



Discussion Paper

Developing a Whole of Government  
State Carers Policy in South Australia

July 2003



## **Our Vision:**

***That all family Carers will be recognised by government, service providers and the community as an essential and valuable part of society, and, as such, will receive appropriate support to enable fulfilment of their role with pride, dignity and security.***

Carers Association of SA – Vision Day 1997

## **Definition of a Carer**

***A 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.***

Carers Association of SA

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# Section 1 Overview

## Summary

### 1) What is the Whole of Government Carers Policy?

The Carers Association of SA lobbied for a whole of government Carers policy in its 2003/04 State Budget submission, in recognition of the valuable role that family Carers play in the community. The state's Minister for Social Justice has established a Ministerial Advisory Committee in order to develop such a Carers policy, in consultation with Carers. It is envisaged that the policy will be a formal statement of recognition for the role and contribution of Carers by the state government, and will enable the consideration of the range of Carers' information and support needs when planning and delivering services across government departments and agencies.

### 2) What Would Be the Aims of the Whole of Government Carers Policy?

The whole of government Carers policy would incorporate a policy position and strategies in a range of areas relevant to Carers. Key expected outcomes for the whole of government Carers policy would be:

- Formal **recognition** by government, via a statement and policy, of the role, rights and needs of Carers and their contribution to the community.
- A **framework** for various government departments to refer to when developing agency Carer policies and considering the contribution, needs and role of Carers.
- Development of a **partnership** in the health and community services sector, between Carers, consumers, and professional staff at both an organisational and service delivery level, in recognition of Carers as co-providers within the health and community services system.
- Enable the health status and needs of Carers to be considered **independent of the person being cared for**. This may occur through *Carer assessments* in the health and community services sector, which contribute to the support provided to both Carers and care recipients.

### 3) What Difference Would the Whole of Government Carers Policy Make for Carers?

The whole of government Carers policy would ensure formal recognition of Carers as co-providers within the service system. It would also facilitate the consideration of Carers as a separate population group within public health, whose health status warrants particular attention separate to the person being cared for. It would ensure that various government agencies, that are relevant to family Carers, have a role in taking into account Carers' information and support needs. It would aim to prevent the situation arising where Carers do not receive adequate information, related to issues connected with national privacy legislation.

#### **4) How Would the Whole of Government Carers Policy Be Rolled Out?**

It is envisaged that a cross-departmental working group would be established to facilitate the rollout of the whole of government Carers policy. The policy would need to be supported by communications strategies within government departments, agency Carer policies, and a community education strategy for the broader community. The implementation of the whole of government Carers policy requires adequate resourcing.

#### **5) How Would We Know That the Whole of Government Carers Policy is Effective?**

Indicators for the success of the whole of government Carers policy would be established by the Ministerial Advisory Group and Carers through the consultation process, and be reviewed by Carers on a periodical basis. The indicators would be used in a continuous quality improvement cycle, to gauge and monitor the success of the dissemination strategy and community education strategies. Indicators for success include resource contribution to the policy, cross-departmental activity to progress the policy and agency Carer policies.

## **A 7 Step Framework for the Whole of Government Carers Policy**

The endorsement of policy by Cabinet is an essential component of policy development. It is envisaged that the policy development framework would include the following steps:

### **1) Ministerial Advisory Group – Priority Setting**

It is envisaged that the **Ministerial Advisory Group** is responsible for setting the broad goals and topic areas to be covered within the whole of government Carers policy, with support and advice from the **Carers Association of SA**.

### **2) Consultation Process**

From these broad directions, an **extensive consultation process** will be undertaken with Carers and non-government agencies, to gauge feedback on these goals and areas and the feasibility of the strategies. The consultation process could seek feedback on *priority areas for legislation*.

### **3) Endorsement of Policy by Cabinet**

The **endorsement of the policy by Cabinet** and by key Ministers across portfolios is important for the success of the policy.

### **4) Implementation Phase**

The **implementation** of the strategy would ideally incorporate the establishment of a **cross departmental working group**, to guide the rollout of the policy, particularly in terms of setting directions for **agency Carer policies** and **organisational communications strategies**. A *developmental approach* to the introduction of the policy across departments and agencies should be adopted to ensure the success of the policy.

### **5) Community Education Strategy**

An effective **community education strategy** would contribute to developing knowledge around and expectations for the policy within the wider community.

### **6) Review Component**

The policy itself would incorporate a **process for review** across departments, with indicators to gauge the success of the policy.

### **7) Legislation**

Finally, pursuing **legislation** in support of the Carers policy, that has a relationship to other relevant legislation affecting Carers, is a longer-term aim of the Carers Association of SA.

## **Section 2      Background**

### **Background to the Whole of Government Carers Policy in South Australia**

In April 2003 the Minister for Social Justice, the Hon. Stephanie Key, called for nominations for the Ministerial Advisory Committee to develop a whole of government Carers policy to support the state's 216,000 primary Carers. The task of this group is:

*'to provide policy recommendations on the formulation and implementation of the whole of government carers policy and provide advice on mechanisms for engaging carers, care recipients and the wider community in the development of the policy'.*

This initiative represents an advance on the Liberal Government's 1993 'Caregivers' Policy and the 1997 'Focus on Carers' Strategy. The 1993 policy was primarily a recognition of the contribution of Carers, and opened the way for resources such as; additional Home and Community Care funding, more flexible and culturally appropriate respite services and a review of respite, research into children as Carers and ATSI Carers, hospital discharge plans which recognised the role of Carers, counselling and support for Carers, a training package for Carers, and a return to workforce program.

Whilst the 1997 'Focus on Carers' policy was not a whole of government approach, it covered a range of areas from flexible respite, skills development for Carers, recognition of Carers in discharge plans, work and care policies across departments and agencies, and a review of relevant legislation and the consideration of new legislation to take into account the needs of Carers. Whilst adopted by the Department of Human Services, obstacles arose in the implementation of the policy due to its related short-term initiatives, and limited resourcing and portfolio approach taken. The development of new legislation to take into account the needs and rights of Carers was not pursued.

