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SA Carers Report 2004 Response



PO Box 410 Unley SA 5061: Telephone 8271 6288: Fax 8271 6388:
Email info@carers-sa.asn.au: Website: www.carers-sa.asn.au

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The release of the SA Carers Report for consultation, with the promise of Carer Legislation and a Carers' Charter and the announcement of extra funds for families and young carers, made it a very significant document.

The Carers Association is pleased that the Report provides strong leadership in advancing a Whole-of-Government Carers Policy for all Carers providing care for people across the age, illness and disability spectrum, as well as providing a foundation for government agency Carer policies and implementation.

The development of the Whole-of-Government Carers Policy is of critical importance to Carers in this State. The Association sees the SA Carers Report 2004 as the beginnings of the formal recognition of family Carers in this State that will have great benefit for all Carers in the long term.

Whilst the Report to some extent gathers together previous work but leaves a number of serious issues not addressed, nevertheless the Association believes that the document is a good foundation for discussion about operational issues and the development of an action plan to develop operational strategies. It is within this context that the attached documents are presented.

The Association's detailed responses are based upon the checklist Template, developed in December 2003, for input into the State Carer Policy consultation process of 2003-2004. The checklist itself was prepared utilising work carried out in other jurisdictions, as well as the Association's continued conversations with our members and the submissions that we have made over the last ten years as we have made representations for the recognition, inclusion and empowerment of all family Carers, as well as increasing practical assistance and support to help Carers in their caring role. The SA Carers Report 2004 plays a significant role in helping to achieve these things.

An implementation strategy and action plan need to be developed in consultation with Carers and key stakeholders to fulfil the implementation of a Whole-of-Government Carers Policy. In addition, because this is to be a Whole-of-Government Carers Policy, across-Government portfolio responsibilities and the creation of Departmental operational policies need also be developed and implemented. The Association recognises that this will all take time and appropriate delegation of responsibility.

The Association welcomes the acknowledgement that the seven Principles outlined in the Report provide recognition of the special needs of children and young people who care and Indigenous Carers.

We believe that special emphasis should be given to:

Assessment of the needs of the Carer as separate from those of the care recipient is a vital first step in providing protection and support to enable family Carers to sustain their caring roles.

- Advocacy for family Carers

The Carers Association is hearing from an increasing number of family Carers seeking advocacy assistance in their dealings with a wide range of service providers. There are only limited avenues for assistance for Carers representing themselves and or the persons they care for.

- Health

The Report rightly highlights Carers' health and wellbeing. There are three principles:

- Carers' health and well being is critical to the community.
- Carers are consulted about their capacity to sustain caring.
- Carers are recognised and treated as partners in the health care of the care recipient.

Recommendation:

- That the Minister and Government display a commitment to advocating the principles of the SA Carers Report 2004 by:
 1. Placing a timeframe on the introduction of Carer Legislation and a Carers Charter.
 2. Dedicating resources in the Department of Families and Communities, with responsibility to Senior Officers to developing an implementation plan.
 3. Continuance of the Carers Ministerial Advisory Council, or similar body including Carers and service providers, as a Carers Policy Implementation Committee.

ate: Guidelines for Comment

Some General Comments

- There is no operational plan
- There are no Carer assessment rights

Principles

The seven core principles in the Report are:

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 Straits Islanders 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.

These principles have been compared with the principles enunciated by the Carers Association in 1995 as part of the 1995 - 1996 State Carers Policy development process. The major gaps in the principles in the 2004 Report are:

- The right to representation and advocacy.
- To gain formal acknowledgment of skills and knowledge acquired as a result of their role.
- To assume all the rights of the consumer as stated in the consumer's health charter where the Carer is acting in place of the consumer due to reduced capacity of the consumer.

The following items from the 1995 principles have been only partially addressed:

- To have emotional, financial and physical security.
- To be included in service planning and policy and program development.
- To be consulted about the impact of treatment on the Carer's capacity to sustain the caring role.
- To have their gender, age, social situation, economic position, geographical location, cultural heritage and any special factors taken into consideration.

There appears to be no recognition of Carers needs to have formal input into State Government policy development and review processes.

CMAC Report

ly describe the role of Family Carers?

Not completely. It ignores the economic role by which Carers save the taxpayer large sums of money each year.

- **Has anything critical to our understanding of Carers been missed out?**

Yes, there is no specific definition of what a Carer is. The economic role of Carers is not described. Also the need of Carers to have an assessment of their own needs is missing.

A specific definition of a Carer is extremely important. It is important that family Carers are not confused with paid care workers as often happens in discussions in the general community

- **How should the community change its attitude to Family Carers?**

The attitude has been evolving for many years and there is now a greater level of understanding of the role and needs of Carers. Carers are better recognised. However this needs to be broadened and deepened.

