

State Carers Policy 2004

Checklist Template

Carers Association

Established in 1989 by a 'grass roots' movement of Carers, the Carers Association of SA Inc. is recognised as the peak organisation for Carers in South Australia.

Association 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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Introductory Notes

1. The Checklist Template is a tool developed to enable analysis of draft and final versions of the State Carers Policy against a series of questions posed by the Association. The Checklist Template has been developed utilising:
 - Literature research of overseas and interstate Carers Policies.
 - Submissions and responses to South Australian State Carers Policies prepared by the Carers Association of SA from 1995 to the present.
 - Discussions by the Carers Association Policy Subcommittee and Carers Policy Working Groups of that Subcommittee.
 - Focus groups of Carers and Service Providers.
 - Miscellaneous input from Association members.

2. The method of analysis using the checklist Template to analyse draft and final versions of the State Carers Policy is to place a mark in the little box at the left of each point: a ✓ will be placed if the policy has covered this point, a P if it has partly covered it and an X if it has not covered it at all. Explanatory notes on inadequacies are to be recorded.

This analysis will inform the Association's responses to the State Carers Policy draft and final versions.

3. SCP = State Carers Policy prepared by the Department of Human Services

4. Notes and/or explanations are shown in italics.

5. "Agencies" includes government and non-government agencies.

6. There is an important distinction between paid care workers who attend care recipients in a professional capacity and the Carers, usually family members or close acquaintances, who provide for their care at all other times. The Carers Association acts as a peak body for the latter group. To avoid confusion this document will refer to them as family Carers.

Definition

- Does the SCP contain a satisfactory definition of who a Carer is?

For example, the Carers Association of SA definition is:

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.

Consideration needs to be given to:

- *A broad understanding of the term family, that encompasses other relatives, particularly as it is understood within CALD and Indigenous communities.*
- *A recognition that non family Carers, usually close friends, are acting like family members.*
- *A recognition that the term 'partners' encompasses married, 'de-facto' and same sex couples.*
- *The differing caring roles played by family members, including parents and siblings, one of whom might be the 'primary' Carer supported in varying degrees of intensity/effort by the other family members.*
- *An understanding that some situations indicate a legal requirement for a person to be the 'nominated' Carer (legitimate representative).*
- *Family Carers who relinquish the day to day care and management to an institution or facility continue to be a family Carer if they carry the emotional, supervisory, monitoring and regular visiting and legal role as 'nominated' Carer.*

- Does the SCP recognise that family Carers may not be family members, and address any issues around this?
- Does the SCP recognise that same sex partners may be family Carers, and address any issues around this?

Recognition

- Does the SCP specifically recognise the role, rights and needs of family Carers?
- Does the SCP recognise family Carers as partners with government and service providers in the care of their care-recipient?
- Does the SCP recognise the cost to individuals of caring?
- In providing recognition for family Carers is the policy underpinned by the values of access and equity?
- Does the SCP recognise the contribution of family Carers to the South Australian community in the delivery of health and other services?
- Does the SCP recognise multiple caring roles?
- Does the SCP recognise the skills developed through the caring role?

Diversity

Carer circumstances differ greatly and include Carers living under the same roof as the care recipient and living separately.

- Does the SCP adequately recognise the diverse nature of family Carers: eg working vs non-working; different age groups including children; different genders; duration of caring; diversity of domiciles; amount of time spent caring; variety of caring roles within the family unit?
- Does the SCP adequately recognise and address issues arising from CALD and Indigenous backgrounds?

Family Carers as a specific group

- Does the SCP recognise family Carers as a specific group with their own needs?

Needs should be interpreted broadly and include health needs, financial needs, support needs and a right to have a life of one's own, among others.

Principles, Rights & Responsibilities

- Does the SCP contain an acceptable set of principles, on which it is based?

For example, see the principles contained in the Queensland Government Carer Recognition Policy. (Appendix)

- Does the SCP reflect these principles ? If not, where are the gaps?

- Does the SCP contain a statement of family Carers rights?

For example, see the rights in the Carers Association document 'Developing a Whole of Government State Carers Policy in South Australia' July 2003, p.15. (Refer Appendix)

- Does the SCP include a statement of family Carers' Responsibilities?