It is the belief of the Carers Association of SA that in order for a whole of government Carers policy to be effective, it must;

- Be endorsed by Cabinet and key Ministers across portfolios such as Social Justice (Disability, Housing, Aged Care), Health, Employment and Training, Education, Transport and Industry.
- Be incorporated into the Strategic Directions of various government departments.
- Utilise joint leadership in the development of the policy, across government, non-government agencies and individual Carers, as evidenced by a vision for Carers, an effective consultation and dissemination strategy, agency Carer policies, and persons designated responsibility for the implementation of the policy across departments.

- A developmental model for the whole of government Carers policy be adopted, with capacity building for departments and service delivery agencies in the form of training and skills development for staff and carers around the policy.
- The policy is tied to an implementation plan and review framework that is established by Carers.
- The policy is supported by separate legislation on Carers that corresponds with existing Acts affecting Carers (e.g. Equal Employment Opportunity, Home and Community Care, Disability Discrimination).

## **Introduction to Carers**

### **Who is a Carer?**

*A 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.*

Carers Association of SA

Carers provide unpaid support in an informal arrangement, and may be caring for family members, friends, or neighbours. Care-recipients may be younger people with intellectual disabilities or frail older people, people with physical impairment or mental illness, a chronic disease or illness, or in palliative care. Carers are mostly commonly caring for a partner (43%), child (25%), or parent (21%) and the majority of Carers (around 70%) are women (ABS 1998).

The caring role is diverse and responsibilities may range from assistance with medication, feeding and bathing, home help and maintenance, nursing procedures and practices (can be intrusive), transport, shopping, organising finances, emotional support, purchasing of aids and equipment, liaising with health and community service professionals, and/or negotiating financial, employment or housing support services.

The needs and activities of Carers may differ depending upon the nature of the kin or other relationship involved, the age-group of Carers, cultural issues, other informal support arrangements, and the ability to access information and negotiate formal support services.

Caregiving work may be short or long term and a life cycle of care should be adopted to understand caring responsibilities and support needs of Carers. Additionally, the episodic and intense nature of care for some conditions such as mental illness must be understood for the effective and timely support of Carers.

Carers take on the caring role for a variety of reasons, and different expectations to undertake informal care may exist within communities. Reasons behind taking on the caring role may include; love and affection, obligations, family ties and expectations, a lack of alternative informal or formal care, the cost of alternative care, and a lack of formal education or employment opportunities. Regardless of the reasons behind caring, the Carer role is essentially unpaid work and should be seen as such.

However, Carers themselves are an extremely diverse group and that means that they have different support needs. Different caring arrangements can include:

### **Primary and Secondary Carers and Living Arrangements**

Carers may either considered to be full-time primary Carers, or secondary Carers assisting the primary Carer. There are 41,800 primary Carers in South Australia, however 1 in 5 households are involved in caring to some extent. Primary Carers are most likely to be women (70%) and 62% are over the age of 65 (ABS 1998). Carers may also be either living with or separately from the person they care for, however this situation may not be indicative of a Carer's responsibilities. A primary Carer may

be living separately from the person they care for, however 75% of Carers care for a person in the same household (ABS 1998).

### **Rural and Remote Carers**

Carers living in rural and remote regions may have particular needs due to their isolation and poor access to a range of services (e.g. transport, health and community services, information) and informal networks. Different methods for providing information and support and involving such Carers in decision-making at all levels should be considered.

### **Carers from Culturally and Linguistically Diverse Backgrounds**

Different cultural expectations may surround Carers from Culturally and Linguistically Diverse Backgrounds and it is commonly suggested that such Carers may have greater difficulty in accessing services, and are under-represented in decision-making processes. Carers from CALD communities highlight the need for culturally sensitive services, and informal and formal feedback mechanisms within services. People from CALD communities are more likely to be living in extended family network environments (AIHW 2002).

### **Aboriginal and Torres Strait Islander Carers**

People, especially women, from the ATSI community are less likely to be living with their partner as they age, and more likely to be living with their children and other relatives (ABS 1999), which may lead to more intergenerational caring arrangements. There is some evidence to suggest that the ATSI community are slightly more likely to prefer community based to residential care (AIHW 1999). Due to the prevalence of chronic diseases amongst this community, the caring role may be quite common, however people may not be identifying with the Carer label.

### **Ageing Carers**

Older Carers are most commonly in spouse relationships and may prefer different respite options (e.g. for their own physical health, or to fulfil retirement hopes for vacations). However, there are many ageing Carers who are primary Carers living with an adult son or daughter with a disability who are particularly concerned about future housing options. Intergenerational caring may be increasingly common for younger people with disabilities, where grandparents may be providing support to grandchildren with disabilities to assist parents who may be in the workforce.

### **Children and Young Carers**

There are around 388,800 Carers under the age of 26 in Australia. There are also around 181,100 young children and teenagers under the age of 18 in caring roles in Australia, around 13,300 of which are in South Australia (ABS 1998). However, as with other Carers, many young people (sometimes through their family's influence) may be reluctant to be categorised as Carers. Young Carers are often overlooked within the service system, however their recognition, education, support and involvement in treatment plans is vital to their own life opportunities and quality of life. ABS figures (1998) show that young Carers aged 15-25 are most likely to be caring for a parent (55%), usually a mother. Young Carers are often in sole parent

families, however they may also be assisting a parent to care for another sibling. The most common conditions being supported are a physical disability or mental illness (Carers Australia 2002). A growing literature exists on the particular experiences of young Carers in families where parents have a mental illness.

### **Carers Who Are Parents**

The impact of caring must be considered in the context of the changed family structure and women's experience in the workforce. Women in the workforce, including sole parents, may be caring for an ageing parent or child with a disability.