- **Are family Carers getting a fair deal from other family members/ the community/ government?**

Carers still do not have codified rights in respect of government policy development processes and the delivery of services by government and non-government agencies. The Carers Association has made submissions in respect of this on many occasions – see for example “State Carers Policy: Checklist Template 2004” (Refer Section Three for analysis based on this checklist) which lays in detail what is required for Carers to receive a fair deal.

- **If you are a service provider, describe any different approaches you have taken and why. Are there any competing issues you are aware of, including how the Report might affect your service?**

Not applicable to Carers Association.

3.3 Section 6. Recommended Principles

- **Carers save the tax-payer many millions of dollars. What is the best way for government to support Carers?**

In addition to all the services and support which have developed over the last twenty years, the establishment of a State Carers Policy along the lines recommended by the Carers Association would go a long way to address this issue.

- **How can service providers do things better?**

The detail of this is laid out in our document “State Carers Policy: Checklist Template 2004”.

supportive and helpful services for Carers?

Identify the needs of Carers and how to best meet them, for example in developing Care packages that meet the needs of the individual Carer.

- Resource Centre Information line providing information and referral to services that meet Carers need.
 - Carer counselling providing one on one and group counselling sessions enabling Carers to discuss issues facing them with trained counsellors.
 - Retreats Program providing opportunity for groups of Carers to have a short break from their caring role.
 - Respite centres and services providing flexible ongoing, short term planning and emergency respite brokerage.
 - Local and regional Carer support services that provide event opportunities for recognition, sharing, peer support and learning about the caring role in order to reduce isolation and improve emotional and social wellbeing.
 - Advocates for family Carers.
 - Young Carer liaison to provide assistance with education authorities.
 - Family assistance packages for families where there are children and young people in a caring role.
 - Workforce assistance program that includes assistance to enable Carers to undertake educational opportunities and the development of Employment and Care policies by government and businesses.
 - Education in the caring role through innovative and flexible training packages.
- **Do Carers have rights? What are they?**

Refer also to discussion in Additional Comments below and in Section Three.

- **Do you have a view or examples about privacy and confidentiality restraints on Carers?**

The following statement was included in the Carers Association's 1995 submission regarding a State Carers Policy :

"Carers are often confronted with situations where they are called on to care for a person with significant health or disability problems yet they are not provided with adequate information to undertake the role. There should be a State policy which enables Carers to have access to necessary information about the health status and treatment of the person cared for (with that person's consent). This could be embodied in the proposed legislation.

In other situations, the person cared for may be unable to provide information e.g. due to mental incapacity. There should be a process available by which this information can be released under authority.

Sometimes the person cared for may be unwilling to provide essential information. There are some situations where carers definitely need information about the person cared for e.g. diagnosis, treatment,

ff, but where the client is unwilling to give agencies to release this information to carers. It is appropriate that carers have access to a process which enables them to seek the release of the information when it is in the best interest of the person cared for. This process should be authorised through legislation."

This statement remains valid in 2005.

In addition the current review of the Mental Health legislation has highlighted the negative impact on Carers of the practice by mental health professionals regarding confidentiality. That needs to be changed so that Carers can receive vital information.

- **What is your community's view on the role of Carers?**

This is encapsulated in the Carers Association vision, which is:

"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."

- **Does the report cover the circumstances of different groups of Carers? This includes young people and Aboriginal Carers.**

Yes.

3.4 Other information.

The Report is very broad to cover all the different caring circumstances and to cover the many different kinds of service providers. The findings from this consultation will help guide government departments develop better service and funding programs for Carers.

Do you have a view on:

- **what different State government departments (such as Health and Education) should do for Carers?**

Government Departments need to implement the policy so that policy changes are embedded in the day to day operation of government services.

The Carers Association proposed in its 1996 submission that all relevant State agencies develop a Carers policy and that they should be held accountable for ensuring effective outcomes within a realistic timeframe. Areas to include were:

- 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.

o Carers.
to Carers.

- Needs of special groups.

Refer to Section Four: Operational Priorities State Budget 2005 – 2006 Submission.

- **what kinds of services the State government should fund in the non-government sector?**

- Carer Assessment to determine the needs of Carers and how to best meet them, for example in developing Care packages that meet the needs of the individual Carer.
- Resource Centre Information line providing information and referral to services that meet Carers needs Carers.
- Carer counselling providing one on one and group counselling sessions enabling Carers to discuss issues facing them with trained counsellors.
- Retreats Program providing opportunity for Carers to have a short break from their caring role.
- Respite centres and services providing ongoing, short term planning and emergency respite brokerage.
- Local and regional Carer support services that provide event opportunities for recognition, sharing, peer support and learning about the caring role in order to reduce isolation and improve emotional and social wellbeing.
- Advocates for family Carers.
- Young Carer liaison to provide assistance with education authorities.
- Family assistance packages for families where there are children and young people in a caring role.
- Education in the caring role through innovative and flexible training packages.

