer expertise and the value of Carer involvement in service planning and delivery.

Carers want a consistent whole of government approach through strategies that recognise the across portfolio nature of the caring role and the need for each government agency to develop Carer policies and programs within a central framework; including short and long term strategic goals.

This strategic approach and its implementation plan occur within the context of the SA Carers Recognition Act 2005, the SA Carers Policy 2006, the South Australian Strategic Plan 2007 and the commitment to social inclusion.

The Challenge

The expectations of increased community recognition and Carer self awareness mean that appropriate resources need to be set aside to address growing need and positively affect the lives of South Australia's Carers on a day-to-day basis.



Partners in Care

Carers are partners in care as they undertake many duties complementary to health and care professionals. Of particular importance is the role of Carers within the health system, where Carers are partners in the delivery of health care as they accompany the care recipient to medical appointments and take responsibility for their health care needs at all other times.

For the partnership to be effective health and other service professionals need to recognise Carers' experiences and their knowledge of the care recipient

and involve them in the planning and delivery of services.

The Challenge

A participation and partnership template will facilitate consistency amongst service providers in working with Carers.

Support for the participation of Carers as partners in care includes the education of Carers in managing their interaction with service systems, education for service providers on Carers and Carer involvement strategies across the entire health and other service systems.

Caring for Carers

Assessment

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. Important in the delivery of services for the Carers is Carer assessment covering the Carer's time commitments, training and respite needs and the social, health, emotional and financial impacts. It needs to identify Carers most at risk and take into consideration the particular needs of special groups.

The Challenge

Developing a common Carer assessment tool from current clinical trials will enable Carers to be assessed independently from the care recipient and provide for a re-assessment when circumstances change.

Health

Carers are at great risk of ill health due to the physical, mental and emotional stresses of the caring role. They have the lowest collective well-being of any group surveyed in Australia. Moving into the caring role is associated with anxiety, depression, sleeplessness and stress. Carers report increased chronic illness making them at greater risk of morbidity, disability and mortality than non Carers. The combination of tiredness, lack of energy, unhappinesses, unfulfilled roles and life goals can act as precursors to depression.

Carers, in putting their needs last, are slow to recognise, acknowledge and seek treatment for their own health problems.

After prolonged care giving, past Carers need ongoing support to recover from the health impacts of caring.

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. Counselling services are witnessing increasing demand and more complex calls from Carers.

The Challenge

The importance of a comprehensive Carer Health Program across all sections of Health to safeguard and improve the health and wellbeing of Carers cannot be over emphasised: including education about Carers, a Carers Health Assessment Tool for use in General Practice and clinical settings, a GPs Education and Liaison Project, post discharge support for Carers who are themselves patients, training resources in health care management for Carers and appropriate provision for counselling.

Respite

Respite is important for Carers to give them a break from the rigours of the caring role. Carers want adequate, appropriate, quality, affordable and flexible respite of all kinds.

In many situations respite is not available, suitable, acceptable or possible so family members do not get the break they need. Whilst government funds for respite rises, programs are increasingly targeted and provide emergency rather than ongoing support; but a study showed that increasing investment in respite gave a return of seven to one to governments by reducing numbers in institutions.

The Challenge

Appropriate and adequately resourced ongoing respite is a major factor in enabling Carers to care over the long term and to make choices about participation in work, leisure, networking and other activity.

Financial Resilience

Many South Australian Carers are living in poverty. One third of primary Carers live in the poorest fifth of households. They struggle to meet the increasing daily costs of caring.

Government bonuses, allowances, concessions and the Companion Card all help: but they have a decreasing face value and many Carers miss out due to restrictive criteria.

The Challenge

An effective concessions and subsidies regime that meets the ongoing rises in the costs of caring is a top priority for Carers.

Regional Carer Support

A network of Carer support organisations plays a vital role in supporting the health and wellbeing of Carers, particularly in rural and regional 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.

Being able to talk to others in a similar situation is the greatest help of all, because Carers best understand other Carers' feelings, concerns, and needs.