### **Sole Parent Carers**

Due to the sometimes negative impact the birth of a child with a disability can have upon a partnership, sole parent Carers are quite common. Sole parent Carers may be more likely to have the added stressors of combining work and family life.

### **Working Carers**

Younger women Carers may increasingly be likely to be working (78% of Carers are of working age) and have particular needs such as alternative care arrangements for the person being cared for, Carers leave, flexible working options, and particular mention in anti-discrimination and equal employment opportunity policy.

### **Multiple Caring Roles**

The Carers Association of SA has seen evidence of Carers being involved in multiple caring roles simultaneously e.g. for a younger child with a disability, in addition to an ageing parent or spouse who is ill or has a disability. Such Carers are particularly vulnerable to stress and burnout, missing out upon health care for themselves, may experience social isolation and may have higher support needs such as training, respite care and peer support. Income allowances and subsidies do not adequately cover the costs associated with multiple caring roles.

### **Consecutive Caring Roles**

Some Carers are caring for the 'second time around', or take on the caring role repeatedly to develop a 'career of caring'. Such Carers may be caring up to a period of 30 years, and the caring role may get harder the second or third time around – especially where there is overlap in caring roles or no breaks in between caring roles to allow the Carer to recuperate. These Carers may be more vulnerable to physical illness and emotional stress, and require adequate support and respite.

### **Contribution of Carers**

Due to the impact of de-institutionalisation and community care policies in the disability and ageing sectors, the significant ageing of the population in South Australia and related increased rates of disability and handicap, and the rise in chronic diseases, caregiving work has increasingly become an important concern, especially for younger women of working age and for older spouse carers. Whilst family caring has become an increasingly likely role for men over the age of 70 (mostly caring for a spouse), 70% of family Carers are women.

In South Australia, there are a significant number of family Carers, 216,000, who care either for a person with disability, or physical or mental illness, or a person in palliative care. Whilst around 59% of Carers are not attached to the workforce, Carers will generally seek to balance caregiving roles with the assistance of adequate and differentiated public services. In addition, Carers deserve due recognition from our government and the community for their contribution to community care, as well as support for their role, and status independent of the person being cared for.

### **Economic Situation**

Most primary Carers are recipients of pensions (around 70%), however their greater economic contribution is often not adequately recognised in government financing arrangements. An Australian Institute of Health and Welfare 1999 report on Australia's welfare, estimated that the total economic contribution of the household sector was \$24.8 billion, with around \$20 billion of this attributed to Carers work. The Carers Association of SA estimates that unpaid care work is worth around \$2 billion to the South Australian economy. Whilst saving the government significant costs by providing an essential component of community care, Carers themselves are often living in poverty with few financial supports. Many Carers do not have access to superannuation, or claims to compensation in the event of a personal injury. Caregiving work should be seen as an economic activity in addition to an affective one.

### **Health & Wellbeing**

Carers, through their role and lifestyle, can be prevented from achieving optimum health status (Stacey 2002). The nature, extent and duration of caregiving work means that Carers health is poorer than non-Carers, and illnesses and disabilities related to the caring role often arise. In 1999, Carers Australia conducted a national survey of Carer health and wellbeing, and this showed that upper body injuries related to caring (60%), back problems (30%) and anxiety and depression (27-28%) are common ailments affecting Carers. Many Carers report tiredness and exhaustion and sleep disturbance related to the caring role. Additionally, many Carers say that they do not have the appropriate aids and equipment to assist them in their caring role. The need for Carer assessments and ongoing training about and support for the caring role is required.

### **Growing Recognition**

Whilst Carers are increasingly being recognised as partners in health service delivery (e.g. through the Home and Community Care Program, and in care planning and case conferencing in general practice), it is often not recognised that they are the foundation of community care and act as 'care coordinators' negotiating a range of financial, health, support, and housing services across the spectrum of public and private services. In addition, Carers' status as a separate Home and Community Care target group is being eroded in favour of support being provided to people with disabilities and the frail elderly people living in the community with out a family Carer to support them, which in turn undermines the sustainability of the Carer's role.

Carers' central role in piecing together supports from various sectors beyond health can be better supported through more effective linkages across the range of

government services. 'Consumer and Carer' participation policies have begun to emerge in such areas as the mental health sector, however they are often developed by a small number of consumers representatives, and driven by the state government. Standard policies and practices to include Carers within a patient-centred medical model are particularly inadequate. Consumer policies are often meant to include Carers, however Carer's needs are often ignored in favour of consumers. Carer and consumer's needs must be differentiated and distinguished from one another and ensuing policies need to be distinct to ensure that Carers needs are addressed. Additionally, Carers rights, needs as co-providers of services, and support needs independent of the person they are caring for, all need to be considered within such policies. Organisational leadership and capacity building is also required to ensure that such policies are effective. The proposed whole of government Carers policy is therefore a welcome step in the right direction for family Carers.

### **Education**

Caring is often associated with low socio-economic status and poor education and employment opportunities. The caring role in itself may negatively impact upon the ability to enter into or sustain education, for Carers of any age. Scholarships for Carers and flexible study arrangements are options that may assist Carers to maintain their secondary or tertiary education. Child Carers may also need extra social and psychological supports to assist them with their primary school education.

### **Employment**

There is a great discrepancy in the number of primary Carers desiring work and actually looking for work, and this can be explained by the lack of suitable alternative care arrangements (ABS 1998). Once in a job, flexible working arrangements and adequate Carers leave are required for Carers to maintain themselves in employment and progress through a career. Anti-discrimination legislation is required to ensure that employers do not discriminate against people with caring responsibilities.

## Carers Perceived<sup>1</sup>

It is important that any State Carers Policy articulate the Government's view of Carers, because it will be this view that will be the foundation for the policy and underpin the way services are provided to Carers in the front line of service delivery.

