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Submission No. 684
(Inq into better support for carers)

Carers SA
AUSTRALIA
Supporting Family Carers

Carers SA Submission to the House of Representatives Better Support for Carers Inquiry

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1 Introduction

Carers SA welcomes the opportunity to present this submission to the Better Support for Carers Inquiry of the House of Representatives Standing Committee on Family, Community, Housing and Youth.

Carers SA acknowledges the support that has been provided through a range of programs of the Commonwealth and South Australian Government for carers.

The intent of this submission is to provide South Australian perspectives and experiences to inform a national framework for, and implementation of, the development of policy and programs for carer support. Much more needs to be done.

This submission complementary to, and supportive of, the Carers Australia submission.

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 carer support sector
- Participation and partnership.

At the heart of the discussion and recommendations presented in this submission are the stories of the carers themselves. We have presented a small sample of comments received by Carers SA in the course of our representative work over the past couple of years.

1.1 Carers SA

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 carers in South Australia. Carers SA is a member of Carers Australia, as are Carers Associations in all states and territories (the Network of Carers Associations).

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 Carers SA members. Refer Appendix One for a selection of carer comments. Carers SA's 6,817 members in 2006-2007 included carers, carer support groups and colleague organisations such as aged and health care service providers.

Carers SA is guided by the following principles:

- Carers have the right to an identity, independent of the person they care for.
- Carers have the right to financial, physical and emotional security.
- Carers and the people they support have the right to live with dignity.
- Carers have the right to access appropriate information and services without discrimination.
- Carers recognise the rights of the person being cared for.
- Carers SA will respect and work with carers and other interested organisations and individuals to meet Carer identified needs.
- Carers from all cultural and special needs groups have the right to be involved and recognized.

1.2 Who are Carers?

Carers SA has been using the following definition (Carers SA 2007):

> "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."

A Carer for the purposes of the South Australian Carers Recognition Act 2005 (South Australian Government 2005) is:

> "A person who provides ongoing care or assistance to someone who has a disability. The disability may relate to a physical, intellectual or mental illness, a chronic disease, a terminal condition or may relate to a person who is frail and therefore needs assistance to carry out daily tasks."
> Volunteers and paid staff (care workers) working for agencies are not included in this definition.

Carers SA supports the position outlined by Carers Australia in its submission to the Residential Aged Care Abuse Taskforce (Carers Australia 2006):

> "The term 'carer' should be reserved for family members or other people providing care on an informal basis. This recognises the extra responsibilities that a person has because they have a family member, partner or neighbour who has a chronic illness, disability, mental illness or who is frail aged."

1.3 Trends

Over 1 in 8 South Australians (222,700) have been 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. 29,441 (71%) of primary carers are female. There are 30,300 young carers of whom 14,800 are under 18. 48% of primary carers provide at least 40 hours per week support. 44% of primary carers themselves have a disability (ABS 2005).

Primary carers in the general population of South Australia have risen from 3.4% in 1994 to 5.9% in 2004 (Health Harrison Research 2004).

By 2031, the percentage of carers is projected to increase by 57%, with 71% more co-resident carers; it is more likely that carers will be older, with an anticipated 56% of carers over the age of 65 in 2031, up from 42% in 2001 (Percival & Kelly 2004).

A "carer crunch' is looming: although the number and percentage of carers has increased, recent projections show that by 2031 carer numbers will increase by 57% compared with a 160% increase for older people requiring care (Percival & Kelly 2004).

1.3.1 "Who is There to Care for You at Home?"

This increase in care is occurring in a new social and service delivery context: South Australian legal and policy recognition of the rights of carers and their role as partners in care; an older population in an ageing State; the increased number of conditions; the rise in chronic, long-term and life-threatening illnesses; increasing privatisation of care; increases in day surgeries; early discharge policies; and an emphasis on providing care within the community rather than in a hospital or in institutions, including the 'hospital in the home' practices.

Carers have less access to additional informal support than in past generations, due to the changed family structure: changes which include less marriages surviving through to people's old-age; more complex inter-kinship relationships; and the role of women in 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 (Lee 2004). All of these factors add to the complexity of how families are going to work out the care relationship.

Regardless of these trends, the expectation, implicit and explicit, continues that any gap will be met by informal carers; that there is always somebody there in the community to care.

1.4 Carer Priorities

The sixth Carers SA Survey of Members (Kilner 2007) was carried out during December 2006 and January 2007. The survey was intended to discover current needs, concerns and priorities of carers who were members of Carers SA.

Carers were asked to indicate the importance of a range of issues. Some issues were not included as they were known as being of high priority including:

- Improvements to the Carers Payment.
- Improvements to the Carer Allowance.
- Support for young carers.

The ten issues given most importance were:

1. Recognition of the needs of special groups across all cultures such as ageing carers.
2. Improved mental health services in the community that support carers.
3. Increasing general community recognition of carers and their needs.
4. Improving concessions and subsidies to help carers meet the extra costs of providing care.
5. Increased funds for programs that support carers.
6. Providing more information to new carers about support services and the caring role.
7. Changes to Government legislation to include carers.
8. Providing education and training to GPs and other health professionals to assist them to understand carer's issues.
9. Recognition of the needs of special groups across all cultures such as carers living in rural and remote areas.
10. Improving the amount of regular, ongoing respite.

1.5 National Strategy, Local Delivery Framework

In order to achieve a consistent approach by the state government Carers SA has called (Carers SA 2007) for a strategically driven whole of government approach that recognised the across portfolio nature of the caring role and the need for each government agency to develop its own carer policies and programs within a central framework; including short and long term strategic goals.

Carers SA welcomed the South Australian government's recognition of the situation and needs of South Australian carers through carer recognition legislation and policy, in particular the encouragement of government agencies and non government service providers to adopt a more consistent approach to responding to the needs of 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 carers by the wider community.

The South Australia experience also occurs within the context of the South Australian Strategic Plan (Government of South Australia 2007) and the state government commitment to social inclusion. This commitment has seen a series of one-off projects including in homelessness, young offenders, school leavers and the mental health system. Carers have been overlooked: the Carers Policy has not been part of the social inclusion agenda.

Carers SA recommends:

- That the first task of the new Australian Social Inclusion Board be to develop a national social inclusion plan, with carers at the core of social inclusion.

- That strategic partnerships be developed between national and state jurisdictions similar to the Commonwealth State and Territories Disability/Council of Australian Governments Agreements be explored as avenues for a national/state strategic nexus for carer support.

1.6 Research

"What is it that makes some carers manage better?" is only one of many questions for which a greater research effort is required. Whilst there is a growing body of research in Australia on carers, its development has been ad hoc to date.

Carers SA recommends:

- That a nationally coordinated approach to research on carers be developed to further our understanding of the contribution of, needs of, and supports required for, carers.

For its part, Carers SA has established a Research Advisory Group whose purpose is to "enhance knowledge based on research evidence about the impact of caring on carers' health and wellbeing and to use the findings to inform the development of services, policy and the future research agenda that contribute to improvements in the area of carer health and wellbeing".

The Role of the Research Advisory Group

1. To promote research strategies which encourage and allow for the active engagement of carers, in the planning, implementation and evaluation and presentation of research.
2. To promote ethical research and evaluation which examines ways in which carers' independence, security, dignity, knowledge, health and wellbeing and rights are affected by service delivery and government policy.
3. To advise Carers SA on research topics relevant to carers that need expansion, which also assist to build a research framework for Carers and advance future policy development.
4. Through members, to create links between Carers SA and research institutions that encourages the development of research on carers in SA.
5. To support Carers SA in its role as a clearing house on South Australian research on carers and link with Carers Australia's national research agenda.

Research project involvement by Carers SA includes partnership in an epidemiological analysis of the health and wellbeing of carers in South Australia (Gill et al 2007) and in national research on the social policy implications of the care-giving responsibilities of children and young adults. Carers SA members participated in the Australian Unity Wellbeing Index study of 2007 (Cummins et al 2007).

2 Carer Role, Contribution, Recognition

Recognition is an important part of bringing about change. Many carers grapple with the term 'carer' and whether or not they want to be seen as a carer. They call themselves a family member, or a friend, or a neighbour, a partner or a lover, but the term 'carer' is often seen to be so objective that they don't want to be called this. Yet, this has been a term that has been applied, because politically it has identified them as a group of people who are saying that they do more, much more than is expected within a normal, everyday caring relationship; and it includes a number of tasks that would normally be carried out by a professional.

Whilst the term "caring" has been associated with a warm, supportive, nurturing, helpful, family, cosy suggestion, in fact carers are doing professional health care tasks; they are the main co-ordinators for the cared for, including dealing with complexities and problems within the system that even the system doesn't realise. Refer Appendix Three: Carer Roles and Tasks.

In the push to reduce the costs of services the needs of carers cannot be overlooked. South Australian 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, equivalent to 3.5% of forecast GDP and 62.6% of other formal health care (Access Economics 2005).

Carers perform the following interdependent roles within the health care system (Carers SA 2005):

- User as a consumer/patient involved in treatment and/or self management.
- Carer representative as an advisory or reference group member involved in quality assurance.
- Advocate for consumer/patient ensuring consumers' needs are met by representing the needs of the consumer via quality assurance systems, treatment plans and clinical processes to improve services provided to the consumer.
- Partner in care involved in clinical process and practice.

These roles must be reflected within language, policy and programs for carers to be valued and recognised within the health and care systems in their own right.

Raising community awareness and acceptance of carers' role in society assists in the validation and self identification for carers themselves. It leads to feelings of being valued and supported. Carer recognition occurs in two ways:

- Through legislative reform to underpin government policy.
- Through general community awareness.

2.1 Legislative and Policy Recognition

Carers have indicated that the importance of recognition legislation is the legal recognition and the 'clout' that legislation and accompanying policy has to drive culture change. Legislation and policy provides a practical and tangible recognition of the impact of caring, acknowledges carer expertise and the value of their involvement in service planning and delivery. It is the beginnings of a streamlined, coordinated response

The South Australian Carer Recognition Act 2005 (Government of South Australia 2005), a formal acknowledgement that carers have rights, recognised carers as partners in care in the community, provided a mechanism for the involvement of carers in the provision of services that impacted on them and on their role and allowed carers to make a complaint about non-compliance with the SA Carers Charter, enshrined in the legislation.

Early action following the recognition legislation included the establishment of the Office for Carers, a Carers Reference Group made up of Carers and representatives from service providers, government departments and Carers SA and a cross government Implementation Group made up of representatives from government departments; the inclusion in service provider contracts of commitments relating to legislative provision and education and training workshops for service providers.

2.1.1 SA Carers Charter Principles

1. Carers have choices within their caring role.
2. Carers health and well being is critical to the community.
3. Carers play a critical role in maintaining the fabric of society.
4. Service Providers work in partnership with carers.
5. Carers in Aboriginal and Torres Strait Islander communities need specific consideration.
6. All children and young people have the right to enjoy life and reach their potential.
7. Resources are available to provide timely appropriate and adequate assistance to carers.