For example, responsibilities include handing over responsibility for care in a considered way; exercising the appropriate duty of care; not causing harm; minimising risks.

Statements of rights and responsibilities could be developed into a Charter of Rights and Responsibilities drawn from international best practice and consultation with family Carers. This could then become a template for individual agency Carer policies.

- Does the SCP outline a Charter of Rights and responsibilities to be used as a template for agency policy and practice?

- Does the SCP provide for the development of legislation, or the amendment of existing legislation, to protect the rights of family Carers (c/f Legislation)?

Information on Family Carers' Rights

- Does the SCP provide that family Carers must be given understandable information on their rights specific to the particular service agency and how that agency will implement those rights?

Duty of Care

- Does the SCP acknowledge that family Carers have a Duty of Care?
- Does the SCP provide for access of information where it impacts on a family Carer's Duty of Care? (Refer Information page 7)
- Does the SCP acknowledge and provide for family Carer responsibilities in managing care recipient finances with regard to access to, and payment for, services?

Consent and Privacy in Relation to Duty of Care

Family Carers as partners in the delivery of care need certain information from service providers about the person cared for, or may need to be involved in care planning, in order to provide effective care and ensure that the nominated Carer can carry out their Duty of Care. The SCP should provide for Carers to have necessary information. However this should normally be with the prior consent of the person cared for. Exceptions to this consent are often necessary when the person cared for:

- *Lacks mental capacity eg because of severe dementia or intellectual disability.*
- *Is under a certain age.*
- *Is unable to give consent because of his/her medical condition such as unconsciousness.*

An unresolved issue is that of the appropriate lower age for consent, whether 16 or 18, and whether the consent is given formally or informally.

Against this, it should be noted that there are privacy issues as well which the policy should address, with reference to the respective roles of state agencies such as the Public Trustee and Federal agencies such as the Privacy Commissioner.

- Does the SCP provide for information to be provided to family Carers with the care recipient's consent except when it is inappropriate or impractical to obtain that consent?
- Does the SCP adequately address privacy issues?

Information

Family Carers need adequate information about the condition of the care recipient as well as information about treatment and services. Adequate information is necessary in order to carry out the Duty of Care. Included are:

- *Information as to the medical condition of the care recipient.*
- *Information about services to be provided.*
- *Information about treatment to be offered.*
- *Information on legal processes.*

Family Carers should also have the right to access necessary financial information appropriately where this has a bearing on the care provided. This is in the context of making financial arrangements where it relates to access to services and payment of fees and services rather than seeking to control the care recipient's financial affairs.

Family Carers also need practical information on care.

- Does the SCP provide for the provision of adequate information (as defined above) to family Carers?

Information provision is not just about acquiring information but also about sharing – family Carers have information based on their experiences in the caring role, but are often not listened to by agencies in the development of services; for example care plans.

- Does the SCP encourage agencies to enter into a dialogue with family Carers in order to learn from them when developing agency Carer policy and programs?
- Does the SCP provide for complaints processes where information is withheld? (Refer Complaints and Appeals page 13)
- Does the SCP provide for situations where a nominated Carer is included in a confidential information exchange, for example in the development of care plans?

Assessment and Provision of Services

- Does the SCP create a right for family Carers to receive (on request) an assessment of their own needs by service providers and to have the results of that assessment given to them and taken into account when decisions are made about any services to be provided to the person cared for?

The right should exist even if the person cared for is not receiving services. Assessment includes (but is not limited to):

- *Family Carer's time commitment.*
- *Financial impact.*
- *Training needs.*
- *Respite needs.*
- *Health impact.*

- Does the SCP provide for the delivery of services to the care recipient where the family Carer is assessed as unable to care?

- Does the SCP provide that a family Carer or Carers must be consulted when a service provider is considering the provision or amendment of services to the person cared for, provided the care recipient has given his/her consent to this (except when it is inappropriate or impractical to obtain that consent)?
- Does the SCP provide for an inter-agency response when the person cared for, or the family Carer, requires support from more than one agency?
- Does the SCP provide for family Carers to receive services also?
- Does the SCP provide for the priority of access guidelines in a way that reflects the real needs of family Carers?
- Does the SCP provide for the right of access to services, in their own right, for young Carers under the age of 18?