Carers can either be seen as **resources, co-workers, co-clients**, as a '**superseded Carer**' (Twigg 1992, Twigg & Atkin 1996), or more recently, as a **partner** in the formal service system.

Carers are most often seen as a taken for granted free **resource** by the formal service system, and family ties and obligations are relied on to ensure such a resource is provided. In this model, family care is seen as the first choice for how people should be cared for, and Carers rights and needs are not heeded.

When Carers are viewed as **co-workers**, they work alongside and with the support of professionals. Carers' wellbeing and morale is considered, largely in the context of the sustainability of their longer term informal care role. When Carers are perceived as **co-clients**, Carers' needs as individuals with their own health and support needs is considered. This model mostly focuses on Carers with a heavy caring responsibilities and high support needs.

In the '**superseded Carer**' model the focus is on the rights and interests of the person with a disability, potentially discarding the need for the caring role. In this model the conflict of interest between the Carer and person with a disability is fully recognised. The goal is to maximise the independence of the person with a disability and in doing this the contribution and role of the Carer is often minimised. However, in reality, there are still many Carers providing a large degree support to people with disabilities, sometimes episodically as in the case of a person with a mental illness.

Finally, when Carers are seen as **partners** they are seen as central to the formal service system and participate at various levels in its structure. Carers and care-recipients needs are taken into account in relation to each other. The focus is on the unit of care, which includes the patient or client, family Carer, other informal Carers, and formal services.

It is recommended that through the development of the whole of government Carers policy, Carers are perceived primarily as **partners** within the service system, and as a foundation of community care.

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<sup>1</sup> See Warmington, R, 'Family Carers – Contributions and Views in a Complex System', paper given to 2003 Conjoint Scientific Meeting, Them and Us, Australian Association of Gerontology SA/NT Division, Carers Association of SA website

## **Rights of Carers**

The Carers Association of SA advocates for the rights and needs of Carers to fulfil a range of meaningful roles, have access to appropriate services, and engage in decision making at both an organisational and individual service delivery level. The whole of government Carers policy should adopt the underlying 'Principles of operation for the Carers Association of SA':

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

## **Vision for Carers in Community Care**

It is also anticipated that the whole of government Carers policy adopt the 'Vision for Carer Support in Community Care' developed by Carers Australia. This vision includes the idea that 'community care' is essentially provided not by services, but by individual Carers (usually women) within their own homes in local communities. Essentially, family care is the foundation of community care.

## **Section 3 Principles and Expectations for Policy Development**

### **Seven Guiding Principles for Policy Development**

#### **1) Recognition**

The government of South Australia recognises that caring is a valuable role, making a personal, social, and economic contribution to the community. The diversity of Carers, their own support needs, and their need for assistance with the caring role will be addressed.

#### **2) Leadership**

The process of the development and rollout of the whole of government Carers policy should demonstrate leadership in highlighting the important role of Carers, and the interdependence between their role and the formal health and community services sector. Demonstrating leadership is a joint role for the state government, Carers Association of SA, non-government sector and individual Carers.

#### **3) Partnership Approach**

The Carers Association of SA is the peak State body representing Carers interests in South Australia, and as such it is expected that they will be primary partners in policy development, and that the state government builds upon the experience and knowledge of this organisation on Carer issues and the process of consultation around policy development.

#### **4) Processes for Decision-Making**

Carers are the cornerstone of community care and as such should be integrally involved in all formal health and community services planning and decision-making. Carer input into decision-making across government will occur due to its inherent value, and the experience of Carers in the process of being involved in decisions and treatment within health and community services is often as important as the outcome of this involvement.

Carers will be treated equally with professionals in the processes of decision making at all levels. Concerns about the negative impact of the national privacy legislation should be addressed through the state government Carers policy and legislation, to make it explicit to service providers that it is preferable that Carers receive information about the person they care for and are involved in any treatment plans.

#### **5) Capacity Building**

Linkages across the service system are essential for supporting the role of family Carers. The effectiveness of the whole of government Carers policy rests upon an effective dissemination strategy and capacity building across government departments.

## **6) Transparency**

Open and ongoing communication between the Carers Ministerial Advisory Committee, the Carers Association of SA, and individual Carers will occur at all times through the development, implementation and review of the policy.

## **7) Accountability**

The whole of government Carers policy will be supported by review mechanisms established through the development of the policy, and the effectiveness of the policy will be reviewed on a periodic basis.

## **Expectations on the Process for Formulating the Whole of Government Carers Policy**

### **Partnership**

It is suggested that there are clear protocols for communication between the Ministerial Advisory Group and the Carers Association of SA, which include:

- Opportunities for the Carers Association of SA and its Policy Subcommittee (Carer Policy Working Group) to feed into the Ministerial Advisory Committee (e.g. through ongoing communication, workshops, feedback and review requests).
- Regular reports on progress directly to the Carers Association of SA and opportunities to access the Minister independently to express any concerns with the process.
- Agenda, Minutes and numbered drafts of documents forwarded well prior to meetings to allow for sufficient input into the process.
- Utilise the experience of the Carers Association of SA in consulting with and representing the interests of Carers - Invitation to the Carers Association of SA in identifying and taking a leadership role with key Carer networks during the consultation process.
- The Carer's Association of SA's representative will not be asked to represent Carers on other subcommittees and consultation processes without adequate communication and consultation with the Carers Association of SA.

### **Partnerships with Non-Government Agencies**

Due to its leadership role in relation to other non-government agencies connected to Carers (e.g. the Carers Service Provider Network which provides a training and information sharing opportunity), the Carers Association of SA is willing to take a leading role in organising consultation and feedback around the whole of government Carers policy.

## **Partnership with Health and Community Services**

Due to their significance to Carers unpaid work, the Carers Association of SA would like to see the development of partnerships with hospitals, general practice, primary health care and community services, as one key outcome of the state Carers policy. An example of how consumers and Carers might be involved in such arrangements is to be found in the service agreement between Flinders Medical Centre and the Southern Division of General Practice.