2.1.2 SA Carers Policy: Supporting Carers

The South Australian legislation was followed in 2006 by the SA Carers Policy (Government of South Australia 2006) which considered the dual focus of ensuring that carers were involved in decisions about those they care for and promoting understanding of carers' own individual needs by outlining strategic development under the seven principles of the Carers Charter, to guide state government agencies in policy development, service delivery and funding.

This Policy aimed at overcoming such obstacles to carer support as significant variation in response to carer needs, including overlapping in funding programs; gaps in service; difficulty in measuring the effectiveness of the system as a whole and difficulties in assessing timely information.

By adopting the seven principles state government agencies and funded service providers would "achieve improved health and wellbeing for South Australian carers" through:

- A more consistent approach to responding to carers' needs
- Better coordination between service providers
- A strategic planned approach to funding and resource allocation
- Participation by carers at all levels of policy development and services planning
- Greater recognition and support for carers in the wider community.

In State Budget submissions (Carers SA 2007) Carers SA has called upon the state government to provide substantial ongoing commitment to further the aims of the Carer Recognition Act 2005 and Carers Charter, including the development of a template for government agency carers policy development. Key elements for implementation at government agency and government funded services level include timelines, information provision to agencies, performance indicators, reporting lines and the development of Carer Impact Statements in consultation with carers.

Ultimately the measure of the policy's success will be in how it affects the lives of South Australia's carers on a day-to-day basis. Carers SA has urged the state government to encourage agencies to develop short and long term agendas and strategies for the provision of one off and recurrent funds for programs that meet the needs of carers including a mix of specific measures and inclusion in generic services. A strategic plan for the undertaking of the work to advance the SA Carers Policy is needed. Critical to the success of the Carers Policy will be the additional resources provided to promote and implement the Carers Policy into the future.

2.1.3 Awareness of Carer Recognition Act and SA Carers Policy

Culture change as a result of the SA Carers Policy is being measured by Carers SA through a new set of questions in its regular Survey of Members. In the late 2006 survey (Kilner 2007) carers were asked about their awareness of the Carers Recognition Act, the Carers Charter and the Carers Policy. The answers were a starting point for future comparison of the growing impact of the Act, Charter and Policy. Over half of respondents were aware of the Act, Charter and Policy. Very few respondents however were prepared to state that the Carers Policy has made a difference to the way service providers responded to carers.

Carers had a wide range of experiences in the human services sector, ranging from "poor" through to "very satisfactory". Around half of respondents gave a high ranking to service providers on both responsiveness and supportiveness. About one in six gave a low ranking.

If carers did not make their contribution the cost would have to be met by governments. The expectation of increased community recognition and carer self awareness as a result of the implementation of the SA Carers Policy means that appropriate resources need to be set aside to address growing need.

2.1.4 Current and Proposed Legislation

The introduction of carer recognition and partnership policies and practices raises the requirement for new legislation to underpin the information and assessment needs of the carer needs.

There are a number of current South Australian Acts which have a bearing on carers, including:

- The Disability Services Act
- The Office for the Ageing Act
- The Aged and Infirm Persons Policy Act
- The Consent to Medical Treatment and Palliative Care Act
- The Guardianship and Administration Act
- The Mental Health Act
- The Occupational Health and Safety and Welfare Act
- The Equal Opportunity Act

Equal Opportunity (Miscellaneous) Amendment Bill 2006

Carers SA has sought provisions in equal opportunity legislation on the grounds of caring responsibilities. Carers SA argued that anti-discrimination legislation was of fundamental importance to carer participation; that it was essential that family Carers have their roles and responsibilities safeguarded whilst they undertake employment, education and other day-to-day activities; that it was unacceptable that a person could be discriminated because of a caring role; and that equal opportunity legislation was important for its recognition of family Carers as well as its core protection from discrimination.

Carers SA welcomed the introduction into the South Australian Parliament of the Equal Opportunity (Miscellaneous) Amendment Bill 2006, introduced by the state government as it had done with the earlier Equal Opportunity Bill 2005, introduced by then Democrat member Kate Reynolds, because these Bills included provision of caring responsibilities as criteria for establishing discrimination.

Carers SA remains concerned that the Bill continues to be held up by opposition to other elements contained within it.

Mental Health Bill 2008

Carers SA has welcomed the introduction of the Mental Health Bill 2008 into the South Australian Legislative Council, in particular the recognition the Bill provides of the role and involvement of carers in the care of people with mental illness.

It does this by including carers alongside family, friends, medical agents and guardians who are to be provided with information and/or consulted concerning treatment and detention orders, in the development of treatment and care plans and who can appeal orders. Also the Bill allows for disclosure of information to the carer regarding the illness and treatment of the consumer if it "is required for the treatment, care and rehabilitation of the person".

Carers SA recommends

- That national carer recognition legislation and associated policy be introduced.
- That a review of existing legislation for potential changes to meet the information, assessment and support needs of carers be undertaken.

2.2 Community Recognition

The SA Carers Recognition Act 2005 and subsequent SA Carers Policy, whilst valuable and welcome developments in the recognition of carers in South Australia, will not, of themselves, significantly raise community awareness. Recognition work being undertaken by the SA Office for Carers amongst the state government agencies must be broadened to the whole community.

Carers SA recommends

- That an ongoing national community awareness campaign on carers be undertaken.

2.3 Carers as Partners in Care

2.3.1 Participation and Partnership Project

The role of carers as partners in care recognises the many functions and duties carers undertake in conjunction with the health and care system complementary to health and care professionals. We have outlined these tasks above (refer Appendix Two: Rights of Carers in Partnership).

Whilst the promotion of the SA Carers Recognition Act 2005 and the SA Carers Policy will build upon existing goodwill in the community and amongst service providers toward carers nevertheless, when it comes to building the participation of carers in service delivery, and a genuine sense of partnership with them, many service providers need guidance.

There is no training for service providers about carers and the provision of support services that would meet their needs in South Australia. A comprehensive education and training program for service providers on carers and the caring role is required if services are to have the capacity to respond to developments arising from the State Government's Carers Recognition Act 2005 and SA Carers Policy. This would serve also to facilitate a consistency of carer policies amongst service providers and the timely development of same.

Such a program would address the knowledge and skills necessary for working with carers across all chronic illnesses, conditions and disabilities; the major issues that have been identified for carers, including the culture of caring and service provision, carer health and well being and the inclusion by service providers of the carer in the care relationship; the diversity of carers; and information, communication, attitude, assessment, service quality and coordination issues.

Carers SA recommends

- That a Participation and Partnership Project be established that would:
  - Develop a carer's participation and partnership template upon which service providers could build their own individual carer policies.
  - Provide consultancy assistance where required in the development of family Carer policies by service providers.
- That a national strategy for the delivery of a carer education and training program to service providers be undertaken.

2.3.2 Commitment to Partnership in Health

In order for the partnership to be effective, health professionals need to recognise carers as stakeholders and involve them in the planning of home based care and in the discharge from hospital, health or residential facilities of the care recipient; and to consult with carers or their representatives when developing policy, planning and programs which impact on carers and the people they care for.

Within South Australia there has been some shift in policy as evidenced by the development of a draft Older Person's Health Plan, including the role of carers; by the inclusion of chronic illness in the

South Australian Strategic Plan (Government of South Australia 2007) and by the inclusion of carers in healthy ageing plans.

However, the lack of recognition of carers within the acute health system, for example by their identification at the time of the clinical intake of the person they care for, is an example of how lack of implementation mitigates against carers being partners in care regardless of any policy initiatives.

Carers SA recommends

- That appropriate mechanisms within the health system to provide for and support the participation of carers in the health care of those they care be established including:
    - Development of an education campaign within the health system on the role of carers and the part that they can play in care programs.
    - Development of strategies to routinely involve carers in care planning, case conferencing and admission and discharge planning in the hospital, general practice and community care settings.
    - Development of guidelines that provide for 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 carers, care recipients and service providers.

3 Barriers

3.1 The Impact of Caring

3.1.1 The Cost of Caring

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

- Many 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, Independent Living Centre 2006).
- 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 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. Half of a 2005 sample reported going without food or medication for their children at some time due to their poverty (StollzNow 2005).
- The average annual electricity bill for 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: Only 4% of young carer primary carers 15-25 are still in school compared with 23% of the general population (Noble-Carr 2001).
- After government payments were taken into account, the annual 'opportunity cost' to carers when compared with people with no care responsibilities was estimated at $9,300 for a primary Carer and $2,600 for other carers (AMP NATSEM 2006).
- Carers who were in the labour force and paying for care spent an average $162 per week, or $8,400 a year, on elder care and $118 a week, or $6,100 a year, on care for people with disabilities (AMP NATSEM 2006).
- For families where the carer had left work to care for a spouse who was also previously working, the reduction in income and living standards would be even greater. If a single person on an

average wage were to give up work to become a carer their weekly income would drop from $1030 to $294 (AMP NATSEM 2006).

3.2 Caring is a Public Health Issue

Carers are a high risk population group due to the physical, mental and emotional stresses of the caring role.

It is now clear that carers as an identifiable group with some common generic characteristics are at risk of greater morbidity, disability and mortality. Carers have been shown to have a measurably lower health status than non carers in the population (Cummins 2007; Gill et al 2007). Up to a third of carers, by virtue of their caring role and lifestyle restrictions may be prevented from maintaining or achieving optimum health status. It is therefore important to monitor and track patterns and trends in carer health (Stacey 2002).

For example research has indicated that:

- Nearly 50% of carers rated their health only fair and getting worse (Carers Australia 1999).
- Nearly one third had delayed seeking help for their own health conditions because of their caring role (Carers Association of Australia 2000).
- Carers experienced a variety of problems including physical and mental health injuries, heavy workloads and a lack of support and training (Independent Living Centre of WA 2006).
- Moving into the care giving role was associated with increased GP visits, increased use of medication mainly for anxiety, depression, sleeplessness and the experience of stress and increased Body Mass Index.
- Carers have the lowest collective well-being of any group surveyed in Australia (Cummins et al 2007).
- Carers and their families have significantly worse mental health and vitality and higher rates of depression than the general population (Edwards et al 2008).

Adopting a public health paradigm and a population approach to carer health offers new opportunities to better protect and enhance carer health and quality of life through more appropriate health monitoring, maintenance and promotion initiatives being put in place for carers. It will help improve carer policy and allow it to respond not only to the individual needs of carers, but in particular identify the most vulnerable groups of carers who are at greater risk of health problems (Stacey 2002).