Regard needs to be given to existing gaps in services when developing operational priorities based on the principles enunciated in the SCP. Such gaps as identified include adequate respite, access to quality care workers, services provided by HACC at the lower end of need, and the higher end resulting in institutional care, and buffers and safety nets in affordability.

- Does the SCP provide for adequate and affordable services to meet the caring role as well as the family Carers own needs for services that address their health and wellbeing?

Increasing concerns are being raised at the need to meet occupational health and safety regulations within any worksite.

- Does the SCP address the need for paid care support workers to meet occupational health and safety standards without a loss in the level of service nor with a transfer of responsibility onto the family Carers?

Carers are concerned that services may be denied where there is a dispute.

- Does the SCP provide for choice of service providers particularly in cases of disputation?

Service Commitments

- Does the SCP provide for appropriate government service commitments to family Carers in a collective sense?

Appropriate service commitments include funding of:

- *Peak body (Carers Association of SA Inc.).*
- *Regional Carer support services.*
- *Respite services: ongoing, short term and emergency.*
- *Education and training.*
- *Counselling.*
- *Advocacy and mediation.*
- *Personal health care needs.*
- *Emergency alert systems.*

- *'What if' factor.*
- *Emergency care plans for family Carers.*
- *Family Carer retreats (Respite hotels)*

- Does the SCP acknowledge that the whole of life service needs of family Carers requires attention in such areas as financial support, health care, affordable and adaptable housing, accessible transport and inexpensive utility costs?

Funded Organisations

- Does the SCP include a provision that human service organisations funded by the State Government will be required to develop their own Carers Policies within a specified timeframe congruent with the SCP including its Charter of Rights and Responsibilities?
- Does the SCP acknowledge that resources will be required to assist funded organisations to develop and implement a Carers Policy?

Principles for agencies' Carers policies include:

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

Legislation

Existing legislation

- Does the SCP identify the range of current State legislation which has a bearing on family Carers and provide for a process of proposing suitable amendments that recognise and support family Carers?

State Legislation affecting family Carers includes:

- *Disability Services Act.*
- *Office for the Ageing Act.*
- *Aged And Infirm Persons Policy Act.*
- *Consent To Medical Treatment And Palliative Care Act.*
- *Guardianship And Administration Act.*
- *Mental Health Act.*
- *Occupational Health and Safety and Welfare Act.*
- *Home and Community Care Act*

- Does the SCP assess the adequacy of the Guardianship and Administration Act and how it operates in practice?
- Does the SCP provide for monitoring of the operations of the Guardianship and Administration Act with respect to their impact on Carers?
- Does the SCP include plans to ensure that relevant funding legislation and agreements incorporate provisions to fund organisations to support family Carers?

Examples of funding legislation include the Disability Services Act; examples of funding agreements include the Home and Community Care Agreement.

New Legislation

- Does the SCP propose the introduction of legislation which:
 - Recognises the role, rights, needs and contribution of family Carers?
 - Recognises the contribution that family Carers make to the South Australian community through the provision of health and other services to the care recipients (consumers)?
 - Permits the Carer to obtain necessary information about the health status and treatment of the person cared for, with the consent of that person (except when it is inappropriate or impractical to obtain that consent)?
 - Provides for a right of assessment of the family Carers needs even if the person being cared for is not in receipt of services and feedback of the assessment?
 - Requires agencies to consult family Carers and take their views and information into account when making decisions, with the consent of the care recipient (except when it is inappropriate or impractical to obtain that consent)?
 - Authorises payment of fees and reimbursement of costs to family Carers who sit on boards and committees or who participate in recognised forms of consultation?
 - Requires agencies to provide services to family Carers?

Whole of Government Approach

- Does the SCP adopt a Whole of Government approach?
- Are there realistic timelines indicated for the SCP including timelines for the development and implementation of government agency Carers' Policies?
- Does the SCP identify a viable implementation process for state wide policies at the agency level?