## **Clarify the Definition of Partnerships Held by the Department of Human Services, Carers Association of SA, and Other Agencies**

The Carers Association of SA requests that a definition of partnership be developed separately and then agreed upon collaboratively, to ensure that those agencies involved in the development of the whole of government Carers policy have a mutual understanding of partnership.

The Carers Association of SA endorses and wishes to abide by the nine principles of partnership identified by the Corporate Citizenship Research Unit at Deakin University as follows:

### **Nine Principles of Partnership**

#### *Recognition*

Each partner to understand its own distinctive organisational culture in order to understand the other partner more effectively

#### *Respect*

This requires a willingness to share skills, knowledge, personnel and resources – there is a spirit of equality defining the partnership

#### *Review*

A willingness to be open, accountable, accessible and pro-active in regard to evaluation and change.

#### *Resilience*

Requires effective leadership, trust, honesty and integrity, sensitivity and flexibility all firmly grounded in ethically and morally acceptable behaviour.

#### *Responsibility*

The need to recognise and accept responsibilities for each one's part in the relationship.

#### *Rewards*

May not always be equal, however, as commitment to mutual benefit which requires "capital" to be thought of in ways well beyond financial.

#### *Resolve*

Although faced with competing claims on priorities, partners maintain their resolve to keep the partnership going.

#### *Relevance*

Partnership should be a routine part of the core business of the organisation, shaping and adding to social, cultural and economic value.

#### *Reference*

Partnerships need to set measurable objectives that distinguish between the partnership itself and specific program objectives.

## **Resourcing the Process**

Capacity building needs to occur for individual Carers and Carer groups, NGOs and state government departments in developing and implementing the policy. Firstly, adequate resourcing for the process in the form of education, development and training to enable groups to participate at various levels (management committee structures), and allow for both informal and formal involvement needs to occur.

## **Involving and Engaging Carers in the Development of the Policy**

Strategies for accessing and enabling groups to participate should be an important feature of the policy.

## **Use of Multiple Methods**

Consideration of informal feedback at health and community services, education centres and workplaces, as well as formal consultation mechanisms should occur. The use of internet for feedback and phone consultations should also be taken into consideration, particularly for home-bound or rural and remote Carers. Obtaining personal stories that can be collated and analysed is a popular method of gaining input from Carers.

## **Use of the Carers Association of SA and Other Agency Networks**

The Carers Association of SA advocates the use of its membership, networks and affiliations for consultation processes, for the development and implementation of the whole of government Carers policy.

## **Engaging Diverse Carers**

Particular consideration should be taken into consideration for the times and methods for consulting with the following groups of Carers:

### *Older Carers*

Informal feedback mechanisms, daytime face-to-face consultations and telephone consultations may be preferable for older Carers.

### *Children and Young Carers*

Schools and specific Young Carer Programs should be approached as an avenue to promote and seek feedback from young Carers.

### *Working Carers*

The use of union networks, out of usual working hours consultations, or telephone consultations could be held to capture the interests of working Carers.

### *Sole Parent Carers*

Whilst many Carers may need respite to be involved, the provision of respite and support is particularly relevant to the involvement of Carers who are sole parents.

### *Culturally and Linguistically Diverse Communities*

The use of existing CALD networks and informal mechanisms are preferable for seeking feedback from CALD communities.

*Aboriginal & Torres Strait Islander Communities*

The use of peers, existing networks and informal methods of feedback may also be preferable for ATSI communities.

*Rural & Remote Carers*

Free-call phone consultations and regional consultation through existing networks can be utilised to consult with rural and remote Carers.

*Different Care Conditions*

The conditions of persons being cared for should also be taken into account in the development of the Carers policy. These include mental health, acquired brain injury, intellectual disability, dementia, palliative care, acute and chronic illness, physical disability and sensory impairment.

## **Policy Framework (Operational)**

Operational components to be included in the Carer Policy Framework:

### **Information Provision and Confidentiality**

- Clear and timely communication about disabilities and illnesses.
- Communication about Carers rights.
- Access to information about the care-recipient.

### **Partnerships in Health and Community Services**

- Service systems.
- Partnerships with hospital staff, General Practitioners and other primary health care professionals.
- Partnerships in the community services.
- Quality, safety & standards in service delivery: HACCC & EQUIP standards.
- Shared decision making in health service planning.
- Involvement in decisions about resource allocation.
- Involvement in treatment decisions (care planning and case conferencing, admission and discharge coordination).
- Communication and information (including culturally specific).
- Service responsiveness and flexibility.

### **Support for Carers**

- Carer assessment - assessment of the ability to care.
- Carers health & wellbeing.
- Preventing social isolation.
- Referral to peer support.
- Respite for Carers.
- Counselling services.
- Training for Carers on the Carers role.
- Training on disabilities and illnesses.
- Training on the health and community services system.

### **Horizontal sectoral and inter-sectoral linkages**

- Communication across services.

### **Education**

- Scholarships for Carers.
- Flexible education and training.

### **Employment & Industrial Relations**

- Care and work policies.
- Anti-discrimination and equal employment opportunity.
- Training for employers.
- Workforce re-entry.

### **Housing**

- Social housing.
- Affordable housing.
- Adaptable housing standards.

**Transport**

- Transport concession scheme.
- Accessible public transport.

**Financial Support**

- Federal issues:
  - Carer Allowance & Payment.
- Superannuation.
- Personal insurance scheme.
- Review of concessions and subsidies:
  - Amenities (gas & electricity), living supports (aids & equipment).