3.3 Carer Health Research in SA

3.3.1 The Health and Wellbeing of Adult Family Carers in South Australia: an epidemiological analysis 1994 – 2004

The Health and Wellbeing of Adult Family Carers in South Australia: an epidemiological analysis 1994 – 2004 (Gill et al 2007) explored statistics gathered through the SA Health Omnibus Survey, about the physical, social, emotional and mental health needs of the growing number of adult carers in South Australia. The report[1] presented the demographic and socioeconomic profile of carers, the health related quality of life of carers, selected chronic conditions and health status of carers, selected health risk factors of carers, health service utilisation of carers and carers loss of days because of health. It found that South Australian carers have consistently shown a lower health status than non-carers; that half the caring population is at risk of having their health affected by caring; that more research is needed on the impact of the caring role on the clinical health status of carers.

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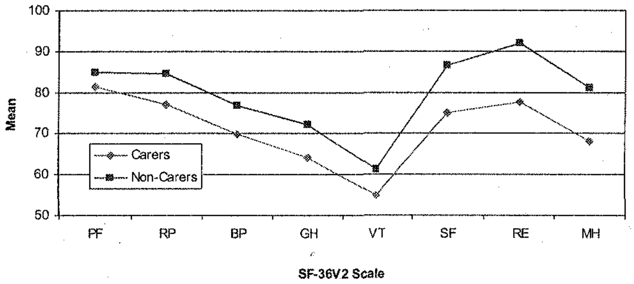
[1] This report was an extension of earlier research thesis work of independent researcher AF Stacey (Stacey 2002) on Carer health as part of the Health Omnibus Survey in association with the Population Research and Outcome Studies Unit, SA Health Department and Harrison Health Research.

The majority of carers perceived that their physical and mental health was negatively affected by their caring role. However, the majority of carers also believed that caring had a positive effect on their sense of health and wellbeing. The report recommended further research to explain the difference.

Carers were significantly more likely to have one (41.5%) or two (21.6%) chronic conditions and less likely to have no chronic conditions (30.2%) when compared to non-carers. They were statistically significantly more likely to have at least one health condition (69.8%) compared to non-carers. There were a higher proportion of carers who reported undertaking insufficient levels of physical activity. Carers were statistically significantly more likely to report high blood pressure (41.6%), high cholesterol (28.8%), or be categorised as overweight or obese (55.7%), compared to non-carers.

Carers were statistically significantly more likely to have visited a general practitioner (60.1%), a district nurse or other community nurse (4.7%), psychiatrist (3.1%), or a social worker (5.4%) compared to non-carers.

Health-Related Quality of Life of Carers



Graph shows PF - physical functioning (limitations); RP - role physical (limitations); BP - bodily pain, GH - general health; VT - vitality; SF – social functioning; RE – role emotional (limitations); MH – mental health

Carers SA recommends

- That a formalised tool for the clinical health assessment of carers be developed.
- That further research on the impact of the caring role on the clinical health status of carers be undertaken.

3.4 Rural and Remote in South Australia

South Australia differs from eastern states in that its regional centres are not the large urban centres of the Eastern states. In the mid north for example there are 30 towns with populations less than 500. The major centre, Clare, has a population of 3,500 – 4,000. The result of this dispersed population is limited infrastructure. Transport, respite and workforce issues are significant.

Transport issues are significant and cannot be underestimated. Long distances need to be travelled, not only within regions, but also to access Adelaide based services. Many health services upon which care recipients are dependant are in Adelaide, such that carers need to travel to Adelaide to access the health care for care recipients. Who cares for the family in that situation? An ageing population moving from properties into smaller towns or regional centres are becoming increasingly isolated from former support structures and networks. How do the city and the country assist? Long distances and limited populations work against the development of appropriate public transport.

The current discussion in South Australia on 'self managed care' or 'self directed care' assumes that services are available. Invariably they are not. Respite services find it difficult to attract staff away from metropolitan Adelaide, limiting their available options, which impacts on carers who then find it difficult to access respite to attend activities such as carer retreats, let alone any ongoing employment options. For example, for carers living in small outlying towns the cost of respite can be prohibitive. Assuming an 8 hour day, with 45 mins each way and half hour for lunch the carer is looking at finding a 10 hour respite block. The cyclical nature of agriculture also puts pressure on respite services.

Promoting work in viticulture or mining during agricultural 'off-seasons' just places more pressure on families, and in the words of one carer, is "asking people to fall in a heap."

Caring issues become acute when the only employment opportunities are some distance away. For example, on Eyre Peninsula, the mother in a family works 5 hours away, leaving the 17 year old daughter as the primary carer for her 63 year old father.

The difficulties for these carers living in rural and remote regions are exacerbated when they are not always well enough to care: who then will care for the person they are caring for in the absence of sufficient respite services, and who will care for them in the absence of nearby family or support services? Increasingly access to GPs is limited as fewer and fewer GPs are attracted to rural and remote communities: waiting times of up to weeks are being reported.

3.5 Essential Services

3.5.1 Between a Rock and a Hard Place

Electricity Costs Questionnaires

Energy costs are a significant burden for carers who rely on year round comfort for those they care for. Carers, already concerned at general price increases, viewed with alarm an expected 25% electricity price rise at the beginning of 2003 when South Australia would deregulate the electricity market.

In response to these concerns Carers SA had sought the views of carers through two Electricity Costs Questionnaires, one in September 2002 (103 returned) and another twelve months later (81 returned).

In 2002 carers were asked about their use of electricity or gas; the potential impact of electricity price rises; their use of, and attitude to, financial assistance; ways they would tackle increasing prices and their opinions on what the government could do to help them.

In 2003 carers were asked about special caring needs that affect the use of electricity; a comparison of their last quarterly electricity account with that of 2002; reactions to the price rises; changes to the way they used electricity following the increases and whether this made a difference to the bill; problems experienced paying the bills and assistance sought and whether the information provided about the price rises and individual accounts was adequate.

There were significant levels of resignation, that is, carers felt that they had no choice but to pay. However, because the need for power, particularly for heating, cooling and life maintaining equipment, was a priority and money was limited, respondents indicated that they cut back on other life essentials including food. Cutting back on the use of oxygen equipment, showering less, wearing two lots of clothes, wrapping up in blankets and staying in bed longer were just some of the measures that they had had to take during the winter months

Highlights

- Energy costs were a significant burden for carers who provided care in the home for family members with chronic illness, disabilities or who were frail aged.
- Carers used 14.5% more electricity on average than other South Australian households.
- Over the twelve months of the survey period carers had experienced electricity price increases of 32% ($80.96/quarter).
- Following the increases carers on a single Carer Payment were paying 11.5% of that benefit on electricity. By comparison the average electricity bill for carers represented only 3% of the Male Total Average Weekly Earnings.
- Carers felt shocked, angry and overwhelmed at the price rises. They were worried about how they could pay their bills. They felt betrayed and robbed.

- Because the need for power was a priority for the health and well being of the care recipient, and money was limited, carers cut back on other life essentials.
- Whilst 73% reported changing the way they used electricity only 47% reported that it had made a difference to their bills.
- 41% said that they had trouble paying their bill, a 5% increase over the twelve months. 15% sought external help; double that of the previous study.
- Carers felt devalued by suppliers and the government.

Carers SA recommends

- That governments and energy suppliers to continue to explore ways to provide appropriate financial and other support for carers least able to afford increased energy costs but for whom electricity is an essential commodity, including:
  - Recognition of the additional burden on carers of the energy costs in meeting the needs of the care recipients.
  - Recognition of the Carers Allowance as a basis for eligibility for concessions and subsidies for household costs.
  - Development of strategic programs of education on entitlements to concessions and subsidies.
  - Increasing carer income support.

3.5.2 On the Up and Up

Two recent newspaper stories highlight the every increasing burden of essential service costs.

- South Australians would pay an extra $75 a year for electricity and gas, reported The Advertiser, 25 June 2008. South Australian analyst Mark Henley was reported to have said that low income families would be hardest hit on the back of rising food, petrol and health costs.

  "The bad news obviously is that for low-income people energy and rent costs keep going up while wage increases are not going up at the same rate. Every price increase just creates more pressure for low income households." he said.
- South Australian families would be forced to pay out an average of $310 more a year following an increase in government fees and charges, according to the Advertiser 28 June 2008.

3.6 Carers of People with Mental Illness

3.6.1 Mental Health and Housing

For many older carers who are caring for adult family members with a mental illness in the home, matters related to housing are of critical importance. Many older carers play a financial role in assisting their family member with housing in the absence of adequate community care and the reduction of public housing stock. And so they are meeting the capital costs that were previously met by disability programs or mental health programs.

Carers are very concerned about providing appropriate accommodation and support for their family members with serious mental illness and associated disabilities.

In 2006/07 only 59% of people with self-reported mental illness who applied were granted public housing in South Australia (Housing SA 2007). Additionally, a survey of inpatients in mental health beds across the country showed that around 50% of patients were still in hospital because they had no home to go to[2]

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[2] Unpublished report Department of Health and Ageing Canberra.

The lack of availability of public housing and appropriately supported accommodation options for people with serious mental illness not only puts those with a mental illness under housing stress, but also makes caring more difficult for the parents, especially as they grow older and their own health starts to deteriorate.

Older carers are particularly concerned about trying to meet their own end-of-working-life transition and accommodation needs, whilst still struggling to provide extensive emotional and financial support for older children either living in their home or in independent accommodation. Not only do their adult children with a mental illness need the infrastructure of housing through a better social housing model, but to be sustainable supports are needed to support people in their homes. Because the family cares for them they are considered to be less urgent cases, and it seems are even less likely to receive the support and housing they need to achieve recovery.

Caring About Housing (Carers SA 2008), a position paper prepared by the SA Mental Health Carers Housing Group outlines an action plan, including:

- A Housing and Support Plan for People with Mental Illness that responds to the various levels of needs of people with mental illness.
- Coordination of suitable and appropriate housing options with the varying levels of ongoing support required to meet the needs of people with serious mental illness and associated psychiatric disability to enable them to live well in the community.
- A targeted assistance program to make private rental or other housing options affordable for people with mental illness.
- Ongoing input by carers and consumers to develop, monitor and report on the effectiveness of the Housing and Support Plan for People with Mental Illness.

3.7 The Work/Life Balance: Employment and Care

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

Other reports indicated significant numbers of carers had reduced their working hours due to the cost of care, or were likely to consider leaving the workforce due to the cost of care (TOCC 2005); many carers working part-time would increase their hours if care were more affordable (TOCC 2006); carers were less likely to suffer from stress if they combined their caring role with paid employment (University of Melbourne 2006) and that carers may need help in order to enter or re-enter the workforce after a period of caring.

3.7.1 Carers as Unpaid workers

It needs to be recognised that carers are either in the paid workforce or are providing unpaid work as a carer. When exploring issues of the work/life balance it is vital that we do not just focus on those in paid work, but on supporting the efforts of these unpaid workers. For carers the caring role is their first job and any paid employment, if possible, is their second job.