Key elements for implementation at agency level include:

- *Timelines.*
- *Information provision to agencies.*
- *Support available e.g. Office for Families and Children.*
- *Performance indicators.*
- *Reporting lines.*

Implementation of the SCP

- Does the SCP assign responsibility for its implementation, and for the implementation of individual agency family Carer policies, to an identified office or area of the State Government: for example, through the appointment of a Minister for Carers, supported by a broad based Ministerial Advisory Committee?
- Does the SCP have an implementation plan contained within it?
- Is there an appropriate mechanism for ensuring that the effective implementation of the SCP is accomplished within specified timelines?

For example, there could be a program set out, with milestones or key performance indicators, or there could be provision for an independent evaluation to be conducted after a set time period.

- Does the SCP provide for compulsory reporting of progress?

Employment, Education and Caring

- Does the SCP incorporate an 'Employment and Caring' component?
- Is this binding on all Government agencies and funded organisations?

Key elements of an employment and care policy are:

- *Child care including care for children with special needs.*
- *Daytime care and/or activities for young/mature disabled adults, frail older people and dementia sufferers.*
- *Flexible working hours and leave provisions.*
- *Availability of part time work.*
- *Availability of sick leave and special leave for caring purposes (not restricted to children) with additional allowances to the norm.*

- *Flexible working arrangements e.g. working from home where appropriate.*
- *Equal opportunity and lack of discrimination.*
- *Education campaigns targeting employers to recognise the skills developed during caring.*

Family Carers may need help in order to enter or re-enter the workforce after a period of caring. For example, they may need to learn how to 'sell' themselves to an employer; skills can go rusty; Carers may need help to know who to turn to. Skills gained during caring should be recognised.

- Does the SCP also provide for and support appropriate educational and other strategies for family Carers so that they may prepare themselves for the workforce (including re-entry into the workforce after a period of caring), or maintain, augment or update skills?

These strategies should include provision for the recognition of prior learning including the caring experience and any Carer specific training modules.

- Does the SCP seek a national legislative approach to workforce industrial issues?
- Does the SCP provide for appropriate strategies such as distance education to ensure that Young Carers are able to continue with their education whilst caring?

Training for family Carers in the caring role

- Does the SCP provide for training and access to information for family Carers in areas such as the Carer's role, disabilities and illnesses, and the health and community services system to support Carers access to services? Aspects of this training to include for example:
- Negotiation.
 - Advocacy for self.
 - How to communicate.
 - Making a complaint.
 - Inform and encourage family Carer access to relevant information about roles and responsibilities.
 - Managing the relationship with paid care support workers.
- Does the SCP provide for training for family Carers as part of a nationally recognised curriculum, including accreditation for other study?
- Does the SCP provide for the pursuit of innovative training strategies; for example family Carer training within the home to be included as part of care packages?
- Does the SCP recognise the special training and information needs of young Carers, in particular children?

Complaints and Appeals

- Does the SCP provide for accessible, appropriate and transparent complaints procedures for family Carers about service providers and government departments and agencies, that meets Australian standards?
- Is there a provision for family Carers to review and to appeal decisions affecting them?

Parameters for an acceptable complaints and appeals process include:

- *Reasonable time to lodge an appeal or complaint.*
- *Provision for internal and external review.*
- *Speedy response.*
- *Affordable to users.*
- *Impartiality.*
- *Informality.*
- *Privacy.*
- *Sensitivity to the needs of people with diverse cultural and linguistic backgrounds (access to interpreters, advocates), people in rural areas, people with limited literacy and/or other skills, Aborigines and people with disabilities.*
- *Right to representation including use of non-legal advocates.*
- *Effective redress.*
- *Family Carers able to make a complaint without fear of prejudice or retribution.*

Family Carers have a right to advocacy in their own right as separate from the care recipient (consumer).

- Does the SCP provide for family Carers to have access to advocates or mediators in their own right?
- Does the SCP provide for the establishment of, and resources for, an independent Carers Advocate?

On occasion complaints are made about family Carers and services are withdrawn without the family Carer being privy to the complaint, nor given a chance to respond to it.