## Outcomes of the Whole of Government Carers Policy

The added value of the whole of government Carers policy will be:

- Formal **recognition** by government of the role of Carers and their contribution to the community.
- Provide a **framework** for various government departments to refer to when developing agency Carer policies and considering the contribution, needs and role of Carers.
- Development of a **partnership** in the health and community services sector, between Carers, consumers, and professional staff at both an organisational and service delivery level, in recognition of Carers as co-providers within the health and community services system.
- Enable the health status and needs of Carers to be considered **independent of the person being cared for**. This may occur through Carer assessments in the health and community services sector, which contribute to the support provided to both Carers and care recipient.

However, a Carers policy must be supported by linkages to other relevant policy frameworks and key government initiatives, the development of agency Carer policies, be effectively implemented, and supported by legislation.

## Policy & Legislative Frameworks

The whole of government Carers policy should be consistent and build upon all relevant national and state legislation, policies and programs affecting Carers, including:

### *National/State Agreements, Policy and Programs*

- National Mental Health Strategy and State Mental Health Reform.
- Commonwealth State Disability Agreement.
- Commonwealth State Housing Agreement and State Housing Plan.
- Home and Community Care Program and National Service Standards.
- Primary Care Strategy – Enhanced Primary Care.
- National Strategy for an Ageing Australia.

### *Consolidated State Acts*

- Mental Health Act 1993.
- Consent to Medical Treatment and Palliative Care Act 1995.
- Disability Services Act 1993.
- Power of Attorney and Agency Act 1984.
- Guardianship and Administration Act 1993.
- Equal Opportunity Act 1984.

### *Consolidated Commonwealth Acts*

- Home and Community Care Act 1985.
- Privacy Act 1988.
- Industrial Relations Reform Act 1993.
- Workplace Relations Act 1996.

### **Linking Carers with Key Government Initiatives**

An essential outcome of the Carers policy should be the routine consultation of Carers in key government initiatives such as the Generational Health Review and Review of Community Care, with the outcome being Carer involvement in the future structures and mechanisms for ongoing planning and decision-making.

### **Agency Carer Policies**

The whole of government Carers policy provides an opportunity to implement the Carers Association of SA's (Kilner 1996) recommendation that all relevant state agencies develop a Carers policy with outcomes and timeframes for action, covering:

- Principles of operation, including Carers rights and responsibilities.
- Recognition of the skills and commitment of Carers.
- Training of staff in respect of Carers' issues.
- Training of Carers to carry out their role.
- Incorporation of Carers into service delivery practice.
- Incorporation of Carers' needs into service planning.
- Information dissemination to Carers.
- Provision of direct services to Carers.
- Needs of special groups.

In addition, Agency Carer policies should also include:

- Leadership and management of the agency Carer policy (e.g. persons designated responsibility for the policy and incorporation of key targets in agency business plans).
- Carer Participation in management of service:
  - Formal structures for Carer participation (e.g. Carer representation on boards of management e.g. hospital, Divisions of General Practice).
- Common Carer assessment tools (i.e. assessment of Carer's capacity to care, Carer health assessment, impacting upon actual services provided to the care-recipient).

- Standards & processes for quality assurance around the Carers policy (i.e. planning, controls assurance, continuing quality improvement and actual performance):
  - Informal feedback mechanisms (e.g. personal feedback to service delivery staff, especially important in the case of Carers from CALD and ATSI communities).
- Recognition of Carers as partners in care.

## **Section 4 Implementation & Review**

### **Implementation of the Policy**

#### **Leadership**

Cabinet must endorse the policy and responsibility must be taken at the highest government level to ensure that the whole of Carers policy is incorporated into policy, programs, and evaluation frameworks such as; DHS strategic directions, disability action plans, ATSI framework agreements, organisational Service Agreements, Australian Health Care Agreement (covers consumer rights and quality improvement), and accreditation processes such as EQUIP.

Apart from agency Carer policies, strategies for implementing the policy could include the following:

#### **Inter-sectoral Approach**

An interdepartmental working group with senior departmental staff should be established in partnership with the Ministerial Advisory Group, to determine the resourcing and effective rollout of the whole of government Carers policy. An intersectoral approach should be adopted and include process indicators such as resource input into the process, community engagement strategies, joint working on agency policies and accountability mechanisms, changes to service provision, and skills development and attitude/behaviour change of staff within agencies.

#### **Management of Carer Participation Within Organisations**

Strategic Directions and business plans of agencies should mention the whole of government Carers policy. Agency Carer policies would be established in conjunction with these strategic directions. Persons should be designated responsibility for implementing the Carer policy within agencies.

#### **A Developmental Model for Carer Participation**

##### *Organisational capacity building*

Basic mechanisms to incorporate Carers in planning and feedback mechanisms are not in place, therefore capacity building for organisations, staff and Carers is required to ensure that the Carers policy is effective. An organisational model for Carer participation should be developed and used by government departments and agencies adopting the whole of government Carers policy.

#### **Dissemination Strategy**

The success of the whole of government Carers policy rests upon an effective and timely dissemination strategy. This should coincide with a public event such as Carers Week, and be supported by multiple methods of communication such as the internet and email communication, a range of local official launches, a summary document, and training packages. The ability of the dissemination strategy to infiltrate all levels of an organisation will be critical to its success, as will the involvement of Carers in the dissemination strategy.

## **Review of Effectiveness**

A continuous quality assurance cycle for the whole of government Carer policy should be in place and incorporate the following:

### *Planning*

- Planning so that the local Carer policy incorporates Carers.

### *Controls assurance*

- Carer participation policies are in place at state government and agency level.
- Standards for Carer input into services are in place at all levels.

### *Continuous quality improvement*

- Carer feedback is obtained upon the effectiveness of policies.
- Review of effectiveness occurs on a regular basis.

### *Actual performance*

- Carer and consumer driven evaluation and reporting framework.
- Key performance measures are monitored.