Health considerations alone indicate that carers need to prepare a life/work balance in their role of providing unpaid work as a carer. Carers must be provided with services that give them a real break from their work as unpaid carers. This requires a range of adequate services that truly recognise carers as entitled to services such as respite in their own right and not as a subsidiary of the cared for person.

Carers do the bulk of the caring work in our community caring for the frail aged, the chronically ill or people with disabilities, providing 70% of the community care system. Two thirds of all care and support is unpaid (AIHW 2001). This unpaid care is worth an estimated $2.66 billion to the South Australian economy annually (Access Economics 2005).

Carers, whether in the paid workforce or not, cannot leave what they are doing. They report that they stay at home "because I could not afford the care needed; if working, access to subsidised care is limited".

As we argue throughout this submission, 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. The terms of reference for this Inquiry attest to a range of special needs groups that require particular attention.

3.7.2 A Coordinated Approach

Coordinated action is required by individuals, employers and community and government bodies to integrate initiatives. Effectively addressing the barriers to carer workforce participation requires not only a coordinated whole of government approach through key portfolios, but also a cooperation across the tiers of government. The July 2006 meeting of the Council of Australian Governments (COAG) agreed to cooperate on a series of reforms aimed at building Australia's 'human capital'. Of the agreed reporting framework the fifth outcome acknowledged the need to provide flexible working arrangements particularly for working parents (ARACY 2006).

Strategic plans and carer policies such as the South Australian Strategic Plan 2007 and the SA Carers Policy 2006 would provide useful frameworks to develop a national perspective.

Carers SA recommends

- That a nationally coordinated employment and care program be introduced including:
- Access to advice, counselling and information for carers.
- Supportive workplaces which recognises individuals have to balance work with other responsibilities and provides flexible work practices and arrangements:
  - Strategies for carer identification at induction and as situations arise.
  - The government to take the lead by developing and undertaking Public Service employment and care policies and practice as a model for the business and community sectors.
- Education campaigns targeting employers to recognise the skills developed during caring.
- Appropriate, adequate and affordable alternative care programs and support services for carers and those they support, including respite, care for children with special needs, daytime care and/or activities for young/mature adults with disabilities, frail older people and dementia sufferers.
- Security of welfare entitlements, at least until paid work is adequate and stable.
- Access to affordable transport.
- Specific strategies for young carers.
- Accessible and appropriate training and education, to update or maintain relevant skills for periods that carers are out of employment, with recognition of the knowledge and skills gained in the role of unpaid, informal carer to support their work related skills development and job applications:
  - Provision of a scholarship program to enable attendance.
  - Provision within government labour market programs for carers seeking re-entry.
- Government rebates to carers for the costs of care which would prevent many carers from leaving the workforce or provide them with the means to increase their hours of work, including:

    - 50% care costs reimbursement up to $10,000 per annum similar to Child Care Rebate delivered either to carer, care provider or employer.
    - Claiming care costs as a tax deduction where it can be demonstrated that paid care was necessary to allow the carer to be in paid work.
- Legislation and regulation that develops a national Carer Policy; identifies carers' rights in terms of services, assessment and alternative care services for the person they support; protects carers' rights at work, for example 'right to negotiate' legislation[3]; and provides for workplace flexibility, equal opportunity and lack of discrimination.
- Superannuation scheme for carers who have to take time out of the workforce to care, including government contributions for periods that carers are out of the workforce or have impeded workforce participation.
- Policies that set out the responsibilities of different departments and agencies and the business sector in terms of adequately supporting carers.
- Research, including:
    - Data collection that identifies carers who are in work or who would like to work.
    - Analysis of census data to determine further demographic, household and financial information about carers in the workforce.
    - Development of models of support for carers.
    - Analysis of the impacts of welfare to work reforms on carers.

4 Practical Measures

4.1.1 Principles

Core principles for practical measures include:

- Health and wellbeing
- Capacity building for carers and the sector
- Participation and partnership

Carers want a good quality of life for themselves and the people they care for: they want control of their own lives.

Principles for the Ageing Carers Project

Carers SA, in developing its Ageing Carers Project, established the following principles in keeping with the Carers SA mission to promote, assist, empower and enhance the lives of carers:

1. Ageing carers to be consulted about their needs and wishes concerning the project.
2. Carers to be involved in all aspects of the delivery of the forums.
3. The needs of carers to take priority in designing the forum program.
4. Carers SA to work in partnership with other organisations to deliver the forums.
5. The forums to be aimed at a generic audience: Culturally and Linguistically Diverse and Aboriginal forums should be separately funded.

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[3] For example, United Kingdom's 'right to negotiate' legislation where an employee has the right to request flexible working from the employer to meet their caring responsibilities for a child under 18 with disabilities and for caring for adults (The Parliament of the Commonwealth of Australia 2006).

4.2 Carer Assessment

Each carer has his or her own needs separate from the care recipient, for the carer is not only providing care but struggling to maintain their own capacity and well being. In particular, carers often find it hard to voice their own needs when attempting to secure adequate and appropriate care for the care recipient. It is too often the 'normal' experience of carers for the different challenges experienced by families not to be taken into account or assessed or even acknowledged by those services. This can be frustrating for carers.

Carer assessment is an important component in determining and in developing appropriate services for the carers themselves and/or referring them to appropriate support services. Such assessment should cover the carer's time commitments, financial impact, training needs, respite needs and social, health and emotional impacts. Whilst recognising that all carers are vulnerable, assessment needs to identify carers most at risk. This assessment needs also to take into consideration the particular needs of special groups such as Indigenous carers, carers from culturally and linguistically diverse backgrounds, young carers, ageing carers, sole parent carers and those from rural and remote regions.

Carers SA is concerned that current practices for service access by carers continues to rely on the care recipient being in receipt of services. However, 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 a protection to carers to have their needs taken into account at that time. It would also provide for a re-assessment when circumstances change, whether for the carer or the care recipient, including receiving greater assistance.

Carers SA has been involved at state and national levels in the development of a Carer Assessment Tool.

Carers SA recommends

- That a common carer assessment tool be further developed and funding provision be made for training in its use.

4.3 Carer Support Services

In South Australia carer specific support organisations across the state, funded by the Home and Community Care program, play a vital role in providing services for carers, particularly in rural and regional areas. These organisations have adopted a strong peer support approach to delivering support to carers, providing a foundation for connecting carers and local services, enabling the accumulation of knowledge about carers and developing support structures for carers within local communities. They have played a vital role in supporting carer health and wellbeing.

Carer Support assists carers and past carers to meet others with similar experiences and:

- Provides opportunities for carers to meet together in social, information, educational and retreat events, to help one another with friendship, information and ideas and to give one another strength and courage to continue in the caring responsibilities.
- Provides opportunities for carers to have time out from caring responsibilities.
- Gives Carers recognition and values their contribution to the community.
- Works collaboratively with services and community organisations to provide appropriate information through newsletters, forums and information resources.
- Enables carers to assist services by participating in forums, committees and focus groups, as well as consultations.

Sustainability and Community Capacity Building

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. Through this support carers are eventually able to offer back support to other people in similar situations and to participate in service providers' structures.

This has created a cycle of sustainability: the creation of a community of carers building community capacity within the wider community. This group of carers, then, has a wider impact on the local community by articulating the need for services and by representing carers on local service committees and advocating for improvements.

In this model carers are considered true partners in the delivery of community care and in community capacity building. Their strengths as a carer are recognised and built on, they are empowered to fully participate and they contribute more widely to the health and community care debate.

The contribution to the health and well being of carers by the intervention of these Carer Support activities cannot be overstated. By their efforts in maintaining carer health and well being Carer Support services are preventing the much larger costs to the community of Carer breakdown. Investment in carer support has been shown to give returns of seven to one to government in financial terms only, not including the quality of life outcomes for carers and those they support (Access Economics 2005).

The South Australian regional Carer Support services have provided a wide range of ongoing assistance and by encouraging and facilitating innovation have attracted other services beyond the core services funded through the Home and Community Care program. These have included carer retreats, forums for ageing carers and carers of people with a mental illness and young carer support, Aboriginal carer support and support for carers from culturally and linguistically diverse communities. Other programs that could be placed within Carer Support include across agency coordination and projects for other special needs groups.

4.3.1 Carers SA Carer Support

Since 1995 Carers SA, for example, has been offering Carer Support services through regional programs in the western metropolitan, Eyre Peninsula, Far North, River Murray and Mallee and South East regions of South Australia using a community development model. Terms of reference have included:

Western Carers

Carer Support will develop a regional network of carers throughout the western suburbs of Adelaide which recognises the uniqueness of the west and its demographic makeup with its diversity of cultural and linguistic communities, and the existing range of carer support groups. It will develop and offer a wide range of choices of carer support: it will offer support through helping carers connect with other carers in the region, access to information and referral to service providers.

Rural Carer Support

Rural Carer Support enables all carers to overcome personal and geographical isolation through mutual support and sharing of caring experiences and information. They are linking carers in ways which promotes their self worth and acceptance within a caring community.

4.3.2 Carer Retreats Program

The Carers SA Carer Retreats Program, funded by the state government through the Home and Community Care program with additional support from Disability, has provided opportunities for carers to have a break from their caring role by offering group and peer support and information through retreats. A retreat is an organised gathering that meets the special needs of a group of carers. The format of a retreat is flexible and responsive to carers' specific needs such as culture, language, location, caring role and interests of the group members.

The underlying philosophy is one of community development. The community development model provides a framework and infrastructure for mutual support, personal and group empowerment, information sharing, networking and system change. The objectives of the Carer Retreats Program have included:

- To provide carers with respite in a manner that will promote and develop social and support networks.
- To provide carers with an opportunity to participate in educative activities that will enhance their ability to perform their caring role.
- To increase the recognition of the contribution made by carers.
- To promote a collaborative approach among organisations to meeting the needs of carers.

The program has provided allocations towards the cost of retreats based on a regionally targeted application process. Retreat Coordinators have been provided with a variety of resources to assist them in the process of planning and organising their retreat. Arrangements for respite for the care recipient have been the carer's responsibility, although payments for respite have been be provided.

The Retreats are organised by the carer support groups themselves to ensure that the retreats meet the specific needs of each group. Benefits for carers have included the development of new friendships, networks and supports; learning from each other; deep relaxation; having an opportunity to have fun, take time for themselves and be pampered for awhile; and the opportunity to re-energise themselves and feel encouraged to continue caring.

The Carers SA Carer Retreats Program has been identified as a best practice model by Culturally and Linguistically Diverse communities.

4.3.3 Across Agency Coordination

Carers need assistance to juggle 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.

Carers SA recommends

- That a national Carer Support program, to be delivered regionally, be introduced.

4.4 Respite

Respite is important for carers to give them a break from the rigours of the caring role. Respite – adequate, appropriate, quality, affordable and flexible respite of all kinds including in home, out of home, emergency, long term and residential - continues to be a major factor in increasing the longevity of carers undertaking their caring role and in enabling carers to make choices about participation in work, leisure, networking and other activity.