- Does the SCP provide for appropriate processes for situations where complaints are made against family Carers to ensure family Carers right to natural justice is maintained: ie incident investigation prior to services being withdrawn?

Reimbursement of Out of Pocket Expenses

- Does the SCP provide that family Carers who sit on government advisory boards, taskforces and committees will be reimbursed for any out of pocket expenses including caring costs incurred when undertaking tasks on behalf of the body?

Refer HCA Protocol Appendix

Consultations and Evaluations

- Does the SCP provide that when the government desires to consult with the community concerning needs and services, then family Carers will be included in the consultation process?
- Does the SCP provide for a model of consultation including:
 - Partnership with peak bodies?
 - Effective consultation with individuals?
- Does the SCP provide for a partnership in consultation with the peak organisation that represents family Carers?
- Does the SCP provide for an acceptable consultation process with family Carers to be entered into on such occasions?

Key elements of an effective consultation process include:

- *Compensation of costs of participation.*
 - *Provision of information in advance in a form which enables participation.*
 - *Adequate time to consult and develop responses.*
 - *Engaging a diverse selection of representative Carers.*
 - *Appropriate and adequate support for individuals participating on committees.*
 - *Different strategies for different people.*
- Does the SCP provide for family Carer involvement when evaluations or reviews of services and programs are carried out?

Community Education

- Does the SCP provide for a community education program about the role and needs of family Carers?

Key goals for such a program include:

- *To make the community more aware of the role and contribution of family Carers.*
- *To enable people who are in a caring role to self identify as a family Carer, in particular, young Carers, and members of CALD and Indigenous communities.*
- *To alert family Carers who may be unaware of services that help is available.*
- *To validate and legitimise the caring role in the community's eyes.*
- *To raise the status of family Carers in their own eyes.*
- *To raise the status of family Carers in the community.*
- *To ensure key gatekeepers such as GPs have appropriate information.*
- *To make professionals more aware of the role of family Carers as partners in the delivery of health care.*

Carer Impact Statements

- Does the SCP provide for agencies to develop Carer Impact Statements to assist in effective service provision?
- Does the SCP provide for Carer Impact Statements to be included in Cabinet submissions?

A Carer Impact Statement refers to the broad impact of policies and programs on Carers. It is different from a Carer's assessment which is specific to an individual family Carer.

Institutional Admission and Discharge Policies

- Does the SCP provide that institutions such as hospitals must have written admission and discharge policies which take into account the family Carer's needs?

Key aspects of such a policy include:

- *Right to be informed of admission and discharge dates and discharge destination for the care recipient.*
- *Involvement of the family Carer in planning admission and discharge of the care recipient.*
- *Access to critical information concerning diagnosis, in-patient treatment and planned treatment and follow-up on discharge of the care recipient.*
- *Access to information that assists the family Carer in managing the care of the care recipient at home.*
- *Support services needed by family Carers on discharge of the care recipient.*
- *All plans to be in writing and a copy provided to the Carer on request.*
- *Responsibility of the organisation to discharge their duty of care in the handover to family Carers through the provision of post discharge support for the care recipient including instructions on medications provided.*

- Does the SCP provide for institutions and hospitals to provide for the inclusion of nominated Carers in admission and discharge planning of care recipients?

Staff Training

- Does the SCP make provision for the training of all staff whether paid or voluntary in government and non-government agencies who work with family Carers?

Such training should include:

- *Background information on family Carers.*
- *Family Carers' needs.*
- *Family Carers' rights and responsibilities.*
- *Developing partnerships with family Carers.*

- *Carer Assessment Statements.*
- *Making appointments.*
- *Family Carer friendly communication and attitude.*
- *Culture of caring: sensitivity to and appreciation of the caring role.*
- *Culture of service provision: respect and responsibility.*
- *Carer impact statements.*
- *Management of the care support worker and family Carer relationship.*
- *Diversity of family Carers including CALD and Indigenous.*

Barriers

- Does the SCP adequately identify any existing and potential barriers to the implementation of each aspect of the Policy?

Review

- Does the SCP provide for a review of the policy and its effectiveness after a set period of time?