## **Section 5 Carer Policies and Legislation: Examples**

### **Previous South Australian Carer Policies 1993 and 1997**

As mentioned, the Liberal Party introduced a 1993 'Caregivers' Policy, which became Government policy on their election. It included a recognition of the contribution of Carers, and opened the way for resources such as; additional Home and Community Care funding, more flexible and culturally appropriate respite services and a review of respite, research into children as Carers and ATSI Carers, hospital discharge plans which recognise the role of Carers, counselling and support for Carers, a training package for Carers, and a return to workforce program.

The 1997 'Focus on Carers' policy covered a range of areas from flexible respite, skills development for Carers, recognition of Carers in discharge plans, work and care policies across departments and agencies, and a review of relevant legislation and the consideration of new legislation to take into account the needs of Carers. However, not all of what was set out in the policy was achieved, and this was partly related to the lack of resources attached to the policy as well as the portfolio approach taken.

### **South Australian Legislation**

Some suggested changes to incorporate Carers' interests into relevant state Acts (refer list above) include:

#### *Guardianship & Administration Act 1993*

Suggested references to Carers could include their incorporation as a separate category under the definition of 'relative' in the Interpretation section, (page 8) and body of the Act. A designated 'Carer' could also be identified as a category in itself. Guardianship 'Principles to be observed' (page 8) could include:

- The capacity of informal Carers to care; and,
- The impact of the absence of guardianship on the person and their informal Carers.

The 'Functions of the Public Advocate' (page 16) include 'to give support to and promote the interests of Carers of mentally incapacitated persons'. This could include the 'rights and needs' of Carers. An application to a 'Revocation of appointment by board' could include the rights of a 'Carer' to make a submission (page 19).

#### *Mental Health Act 1993*

A designated Carer could be included under the interpretation of 'relative' and included separately in the Interpretation section as well as in the text of the act (page 6).

Objectives of the Act (page 7) do not adequately mention Carers at all. They could include:

- To ensure that services and professionals work closely with family Carers to ameliorate the adverse affects of mental illness upon family life.
- To provide adequate information and training to family Carers on mental illness conditions and treatment.

Register of patients (page 8) could include requirements to record the name of family Carers.

Continuing Detention Orders (page 10), Revocation of Treatment Orders (page 13), and Appeals against initial Detention (page 17) sections could all include an application being made by a family Carer.

#### *Disability Services Act 1993*

Refers to Carers throughout the Act, therefore the objects of the Act should include 'setting out a set of principles to be applied with respect to Carers of persons with disabilities.'

#### *Consent to Medical Treatment and Palliative Care Act 1995*

A Carer could explicitly be referred to in the Medical Power of Attorney Section 8 'Appointment of agent to consent to medical treatment'. This would afford a Carer status in the ongoing treatment of the person undergoing medical treatment or palliative care.

Whenever the 'patient's representative' is referred to, this could also include 'Carer' as a separate category, e.g. Section 17 'Care of people who are dying' – (a) with the consent of patient or the patient's representative – should include the term 'Carer'.

Carers providing informed consent for treatment would obviously require adequate training and information about the relevant treatment. A 'Carer' should be explicitly referred to under Section 15 'Medical Practitioner's duty to explain'.

#### *Equal Opportunity Act 1984*

This Act could include provisions to prevent family Carers from being discriminated against in accessing and maintaining employment, and in training and promotional opportunities within employment.

This would include the need to develop a clear definition of a Carer for the purposes of the Act.

Suggestions for amendments include; the provision of flexible working hours to accommodate Carers role if not providing undue hardship to the employer, and confidentiality around matters pertaining to caring responsibilities.

## **Interstate and Overseas Carer Policies**

### **NSW Government Carer Statement October 1999**

The NSW Health Ageing & Disability Department endorsed a Carer Statement in 1999 that is primarily a brief statement of recognition for the role of Carers, providing a rationale for supporting Carers, a picture of the situation for Carers in NSW, characteristics of Carers, and identifies the current supports for Carers in NSW. The NSW government advocates supporting Carers by:

- Acknowledging the importance of Carers in the lives of those they care for.
- Working cooperatively with Carers in the provision of services.
- Recognising the diverse needs and circumstances of Carers.
- Attempting to provide services equitably, regardless of race, culture, language, gender, sexuality, social circumstances or geographical location.
- Seeking to promote Carers' independence, choice and participation in community life.

### **Draft Queensland Government Carer Recognition Policy May 2003**

The Draft Queensland Carer Recognition Policy is more comprehensive and has also been developed in formal recognition of the role of Carers, independent of the person they care for. The policy will purportedly impact on Carers via:

- Emphasising the value of the role Carers perform.
- Improving the flexibility of services to Carers.
- Providing a broad framework to guide government agencies on Carer issues.
- Providing a platform for future government and community responses to Carers.

A series of key **principles and operational guidelines** have been developed to underpin the policy. Principles include recognition and respect for; the valuable contribution of Carers, the significance of the role of Carers, the expertise and skills of Carers, and diversity of Carers' needs. Operational guidelines include; the encouragement of care-recipients to identify their Carer, the requirement that government agencies recognise Carers as a specific group and check the capacity and ability of Carers to provide appropriate care, and the acknowledgement of the specific needs of child Carers.

The background to the policy is supported by research on trends relevant to Carers including demographic trends, National Standards (e.g. HACC), and other relevant Queensland Legislation.

The policy is being rolled out through the establishment of an interdepartmental working group.

## United Kingdom National Strategy for Carers

The three key elements of the UK national strategy include:

- **Information** to enable a care partnership e.g.
  - Charter on what Carers can expect from services.
  - Health information for Carers.
  - Helpline for Carer information.
  
- **Support** for Carers, e.g.
  - Carer involvement in the planning and provision of services.
  - Feedback and consultation mechanisms to involve Carers.
  - Development of policy to assist family friendly workplaces.
  
- **Care** for Carers to assist them to be recognised, maintain their own health, and enable choices, e.g.
  - Respite for Carers.
  - Local authorities providing services for Carers.