Carers SA, in supporting the ongoing delivery of respite, discourages the blanket view that respite will solve all the needs of carers. In many caring relationships respite is not available, suitable, acceptable or not possible which ultimately means that family members carry the duty of care. In providing care there are many other ways that carers require assistance, as this submission attests.

Whilst Carers SA acknowledges governments' support for respite Carers SA remains concerned that respite allocations, in particular through the Commonwealth Respite and Carelink program are increasingly targeted and continue to be focussed more on emergency respite than ongoing support.

The need for carers to have a long term plan and access to respite in order to plan quality of life activities beyond necessities is important: carers have a right to a quality of life that is provided by having a break or a holiday that others in the community enjoy.

4.5 Transport

The provision of low cost accessible transport options, particularly in rural regions, has a vital role to play in the accessing of services and reduced social isolation for care recipients and carers alike, particularly in the case of young carers. Affordable options for the care recipient would provide significant relief to the carer who otherwise is responsible for providing the transport needs for the care recipient to services and appointments.

In South Australia Carers SA has acknowledged reforms to South Australian Transport Subsidy Scheme including the Plus One scheme where the carer accompanying the care recipient travels for free on public transport, the increases in the number and value of vouchers and the use of multiple vouchers per trip and an increase in the number of Access Cabs.

Carers SA has called (Carers SA 2007) for greater promotion of accessible bus routes and times and for further consideration of ways of supporting alternative transport options in areas where, or at times when, accessible transport is not available is required and the development of secure anti-fraud measures to enable greater flexibility in the use of the South Australian Transport Subsidy Scheme, in particular the allocation of vouchers based on need rather than quotas.

4.6 Advocacy: Complaints and Appeals

There is a need for accessible, appropriate and transparent complaints procedures for carers about service providers and government departments and agencies that meet Australian standards. The South Australian experience is one of limited and decreasing resources.

The establishment in South Australia of the office of the Health and Community Services Complaints Commissioner has been important to redress attitudes to service complaints. Carers, however, are low users of complaints: not that they do not have complaints but their exhaustion and everyday battle with the basics means they need additional support and counselling to think of making a complaint. In addition, carers have real concerns about retribution.

Carers SA recommends

- That a nation wide personal advocacy service for carers be introduced.

4.7 Carer Health

Whilst carers, in putting the needs of the care recipient before their own, are slow to recognise, acknowledge and seek treatment for their own health problems, it is vital that health professionals within a clinical and population approach can identify them as carers and address their concerns as identifiable, treatable and preventable.

The development of a clinically based carers health assessment tool, in association with a common carer assessment tool, would assist this process, particularly at times of changing circumstances.

General Practitioners have always been an important point of contact for carers as many carers accompany the person they are caring for to medical appointments. 75% of Carers first point of call is a GP. GPs can provide information and emotional support to carers, as well as monitoring their health needs. A resource for training GPs in the needs of carers, the GP Kit, including who carers are, their needs; and the importance of providing information and support to Carers and linking them with carer support services has already been developed by Carers SA but assistance is required in order to update, promote and undertake its use.

Australian research has indicated that one third of Carers were severely depressed and/or stressed (Cummins et al 2007). The combination of factors such as tiredness, lack of energy, unhappinesses, unfulfilled roles and life goals can act as precursors to clinical depression. One additional factor which can push pre-depression into a clinical stage is the deterioration of the cared for person's physical or mental condition.

Therapeutic counselling that addresses stress management, isolation self-care, grief and loss and transition decision making continues to play a vital role in preventing the complete collapse of carers overwhelmed with their circumstances, and/or in maintaining carer well-being. Carers SA is witnessing increasing demand both for formal and informal counselling through its services: for example, staff of the Carers SA Carer Advisory and Counselling Service are reporting carer needs becoming more complex, requiring greater levels of assistance.

Carers SA recommends:

- That the National Carer Counselling Program be further enhanced.
- The a Carers Health Policy be developed including:
  - An education campaign within the health system about carers.
  - A Carers Health Assessment Tool for use in General Practice and clinical settings.
  - A GPs Education and Liaison Project.
  - Education campaigns within the health system and the community about the importance of good health for carers.
  - Specific injury minimisation programs for carers.
  - Training resources in practical nutrition and health care management for carers.
  - Specific mental health programs.

4.8 Ageing Carers

4.8.1 The Ageing Carers Project

Carers SA undertook an Ageing Carers Project, Ageing Carers of a son or daughter with a disability or mental illness – planning for the future, in response to the needs of ageing carers, identified as including the physical burden of caring, feeling helpless and not in control, with problems unappreciated by professionals and the challenging behaviour and strain of looking after their adult child. The carers were getting older themselves, had been caring for many years continuously, tended to be 'lone carers', had become isolated from professionals and the service system and as a result were self-sufficient and unwilling to ask for help. They needed information and education about navigating the service system, the legal and financial requirements of permanent care arrangements and their options for permanent care arrangements. Their own needs included respite, caring for their own health and wellbeing and future life planning.

The project sought to provide assistance with the issue of transition of care. The project was delivered through a series of ten forums held in metropolitan and country regions across South Australia. The forums focussed on the planning needs of ageing carers caring for a son or daughter with a disability including mental illness by providing:

- Information
- Opportunities for carers to meet, network. and connect with Carers SA and local Carer Support.
- Recognition of carers for their contribution to the community, including Aboriginal and Culturally and Linguistically Diverse carers.
- The chance for carers to meet local service providers, to hear about their services, including new initiatives.
- Feedback from carers about service delivery and the impact of this on carers' needs from carers.

Project resources included the background paper, Ageing Carers of People with a Disability, a future planning Checklist, a Contact List and Information Pack.

The ageing carers who attended included[4] 26.3% who cared for a son or daughter with a mental illness, 44.1% who cared for a son or daughter with a disability, 23.7% who cared for a son or daughter with a dual diagnosis and 5.9% who did not identify the condition of their son or daughter. 60.7% had been performing the caring role for over 40 hours per week, with 64.4% caring for between 36 to 56 yrs.

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[4] Based on 120 completed data collection forms.

5 Opportunity and Choices

5.1 Financial Resilience

5.1.1 Support for Carers as an Anti-poverty Measure

Many carers in South Australia are living in poverty. 37% of carers in South Australia rely solely on a Government pension for their income. One third of people who provided primary care for the elderly or people with disabilities lived in the poorest fifth of households in Australia (AMP NATSEM 2006).

Carers on a limited income struggle to meet the increasing daily costs associated with the additional burden of the expenses related to the caring role. The South Australian government has played a role by maintaining and strengthening a regime of concessions and subsidies. However these have developed in an ad hoc fashion, with an inequitable criteria and decreasing face value, nor do they reflect the particular financial pressures faced by carers in providing care in the home. Similarly the introduction of a Companion Card has brought some relief to some carers, but feedback to Carers SA indicates that not all carers are finding themselves eligible.

Whilst national initiatives such as the Federal Budget Carer Bonus and the Utilities Allowance are valued by those carers who are eligible, many carers miss out due to restrictive eligibility criteria.

Carers SA recommends

- That a national review of concessions and subsidies schemes across essential services be undertaken, in conjunction with increases in Carers Allowance, to examine the scope, targeting and possibility for an extended and cohesive national concession and subsidies system, including utilisation of Carers Allowance as a basis for eligibility and a national companion card.

5.2 Information and Education for Carers in the Caring Role

In order to be able to make informed choices carers need:

- Appropriate information about the caring role and the options they might have.
- Appropriate information about what, if any, services are available for the care recipient.
- Referral to services for themselves and the care recipient.

The bulk of care by carers is provided in the care recipient's home. The changing modes of community and health delivery rely heavily on the expectation that 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 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, for example, is largely informal, ad hoc, uncoordinated and very limited in scope.

Training is required across a range of topics such as the carer's roles and responsibilities; disabilities and illnesses; manual handling; carer personal care and health and well being; communication and relationships; negotiation and advocacy, including making complaints; the health and community services system where it provides support to carers and the care recipients; and managing the relationship with paid care support workers.

Any training framework developed needs to offer flexible approaches including in home, informal workshops/forums as well as more formal course structures, in order to accommodate the time pressure on carers, their physical and emotional status and the changing needs of care recipients. For example, each new carer in the Home and Community Care program, or in receipt of commonwealth packages, could receive one hour of assessment and training in physical care techniques in the home.

Carers SA recommends

- That a national Carers training framework/strategy be developed.
- That a national carers training scheme be introduced.

5.3 Appropriate and Adequate Services for the Cared For

The needs of the Carer, though separate, are inextricably linked with those of the care recipient. They seek quality services for themselves and the care recipient. Recent reports indicate that the elderly entering nursing homes are much frailer than previously, highlighting the load on carers who are caring for these people prior to their admission into an aged care facility.

The Home and community Care program (HACC) has been of fundamental assistance to carers in their caring role, but HACC is dealing with increasing care in the community with the result that the amount of time people get from HACC is decreasing as demand increases. Often this is but a few hours each week. Unmet need gravely impacts on the carers who are left to pick up the caring burden.

Carers SA welcomed the commitment of the federal government to the improvement of services for people with disability and mental illness in the 2008 – 2009 Federal Budget and announcements of national strategies or action plans.

Carers and the people they care for require:

- Clear information and guidelines about services for care recipients.
- 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.
- Provision of affordable quality options for the care recipient that operate at times that fit with paid employment.
- An increase in Home and Community Care funding by 30%, including recognition of mental illness as eligibility for HACC services.

Carers SA recommends

- That Home and Community Care funding be increased by 30%.
- That Home and Community Care criteria be changed to include people with mental illness and their carers be eligible for HACC services.

6 Special Groups

In South Australia the SA Carers Policy points to special needs groups that require particular consideration, including young Carers, Aboriginal and Torres Strait Islanders, 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 recommends

- That a mix of ongoing support and one-off special projects that are flexible to respond to changing local circumstances be funded to be delivered through regional Carer Support organisations.

6.1 Aboriginal Carers

6.1.1 Aboriginal Partnership Group

The Carers SA Aboriginal Partnership Group provides Carers SA with a forum to identify and discuss the broad issues as they relate to services for Aboriginal carers. This partnership group is a strategic and proactive group that develops relationships, a support network and opportunities for collaboration in providing a more comprehensive and seamless service for Aboriginal carers.

Membership includes representatives from Carers SA, Council of Aboriginal Elders SA, Aged Rights Advocacy Service, Aboriginal Health Council of SA, Aboriginal Home Care and the Department for Families and Communities.

Feedback from this group indicates that specific services and communication methods to support Aboriginal carers, including Aboriginal young carers and older grandparents, is needed.