The Challenge

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

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

Carers in Rural and Remote Regions

Carers across rural South Australia face long distances, limited or no public or community based transport options, services based in Adelaide, lack of care workers, 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 Challenge

Social inclusion means developing properly resourced strategies to overcome the particular isolation of rural and remote Carers.

Special Needs Groups

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.

The Challenge

Specific services and communication methods are required to reach out to, and support, Aboriginal Carers.

Culturally and Linguistically Diverse Carers

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.

The Challenge

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

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 sole parents.

The Challenge

Services that provide 'all of life' support tailored to the individual family needs will underpin the caring.

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. Studies show significant numbers of young Carers carrying out caring duties over 50 hours per week, with children as young as five becoming Carers and remaining Carers for over a decade.

The Challenge

A program that integrates community and schools based programs would facilitate the development of young Carers as individuals, with educational participation, resilience and the maintenance of their health and well being. Services to the whole family would enable them to reduce their caring role.

Ageing Carers

Carers who are getting older themselves may have been caring for many years and are concerned about who will care when they cannot. They need information about options for, and the legal and financial requirements of, permanent care arrangements as well as ongoing respite and other support.

The Challenge

Assisting with transition of care is central for ageing Carers.

Working Carers

The fulltime employment rate of primary Carers is less than half that of the general population. Many Carers work below their skill and experience levels and can face multiple difficulties in the workplace. Remaining at work relieves financial hardship and social exclusion.

The Challenge

Coordinated action by employers, unions and government through integrated Carer friendly workplace programs will enable caring to be compatible with paid work.

Carers of People with Mental Illness

The insufficient ongoing state resources for community based care, social support and housing options for people with a mental illness results in considerable burden on Carers who need support in their own right.

The Challenge

Creating suitable and appropriate housing options with ongoing support to enable people with serious mental illness and associated disabilities to live well in the community will significantly reduce the overwhelming burdens on their Carers, particularly ageing Carers. A mental health education and liaison program for Carers will provide tools and links for their caring.

Comprehensive Quality Services

The needs of the Carer are inextricably linked with those they care for. Unmet need gravely impacts on the Carers who are left to pick up the caring burden. Carers want clear information and guidelines about the services for the care recipient; access to timely, affordable and quality equipment; adequate, qualified and credentialed care staff; clear service delivery agreements between themselves, the care recipient and service providers; affordable quality respite options for the care recipient that operate at times that fit with education or employment and

recognition of mental illness in the criteria for HACC services.

The Challenge

As demand for care in the community continues to increase 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.

Who is There to Care for You At Home?

The Facts

- 1 in 8 South Australians (222,700) provide 'informal care'.
- 30,300 are young Carers under 25, of whom 14,800 are under 18.
- 18% (41,290) are primary Carers, with major responsibility for another person's well being.
- 71% (29,441) of primary Carers are female.
- 48% of primary Carers provide at least 40 hours per week support.
- 44% of primary Carers themselves have a disability.
- Primary Carers have risen from 3.4% of the general population in 1994 to 5.9% in 2004.
- Carers are getting older: 56% will be over 65 in 2031, up from 42% in 2001.
- By 2031 Carer numbers will increase by 57% compared with a 160% increase for older people requiring care - a 'Carer crunch'.
- An estimated 64 million hours of caring are provided by Carers each year, valued at \$2.4 billion (Access Economics).

A New Social and Service Delivery Context

- South Australian legal and policy recognition of Carers and their role as partners in care.
- An older population in an ageing State.
- The rise in chronic, long-term and life-threatening illnesses.
- Increasing privatisation of care.
- An emphasis on providing care within the community rather than in a hospital or in institutions.
- Carers have less access to additional informal support than in past generations, due to the changed family structure including more marriage breakups, more complex inter-kinship relationships and women caring for extended ex-partners' family relationships.
- Carers may also be juggling multiple roles in paid and unpaid work, with a high degree of transition into and out of the caring role.

The Challenge

Carers SA acknowledges the ongoing and increasing support for the work with Carers.

Support for the range of measures outlined in this document is needed by Carers to build on existing and developing work across the government and wider community.

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 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.

Election comment the responsibility of Rosemary Warmington 58 King William Road Goodwood.