The government's Carers package is supported by legislation, the Carers (Recognition and Services) Act 1995 (see below).

## The Carers' Manifesto Scottish Parliament Election 2003

This document was produced as a lobbying document by Scotland's national Carer organisations during an election period, and based upon questionnaire feedback from Carers. It includes areas such as health, Carer support, information, breaks from caring, employment, education and training, transport, finance, and children and young people.

Questionnaire results included information such as;

- 49% of Carers saying that health affected their caring greatly.
- 1/3 of Carers said their GP was not supportive of their caring role.
- 70% of Carers said they did not get enough support, with most support being provided by family and friends (44%) and then the voluntary sector (24%).
- 63% had not had a Carers' assessment that has been legislated for.
- 47% of Carers had not had any respite.
- 52% of Carers said that transport was a problem.

The manifesto calls for such things as; accountability for expenditure on Carer support, access to respite and transport for Carers to attend health services, access for Carers to preventative screening, best practice on patient discharge from hospital, adequate funding for Carer assessments, adequately informing Carers of their rights and support services, accessibility of employment initiatives for Carers, Carer and family friendly work practices, physically accessible public transport, an income maximisation campaign to increase Carers take-up of benefits, and age appropriate information and support for young people with caring responsibilities.

## **Interstate and Overseas Legislation**

### **NSW Anti-Discrimination Law**

NSW introduced anti-discrimination law that started on 1<sup>st</sup> March 2001, covering Carers who are immediate family members or guardians (or in other specified relationships), in relation to obtaining and maintaining work.

Employers are obligated to provide special arrangements to support the maintenance of caring responsibilities as long as this does not cause unjustifiable hardship, for example; working from home arrangements, flexible working hours and start/finish times, and amount of unpaid and paid leave taken. Carers rights to promotion, transfer or training should not be affected by their caring responsibilities.

### **Queensland Carers Recognition Act** (proposed)

The Queensland Government is in the process of developing a Carers Recognition Act, in partnership with the Queensland Council of Carers. The recommended objectives of the legislation are:

- To promote recognition within the community of the valuable contribution Carers make.
- To ensure that Carers have the same rights to equality and consideration before the law as the rest of the community.
- To ensure that Carers are not discriminated against because of their caring role.

Carers rights proposed to be adopted through Carer legislation include:

- The right to recognition of Carers contribution within the community.
- The right to be respected as individuals with their own needs.
- The right to advocate on their own behalf, as well as on that of the care recipient.
- The right to culturally appropriate information, education, training and support.
- The right to actively participate in decisions that affect their lives, including access to information.
- The right to continue to be involved in care provision when the care recipient enters care.

Other broad areas suggested for the coverage of legislation include; financial security, services for Carers, services for care-recipients, care recipient health care, workforce and employment, government, and other areas (e.g. education, provision of goods and services, accommodation, accessing premises, land and clubs and incorporated associations).

## **The Carers (Recognition and Services) Act 1995 UK**

This came into power on 1<sup>st</sup> April 1996 and contains two essential elements:

- Carers' right to ask for an assessment of their ability to care.
- Local authorities' duty to take into account the results of this assessment when looking at what support to provide the person cared for.

Research into the impact of this legislation found that although the Act was a motivator in securing changes to incorporate Carers' interests - many local authorities (46%) had developed new procedures as a result of the Act. More than half felt that they had difficulty in meeting Carers' needs for support and that there was little time to undertake such assessments (Carers National Association 1997).

Additional funding to support the Act was perceived to be a major obstacle to its implementation. Authorities responsible for implementing the legislation also felt that there should be *standardised* Carers' assessments and services and a *legal right* to respite care. It was suggested that knowledge of the act across communities was variable, and this was tied to different education strategies – 53% of Carers had not been informed of their rights. It was felt that the government should produce a National Carers Strategy with input from diverse public and private agencies, and that local authority Carer policies should be endorsed to ensure that Carers were told about their rights and are informed about their assessments (Carers National Association 1997).

Following the Carers Act 1995, the House of Lords ruled in favour of a local authority (known as the Gloucester Judgement (1997) struggling to provide a service to Carers. This judgement declared that local authorities could draw up eligibility criteria that balanced the need for support with available resources – essentially enabling authorities to cite a lack of resources as a reason to not act upon a Carer assessment.

### **Conclusions - Policy and Legislation**

Adequate recognition, support and information for Carers (including young Carers), as well as Carers' rights to independence, assessment, access services or being maintained in employment, are common themes in interstate and overseas Carer policies and legislation.

Teachings from interstate and overseas suggest that a policy should be supported by legislation, and in turn, in order to be effective, legislation must be supported by adequate resources and a community education strategy. Decisions around what will be resourced through policy or legislation should occur in conjunction with its development, and well prior to a comprehensive whole of government policy being rolled out. A more effective policy will be limited by scope to what it can produce.

A whole of government approach also appears to necessitate an inter-departmental working group, organisational communications strategies, and agency Carer policies, all of which require significant resources.

From the UK, we can heed the need for standardised Carer assessments and the consideration of Carers' legal right to respite care. Additionally, it has been suggested that the top-down approach to the introduction of the policy in the UK was not as effective as it could have been if local agencies had been more involved in the process.

Care and work appears to be a key area for legislation in NSW, and an amendment to anti-discrimination legislation in South Australia could be considered as part of the current process. Employment will be an increasingly important concern for Carers in South Australia, as more people of working age (particularly women) will be caring for parents, due to the significant ageing of the population.

Whilst concessions and aids and equipment have been considered in some policies, the accessibility and appropriateness of housing and transport have not often been given adequate attention.

With the advent of the State Housing Plan in South Australia, there is an opportunity to advocate for and promote the adoption of the adaptable housing standards in public and private housing. Acknowledgement for Carers' hidden role in contributing to 'social housing' through their support of people with disabilities should also be provided.