6.1.2 Northern Country Carers Aboriginal Project

The Carers SA Northern Country Carers Aboriginal Project provides appropriate carer supports to Aboriginal carers of young people (under 25) with a disability. The program is funded by the Home and Community Care Program. The services include linkage to other carers and services, peer support, forums and information sessions, advocacy and transport. Activities include cook outs, fishing, collecting and preparing bush medicine and boat trips.

Carers SA's experience with this group indicates that much more of the approach taken by the Project is required to overcome cultural barriers to the often elderly Aboriginal carers seeking support.

This program covers the local government areas of Pt Augusta, Flinders Ranges and Port Pirie and districts, a large rural area that includes the "outback gateway" city of Port Augusta and the industrial city of Port Pirie.

6.1.3 Nunga Carers in the West

In the Adelaide western metropolitan region Nunga Carers in the West targets Aboriginal carers who provide care to frail older people and younger people with a disability, providing a critical link with the elders. It provides similar services to the northern country project. Group activities have included include arts and crafts, support group, boat trips and BBQ's. Following the loss of supporting monies for cultural activities the group's role is now as a reference group, along with relevant service providers, to provide advice to Western Carers on current issues.

6.2 Young Carers

Like other 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 the maintenance of their health and well being, is only possible if services are delivered to the whole family.

Carers SA has undertaken state wide initiatives across a range of portfolios in particular mental health, education and children's services. Special projects have been provided in information, identification, counselling and retreats through liaison with regional and school communities and representation on national policy and action groups. Carers SA is a member of the state coordinating network, the South Australian Network of Services for Young Carers (SANSYC).

Carers SA has acknowledged the involvement of staff of the Department of Education and Children's Services in joint projects for young carers and current State Government commitments to young carer programs such as Raw Energy and Breakthru.

Carers SA has called for an overall policy framework within the context of the requirements of the SA Carers Recognition Act 2005, even as priority measures are addressed. Such a policy needs to consider the young carer within the family unit.

6.2.1 The Young Carers Mental Health School Liaison Project

The Young Carers Mental Health School Liaison Project, one of a number of projects funded through state government mental health monies, set out to raise awareness about the needs of young carers at the Elizabeth Grove Primary School in the Northern Metropolitan Region of Adelaide who are caring for parents with a mental illness. The project aims were to:

- Raise education and health care system awareness of the needs of young carers who are caring for a family member who has a mental illness.
- Assist the development of links between local mental health services and young carers and their families.
- Assist the development of communication and linkages between the school and the local adult mental health service which in turn will benefit families and children who are caring for parents with a mental illness attending this school.
- Assist the Elizabeth Grove Primary School to develop its capacity to identify young carers and ensure that children attending this school who provide care to a parent or other family member who has a mental illness are provided with recognition and support.

Project partners included Carers SA, the Northern Adult Mental Health Services, the Department of Education and Children's Services and the Turn Around Program of the Early Childhood Development Centre at Elizabeth Grove Primary School. The project objectives included:

- Establish effective partnerships with the schools sector.
- Increase the awareness of school counsellors and all personnel regarding the prevalence and needs of young carers.
- Help develop links between the school, families and mental health services in supporting and enabling young carers.
- Identify opportunities for schools and mental health services and other relevant agencies to identify and support young carers and advocate for system change at all levels and across sectors.
- Build knowledge of gaps in service, barriers access and other issues.
- Embed system change in the way that schools, mental health services and other agencies work together to respond to the needs of young carers and their families.
- Identify and establish pathways for the mental health service to link with the school that enables mental health case managers of the mental health services to respond appropriately to children and families when the school identifies a family mental health issue that is impacting on a young carer.

The project included a Statement of Commitment from stakeholders, an evaluation plan, educational material and workshops for school staff, mental health workers and Elizabeth Grove Primary School students. In 2008 the project moved to work with Smithfield Plains Primary School.

The project report highlighted among other things:

- Carers' families usually have multiple problems: there is a need to engage a variety of agencies to get coordinated approach.
- Intervention should be focused at a geographic area that is relevant for all sectors.
- Awareness raising is not enough; there is a need to engage carers, teachers, families and mental health care providers in the development and implementation of change.

- The focus should be on building awareness across the school community of the prevalence of young mental health carers and their issues, and from there to build accessible and appropriate pathways and supports.

Nevertheless schools are a critical point of intervention in building capacity and resilience in young people who otherwise are at risk of underachievement.

6.3 Carers in Armed Forces Families

The participation of veterans groups in Carers SA programs has raised the issue of carers in armed forces families, including carers of veterans. Issues facing carers within families of active service personnel include being in effect a single parent, for example, of a child with a disability for significant periods; high mobility and short notice of changes in service that disrupt planned arrangements, service provision and support networks.

Issues facing carers of veterans include lack of understanding by the wider community, and often the family, of the affect of war service on veterans; forgoing family outings because veterans cannot cope with social interaction, even many years after their war service; loss of service pension if they leave their partners because they can no longer cope with them, even after for example 30 years of caring; difficulty in meeting Centrelink eligibility criteria when caring for a veteran with behavioural problems or mental illness; lack of appreciation by Centrelink of "totally and permanently incapacitated" and reviews considered by carers to be distressing and time wasting; and lack of recognition and appropriate support services by the Department of Veterans Affairs.

6.4 Past Carers

Carer Support services in South Australia continue to provide services for past carers, even though this falls outside of funding agreements. They do this because past carers need ongoing support following their caring experience. Past carers need time to recover from the health impacts of caring, and the grief and loss and social isolation; and to rebuild their lives.

After prolonged caregiving, a period of recovery and 'rehabilitation' may be necessary to restore the carer to their optimum health, well being and independence. Research (Schofield et al, 1998, cited in Stacey 2002) has indicated enhanced life after ceasing caring in comparison to "the decreasing life satisfaction of continuing carers". However research also indicates that even after relinquishment, the longer term impact of caring in many individuals may be an enduring one and perhaps in some, be irreversible. Some individuals never regain their health and well being, with major health problems and even premature death.

Past carers involved in Carers SA programs provide valuable mentoring assistances including in a number of cases as Carer Ambassadors.

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8 Appendix One: Carers Comments

8.1.1 "I don't have a normal lifestyle"

It is too hard to access information. It is confusing because so many service providers do the same thing. We often hear about really good stuff from friends and meetings, when we should be hearing about it from Novita and Disability SA.

There is the stigma of a child in a wheelchair seen as more disabled than someone not in wheelchair – like you need a label: my daughter has a "syndrome" but because she does not come under the label of CP it is harder for me.

We are sick of begging for respite: it is demoralising. Centre based respite houses have huge waiting lists for overnight just for a break. I see an inequality of respite hours between families; ie families who have been allocated lots but don't use it, but are allocated the same the following year.

I do not like receiving a letter from Centrelink asking if my child is still disabled. I broke down in tears last time for an hour. I told them, "she was born with it, will die with it, it doesn't end." If feeling down on the day you get the letter it crushes you. It is so demoralising.

There should be government sponsored education that shows what life is like for Carers: the majority of people in the community have no idea: I am more aware, but I still get picked on for parking in disabled car parks. Others are assuming only adults are disabled. I get it all the time.

I can't work. I would like to take up a hobby but it only lasts an hour with my daughter. We have no family support and that makes a huge difference.

There should be a lot more psychological help for families with children if the child with the disability is starting school.

There is a huge need for more help for fathers of disabled children. I can get a psychologist to come and see me but fathers rely on information from wives when the father is in workforce. My husband has put less time into work to help at home. I have often needed him to come home to help and he can't. It is easier to call him than calling emergency respite and having to teach new people; can't do that when sick.

If you put out a survey on substance use you would find a large number of carers using substances legal and illegal to dull the pain: both mother and father: that's the worrying thing.

Basically I can't live a normal life. I don't have a normal lifestyle; ie job, hobby, leisure, going out with my husband. We can't go to normal venues with family, only selected ones because of how my daughter will react. Actually don't go out as a family anymore.

Myself and other friends are having to pay for own services particularly physio/therapy because Novita are stretched. They may as well bring out self directed care because we are doing that now. Can't see how I will last until I'm 60. My health has deteriorated so much in the last two years and I'm only 42; and my husband has heart trouble.

Carer, June 2008

8.1.2 Rural Services?

Rural services are minimal; some are not there at all. Carers Link locally is not given the funds to adequately service the needs of Carers.

Finding where to apply for services and where to get it is like a minefield. Transport in rural area is a big and forgotten issue and near impossible to get, except for medical appointments. Most organisation and activities in this region are in Clare, 45 kms from here and there is no transport as such. Last year an invitation was sent to us by one to attend their AGM with guest speaker and lunch. We phoned we would be interested in attending and asked for transport – and were told *"sorry not available"*, so it goes on. Two years in a row I asked for transport from another for shopping: twice they fobbed me off; "Sorry lack of communication in our services: in future we will try and provide you that service providing we have the funds".

I keep writing to politicians regarding all these problems we have in rural areas and all I get back is a political answer with no meaning whatsoever. The Transport Minister and his Parliament Secretary and Minister for Family and Community Services, and Aged Care are the worst offenders. This does not mean that the others are better. Where is the money that politicians say has been released to improve Carers' situations?

Another point is the lack of affordable rental accommodation for the aged/disabled, locally. The stress keeps building up and no joy in retirement. People in government and government organisations have no compassion and no understanding of all the difficulties encountered by the aged/disabled in rural areas and that is a hard and sad fact.

I would like to see ongoing respite care.

Carer: "So many issues" Carers Talk 2006

8.1.3 The Future

My wife and I have three children. One daughter developed chronic rheumatoid arthritis at two years of age. Her prolonged treatment with steroids (cortisone and prednisolone) had an effect on her sight and her height. She now has extreme limited vision; in her right eye she has no vision and her left eye about 5% only. She is classed as legally blind. Therefore my daughter has a lifelong disability; she is now 53 years of age and requires constant help. We are almost 80 and have cared for my daughter for over 50 years.

My wife and I need to look at any special needs for the future for the three of us. What would or could happen with Sue when we "fall off the perch"? Our daughter needs to feel comfortable with where she lives and can somehow manage as much as possible on her own. She has been encouraged to live as close to a normal life as possible and to keep active within her limitations.

We've looked at ours and daughter's future regarding services available, including legal and financial, to try to organise future arrangements for care. To action a plan for the future seems to be so important; as once done it relieves one's mind and then it's a matter of getting on with living.

We sold our home a couple of years ago and bought a unit at Burnside that is quite close to our other daughter. The unit is one of four managed by the ECH group. ECH also provides ongoing care into later life, whether it is my wife, our daughter or myself. They do provide care for older persons, both high and low care.

All Carers require an easy approach to access information so as to talk about and or help sort out their problems about the future. Arranging for housing and transport, particularly for low income families, must be a real deterrent to reach a reasonable standard of living.

Carer Story: Ageing Carers of a Son or Daughter with a Disability (Including Mental Illness) – Planning for the Future Report

8.1.4 Mental Health

I support everything contained in (your submission) and can only hope that it has the desired effect. Having cared for my adult mentally ill son at home 24/7 for the past 10.5 years has taken its toll and the day will come when I can no longer continue to give him a roof over his head and the level of care he needs.

Carer, June 2008

8.1.5 Mental Health

SA is an ageing state: so many ageing Carers doing it tough: they are spending their superannuation caring (if they have any).

Carers caring for someone with a mental illness find how hard it is to access Carer Payment/Carer Allowance; the criteria relates to physical care. The form is not relevant; need new form that applies to people caring for person with mental illness. Even Centrelink agrees: put form in the post but... Eligible for Carer Payment because talk about recovery, living independently not account that it is a disability that people do not recover from. Recovery model does not acknowledge people with permanent psychological disability. Looking at reform of doctor system (they approve – change attitude of doctors, assessment of care provided: relationship with other Carers not just care recipient; assessment by nurse who is closer to the care provided to care recipient).

SA mental health legislation does not recognize Carers (the latest Bill does): needs to be there.

Cynical; never see it happening, the acknowledgement of Carers of people with mental illness.

Employment stigma around someone caring for person with mental illness: eg easier to say care for mum and dad gone into aged care than son/daughter burnt home down and have mental illness.

It is a requirement to have a Key Worker for the person with a mental illness but not enough resources to employ them.

If you are not part of the mental health system there is no support. Once outside the public system it is very difficult. There is a huge gap between the public and private systems: lot more support in the public system. The issue for Carers who have to manage it themselves is that they are locked out of the system. Then there is reliance on family – when it works it is OK but it is not a fair system. The person with the mental illness can't always get into hospital: if seeing a psychiatrist without admittance rights can't get into hospital. Private hospitals do not detain. Lot of private psychiatrists isolated from what is happening in psychiatric/social support. Private might be OK for the consumer but there is a lot less support for the Carers.

There are no services in rural and remote regions: peer worker is neighbour. Financial costs of travel are huge for country people: eg no subsidy to visit son or daughter in an Adelaide institution.

The system is not funded for carers: all funding on patient: rest unfunded: find a way of formalizing contact with families that would make a difference. Staff might want to work with family but not recorded as a 'statistic.' Funding not reflect the extra work when involved with the family.

Mental Health Carers Task Group, June 08

8.1.6 Recommendations to Government on Mental Health

Carers

- ⋆ Ensure Carers have access and are informed of important information about the person they care for including medication, up coming medical appointments, support requirements, health and well being
- ⋆ Implementation of the Carers Recognition Act principles and charter throughout the mental health system
- ⋆ Carer Consultants located on every acute care ward in South Australia to support and assist Carers to navigate the system and who can advocate on behalf of the Carer within the system
- ⋆ Education and training for Carers, service providers and the work force about mental illness, looking after and supporting the Carer, communication, Carer Recognition Act and Charter, co-morbidity and drug and alcohol
- ⋆ Awareness raising campaigns within local communities and at a state and national level to reduce stigma and increase recognition of the role of Carers of a person with mental illness

- Education program for schools and universities targeting teachers and students which raises awareness about the needs of children and young people who care for a parent who has mental illness, mental health and caring
- An extensive media campaign to raise awareness of the needs of family Carers across the state including rural and remote areas and Carers from Aboriginal and culturally and linguistically diverse backgrounds

Services

- Improved availability of psychiatric support for people with a mental illness in acute care and in the community
- Ongoing and flexible community support for people with mental illness which provides Carers with a break
- Community support for Carers of people with mental illness including advocacy, counselling, education and training, respite
- A state wide training program developed and implemented for SA Police and SA Ambulance Officers which focuses on mental illness and Carers
- An allocated Case Manager and/or Key Worker for every person with mental illness who works in partnership with the consumer and the Carer on an ongoing basis

Workforce

- Funding for training of professional's within the mental health system around family sensitive practice and Carer involvement
- Carer Consultants in every ward and in the community to assist and support Carers to navigate the complex mental health system
- Incentives provided to staff employed in mental health to increase and strengthen the workforce as well as to provide consistency for Carers and consumers
- An extensive media campaign in schools, TAFE and University to promote mental health as a career and attract more staff

Accommodation

- More available permanent accommodation appropriate to the needs of the consumer and the Carer which enables people with a mental illness to live in a stable environment in the community close to family and social support
- More accommodation, housing and supports available to people with mental illness to enable them to live successfully and be integrated into the community
- Guaranteed ongoing financial support for people with a mental illness to allow them to continue living in the community

Funding

- Guaranteed ongoing and consistent funding for services and programs provided to people with mental illness and to Carers
- Creative solutions to decrease the social isolation experienced by consumers and to reduce the isolation and dependence on their Carer
- Funding for further young Carer projects

Mental Health Carers Task Group October 2007

8.1.7 "4 hours a week just doesn't cut it"

I have a three year old with profound disabilities. She is total one to one dependant. I get 4 hours a week respite. Are they thinking about increasing the respite? I need it when she is little. When she is at school I can get more but I won't need it because she will be at school.

I have had to work hard to get her to achieve what she has. My husband has only just started working two days a week. 4 hours a week just doesn't cut it. I was quite surprised that I get the same as a person with a child with minor disabilities.

The only way my friend got more respite was to say she could not cope anymore and was thinking of giving her child up. They put her in (mental) hospital for a little while and gave her more respite. Most of the people I know have got depression, including me. I think they just don't understand how hard it is.

Carer: "So many issues" Carers Talk 2006

8.1.8 Holiday Respite

My son has an intellectual disability, brain injury, uncontrollable epilepsy. He does not want to go to a respite house. He says, "What I need is a holiday with a paid worker." It is his right to have that and if he gets a holiday I get a holiday.

It doesn't matter how many respite houses they build. On unmet need, every Carer would have something to say. 1 week/year 'holiday' would be good; 2 would be unbelievable. Should be a right, but can't get that through respite centres.

My son needs to be in a place where there is active overnight care. For 38 years I have listened for him at night (as you would a baby). Can't even leave him in early evening now either; and then can't leave him during the day after a seizure.

Need to urgently go to a family wedding and trying to organise with daughter for this.

Carer: "So many issues" Carers Talk 2006

8.1.9 Unmet Needs

I have been Carer for 38 years. We need a register of unmet needs of Carers; people to acknowledge that we are Carers. They need to ask Carers their opinions, not service providers.

You can throw millions at disability services for respite but that won't affect me, it filters down. The criteria for some organisations are no help. You can't book a paid attendant ahead. I get four hours Monday to Friday but no overnight or weekend when I may need it; no help if suddenly ill on the weekend. By the time services filter down our unmet needs are very great. I am getting older and need respite that is suitable for the care recipient. I don't mind but only want this little thing. Who decided that I get 4 hours?

Carer: "So many issues" Carers Talk 2006

8.1.10 Running the Car

It is a long haul. Remind them of what Carers are worth and how many there are. I find it difficult, expensive with running around as a Carer. My husband is high care and shouldn't be at home but he is at home and needs 24 hour care. I don't live in town so can't walk to the shops. I am ruined with use of the car. I get nothing when I think about it. It costs $20 in 5 days just running to the shops for my husband.

There is a community car but I haven't had time to fill in the paperwork. It's hopeless to get him in to a car – it takes 15 minutes. My fault for not using the community car. Got to give a reason to use it.

The girl looks at you and asks "when's the appointment?" I just want to get to the chemist, so use my own car.

There are so many things – absolutely – to talk about. Where do you stop complaining but at the same time... Only reason I get 5 minutes to talk to you is I popped him into the hospital last night.

Carer: "So many issues" Carers Talk 2006

8.1.11 Motor Registration

The State Government is re-assessing motor registration fees; looking at charging more for larger vehicles. We would not own a two tonne vehicle except we have a profoundly disabled child. Need exception for the Hiace. We need provision in the legislation for this penalty against Carers of the profoundly disabled. If there is no choice for the Carer something should be done. This will affect everyone who needs a large vehicle to care for a person with disabilities.

Carer: "So many issues" Carers Talk 2006

8.1.12 Bonus Talk

I am writing this email in dismay that this federal Labor government is looking at scrapping the carer bonus, it just shows a lack of compassion or recognition of carers. Us carers lives are consumed with the care of our son, daughter partner etc we don't go out as we don't have the money to go out, we sacrifice a lot of ourselves when we are caring, having that bonus to look forward to gave you the opportunity to have some money to spend on yourself, a bit of self pampering or to go out to dinner with your family or even to buy that appliance you've been without all year, like I did a vacuum cleaner. I just did not have $100 spare to do that.

Over the last few years I have had serious stress related health issues. I am on a special diet as I have to eat food that does not cause a yeast build up so I have to buy special bread that cost $15.80c a fortnight, I have no sugar therefore I use expensive sweeteners and I have to eat fresh fruit which is expensive and nuts which are expensive too. I have to stay on my diet as I will get too ill having normal foods that everyday persons enjoy. I am now going to a ladies gym that is tax payer funded as I can't afford it. This is for my mental and physical wellbeing.

We also have a car to maintain but we only just manage to keep it running with the cost of fuel, since this new year it has broke down a few times and has caused us stress and tension as we just don't have the extra money to get it fixed so we asked a family member who is financial to help us to get back on the road. So you see minister life is hard and demanding as a carer and so you see minister this carer bonus is extremely valuable to me as a carer.

Carer response during Carer Bonus discussion March, April 2008

8.1.13 Financial Support

I am a fulltime Carer of a most profoundly disabled child.

I can't afford to not work part-time. My wife works fulltime but we need the money. What I earn in the shop is equivalent to the single pension.

When we could get the Carer Allowance for Carers of profoundly disabled children under 16 there were 5 medical criteria. We had to meet 3. My son met all 5 but we were means tested out of the Carer Payment. There should only be medical reasons not means testing for the Payment.

Why can't they give me a health care card? My teeth are rotten. It has taken me years to be able to do something about it. It costs $300,000 per year to support my son. They can do something for us. We are doing the right thing, shouldering responsibility but getting no support. I'm 56. My health is going down. I can't afford health care so I go without.

I'm extremely fortunate with work two days per week. I can make hours to suit me. Very obviously the country is going to a regime of self funded retirees. I am working part-time paying superannuation, putting in an extra 20 hours per week but it is not worth it at the end of the day. The Government should be paying into a super fund, e.g. $50/week, for us otherwise we will be living off the pension. We are saving the government millions.

When my son leaves school in two years time he will be home fulltime. I will have to give up my job. We will be getting nothing but poverty in our old age, but the federal government says "help those who help themselves".

Carer: "So many issues" Carers Talk 2006

8.1.14 Overseas Veteran Misses Out

My husband is 80 and I am 75 and have been his Carer for several years. I get an allowance from Centrelink. He is suffering from Post Traumatic Stress Disorder having fought in Burma in World War 2. We have been living in Australia for over 40 years, now Australian Citizens, but not treated as Australians by DVA and do not get the same benefits or same rights as Australian veterans. This makes my husband (and others in the same situation) more bitter and angrier and frustration shows in various sides of this life.

Federal politicians of any party have failed to recognise the claims of forgotten soldiers. Qualifying service has been determined by people who had no knowledge of WW2 situation and refused to accept the opinion of those who did.

There was a PTSD program for Australian war veterans and their partners. We wrote to attend the program, but it was refused as: unfortunately this is a complex issue at present. The view of DVA is that the British Government remunerates the Australian Government for medical treatment provided to British veterans in Australia. *"Your husband would need to contact DVA and process an application to the British Government for acceptance to participate"*. Their answer was UK Veteran Agreement does not apply here, which are not in place for British Veterans in UK.

Besides PTSD, my husband also suffers from Parkinson Disease, cancer and other ailments. He cannot sleep because of his nightmares from the war and keeps me awake as well.

Carer: "So many issues" Carers Talk 2006

8.1.15 Making a Difference for Families

As families we need to be working together to support each other, be building networks and strengthen these avenues as pathways to assisting each other. The people who have come before us, who have older children with disabilities have learnt a lot about the sector and what has and has not been done, can we learn from this at all, and what works best and not make the same mistakes as before, because as we all know our children with disabilities need quality of life, life can be short and we don't won't to waste time, money and dignity.

I have worked with families who have a child with multiple disabilities/conditions with no clear diagnosis and the things that would make a difference are:

- Great understanding from the community about how disability affects the family.
- Educating the great community about disability and how the community can support disability in a positive way, through: how to talk to a family affected by disability; how to walk beside a child with a disability; how to include a child with disability in mainstream activities such as singing, drama, music, art etc; how to greet a child with disabilities; People who have a disability can have these things affected vision, hearing, learning, walking, talking, eating, drinking, playing, singing, dancing, breathing; toileting; digesting; sleeping; absorbing; growing; understanding; comprehending; remembering; reading etc....a lot of the doing words, however they are human, they feel like all of us, we all do things differently and we all have a right to services and opportunity to reach our potential.

- Training more Carers to assist families have a break from caring, tapping into the TAFEs who are training and educating people to become paid carers and child care workers etc and linking these people up to agencies who provide care and respite to families. There are not enough carers listed and this whole sector is not managed correctly, and complaints not occurring and quality assurance needs to occur, as families are not receiving the care they deserve.
- Empowering families who are caring and people with disabilities by offering them opportunities to further their lives and reach their potential, by offering incentives to study and work. For example scholarships at university and TAFE would assist family Carers and people with disabilities. Assistance with child care to help family Carers to work and study. Current funding for child care is capped at 5 hours per day, so the child misses out the other 2 or 3 hours and the family carer is not able to continue working or studying for that day.
- Greater access to transport for children with multiple and severe disabilities. This would happen through improvements to the Access Cab system, to make this system more efficient; e.g. paint these cabs all the same colour so that they can be seen on the roads. More of these cabs. More financial support to assist the cost of accessing these cabs to be lower for the consumer.
- Petrol discounts for family Carers and people with a disability. The amount of appointments families have to attend when they have a child with disabilities is astronomical. Some children have up to 30 appointments a month.
- More community respite programs in home care, where children with disabilities can receive quality care in a home environment. Funding for families to get away for a holiday once a year with a support carer to assist if needed. Many families never get to go on a holiday, when they have a child with high support needs.
- Assistance with transitions: families need extra support when given new diagnosis for their child and additional diagnosis and when their child with disabilities is transferring from child care to kindy and to school, high school etc. These are major transitions and families need extra support and guidance at these times, so funding needs to be directed into the support services assisting families and into the education services providing the service.
- Discounts and opportunities for families caring for a child with high support needs for access to sponsorship to purchase a motor vehicle that is used for transporting their child and family together around. These vehicles cost $59,000 new and $30,000 second hand. Families on a low income cannot afford this.
- Funding into early intervention for 5 years of life, not 3 and a half.
- Funding into therapy services to assist a child to walk, talk etc and people with disabilities.
- Funding into equipment, so that the child or adult with disabilities does not have to wait a year or more before they receive the equipment needed to make their life more independent. Especially for walking, mobility, eating safely, sleeping safely etc.
- Funding to establish and maintain toy libraries in the communities which support child and adults with disabilities.

These requests are the major requests for families to make a difference in our quality of life.

Carer: "So many issues" Carers Talk 2006

8.1.16 Port Pirie Carers

Could you please on offer these concerns on my behalf as a carer. Some of the raised issues are also that of carers who have asked that I submit on their behalf. I would say that all cares have a common thread of need.

1. The feeling of **guilt** should you wish to pursue outside activities other than caring for the caree. These feelings are reinforces by the caree and other family members.
2. The **ability to work** and look after the caree is severely diminished due to the needs of the caree and the time that is required to care for them.
3. The feeling of **isolation** due to the nature of caring at home constantly.
4. The **embarrassment** of being a carer because you are out of the work force and needing to explain to others why you don't work. They do not understand. This is particularly hard for some of my male friends who now have to stay at home looking after their wives.
5. **RESPITE** is an enormous issue for carers. Some agencies who supposedly provide care say they only provide a one off emergency service. Others cannot provide a service to the isolated small country town as they do not have anyone who can go to that location.
6. Other issues are that the **caree** needs to have respite from their normal surroundings.
7. **Different types of Respite** are required to be offered for the country areas that are not currently met. They are respite for the **intellectually** disabled and the **mentally ill** and their carers.
8. **Timeliness of respite**. Cares and carees need respite, day and or night or weekends and the time of day which is convenient to them.
9. **Financial hardship,** caring is not only emotional there is the hidden cost of appliances and fixtures, modified or larger vehicles for specialized transporting for the caree, fuel, sitter costs if you can get a sitter, nursing pads and other hygienic necessities and the list goes on.
10. **STRESS** is an enormous issue for carers. Caring is not an easy task. **Dementia** patients are notoriously difficult to care for as you have very difficult personality changes as well as the other significant issues of the illness. It is particularly hard for an aged carer to look after their spouse.
11. **Mental health** patients are a significant burden for their loved ones. Not lonely do they have to look after them 24 / 7 but the issues that arise with a mental health patient are enormous. They (the Caree) can become very difficult and need often to be detained for their own health and well being. Unfortunately with our current laws they then can choose to leave detention despite not having the health level that they require to remain well. Then the carers are left to deal once again with a person who has significant issues.
12. **Medication** is also and issue for carers. I have heard of cares that stay up most of each night trying to give their loved one their medication and oftemn without success.
13. **Depression**
14. Carers are often **overlooked** by their own family and significant others as a person. Their **needs and desires** are ignored and they are often also expected to be the **only person** within a family to care for the Caree. This results in **stress** and is quite often resulting in a breakdown both mentally and physically. They feel ignored, stressed they have **no control** over their own lives, they have **no options,** they feel as if they should not go out at all as the **Caree is so dependent** as is the rest of the family. They get **frustrated and angry** that they are no longer their own person.

This is in the words of several carers and I only have small groups, so it is obviously the tip of the iceberg.

I had better leave it at that. I could write a book on what is needed for carers but the most significant is the Respite, the type of respite and the financial hardship and the stress and depression. Mental health carers are significantly overlooked with respite and services and support as are cares of the intellectually disabled.

June 2008

9 Appendix Two: Rights of Carers in Partnership

- Family Carers have the right to participate on consumer participation structures and have their various roles recognised as service user, representative and a partner in the delivery of care.
- Family Carers have the right to have their role as a partner in care recognised and valued by health professionals and the broader health care system and as such family Carers have the right to be involved in processes and planning with health care professionals i.e. developing care plans and discussions about treatment options and clinical information about the person they care for.
    - Family Carers have the right to be provided with open and honest information of a clinical nature about the care recipient from health professionals and the broader health system.
- Family Carers have the right to raise concerns and complain on behalf of the person they care for in relation to their health and well being, treatment options, care plan and service delivery.
    - Family Carers have the right to express their concerns about the service delivered to the health professional delivering the service.
    - Family Carers have a right to formally express their opinions about service delivered by health professionals to the care recipient.
    - Family Carers have the right to be involved in the evaluation of services provided to the patient whilst they are in care both in hospital care and community care.
- Family Carers have the right to have a say and be listened to:
    - About the health and well being of the person they care for.
    - About their own needs in relation to providing care as a family Carer.
- Family Carers have the right to have their own health care needs recognised as separate from those of the person they care for. Family Carers also have the right to temporary and additional support while they are unable to provide care due to health problems of their own.
- Family Carers have the right to be provided with other information about services that will assist them to continue in their role as a family Carer i.e. Carer support groups, counselling support, financial assistance, respite options, accommodation etc.
- Family Carers as 'partners in care' have the right to relinquish care.

Excerpt: Carers SA Carer Participation Position Statement (Carers SA 2006)

10 Appendix Three: Carer Roles and Tasks

a) 'Professional tasks and activities'

- Peg feeding, wound management, tracheotomy care
- Administering medication
- Monitoring treatment plans and communicating health information
- Coordination of care and support within and across sectors. Carers are often the main 'care coordinators' for patients, especially for services *beyond* the health sector
- Diet and nutrition (including ensuring that diet improves if care-recipients experience undernourishment in the hospital setting)

b) 'Duty of care and responsibility'

Carers often take responsibility for tasks formerly the duty of formal services, however it is sometimes unclear who has the 'duty of care' or ultimate responsibility should treatment go wrong.

- Taking responsibility for care-recipients whilst on hospital premises (e.g. waiting 10 hours in casualty with a mentally unsettled person).
- Taking responsibility for treatment in the context of 'Hospital in the home' programmes, after health professionals first prescribe this.

c) 'Informal and Formal Advocacy roles'

- Where formal arrangements exist (e.g. guardianship), health decision-making and consulting with health professionals over treatment options
- Advocacy on behalf of patients whilst in treatment settings
- Advocating for accessing services such as housing and respite
- Advocacy in groups for obtaining services that do not exist (e.g. accommodation for younger people with disabilities)

d) 'Routine roles'

- Organising or providing accommodation and housing support such as cleaning, gardening, food shopping and meal preparation
- Personal assistance with bathing, showering and dressing and cosmetics
- In the case of parents of children with disabilities, organizing specialist appointments, engaging in remedial play and learning, and balancing work/study with the constraints of school based or other support
- Organising finances or assistance with financial planning
- Providing transport to shopping, recreational, medical and allied health appointments
- Selecting and purchasing aids and equipment, and/or making home modifications
- Providing important emotional support to care-recipients and other family members

Excerpt: Battams, Understanding the Role of Family Carers in Health Care: implications for the health and community service system. (Battams 2005)