- **how the non-government sector should support Carers?**

Development of Carers policies and their implementation. Refer Section Three, Carers Association's State Carers Policy 2004 Checklist Template for references to the non government sector generally.

These guidelines are to provide assistance only. Please feel free to add any other information or comments you think are relevant

Additional Comments

The document would benefit from significant strengthening in a number of ways. In regard to principles the following should be added :

- Service providers and government work in partnership with Carers.

As well as these principles, the paper could be strengthened by discussion of the following rights and responsibilities which were incorporated into the Association's State Carers Policy Checklist Template (Refer Section Three).

- To be recognised and taken into account by the State Government and State agencies.
- To be included in planning of home care and treatment which affects home care, including discharge planning from health care institutions.
- To decide how much care they will provide and the manner in which it is to be provided.
- To access services which directly support them in their caring role.
- To be consulted about the impact of treatment on the carer's capacity to sustain the caring role.
- to have their gender, age, social situation, economic position, geographical location, cultural heritage and any special factors taken into consideration.
- to be provided with information about services and treatment.
- To access necessary information about the health status and treatment of the person cared for (with that person's consent).
- To be provided with suitable equipment and training with which to carry out their role.
- To maintain an independent identity outside of the caring role.
- To have emotional, financial and physical security.
- To live in dignity.
- To safeguard their own health.
- To be included in service planning and policy and program development.
- The right to representation and advocacy.
- To gain formal acknowledgment of skills and knowledge acquired as a result of their role.
- To assume all the rights of the consumer as stated in the consumer's health charter where the carer is acting in place of the consumer due to reduced capacity of the consumer.
- The right to comment, complaint and redress.

Carer responsibilities

- Carers have a duty of care towards those they care for.
- Carers have a responsibility to terminate or alter the caring role in a manner which does not prejudice the well-being of the person cared for.
- Carers have a responsibility to notify professional caring systems of any change in circumstances affecting their caring role.
- Carers have a responsibility to consider the opinions of professional and other staff and recognise their skills in providing care and treatment.
- Carers have a responsibility to co-operate as far as possible with reasonable treatment programs.
- To provide relevant information to service providers about the situation of the person cared for.

ist of rights and responsibilities we emphasise the

- The importance to Carers of being allowed and enabled to decide how much care they provide. Each Carer is different and at different points in time the same Carer may vary in the amount of care they are able or wish to provide for many differing reasons (Personal health, other family commitments, support available to Carer, personal needs, finances etc). Government and service providers need to understand this.
- The need for suitable equipment as many Carers wreck their physical health due to not having access to suitable equipment.
- The right and associated mechanisms to comment, complain and redress.

By far the biggest problem with the document is that it is only a set of principles which is not binding on government and non-government agencies providing services. It also lacks an Implementation Plan showing how agencies will operationalise the principles.

Carers Association State Carers Policy 2004 Checklist Template

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 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 been covered it at all.

Explanatory notes on inadequacies are to be recorded: shown as Response using Times New Roman font (original document in Tahoma).
3. SCP = SA Carers Report 2004 prepared by the Carers ministerial Advisory Committee (CMAC).
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.

□ 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.

Response: This definition is not specifically used. In fact there is no definition as such although the discussion in the Report arrives at a similar endpoint.

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.

Response: Satisfactory

- A recognition that non family Carers, usually close friends, are acting like family members.

Response: Satisfactory

- A recognition that the term 'partners' encompasses married, 'de-facto' and same sex couples.

Response: Satisfactory

- 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.

Response: Not clearly identified

- An understanding that some situations indicate a legal requirement for a person to be the 'nominated' Carer (legitimate representative).

Response: Unsatisfactory

- 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.

Response: Satisfactory

□ Does the SCP recognise that family Carers may not be family members, and address any issues around this?

Response: This is recognised but the issues are not identified or addressed.

□ Does the SCP recognise that same sex partners may be family Carers, and address any issues around this?

Response: This is recognised but the issues are not identified or addressed.

Does the SCP 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?

Response: Partnership is recognised in respect of service providers but not clearly so in regard to Government.

Does the SCP recognise the cost to individuals of caring?

Response: Not mentioned.

In providing recognition for family Carers is the policy underpinned by the values of access and equity?

Response: It is recognised implicitly rather than explicitly.

Does the SCP recognise the contribution of family Carers to the South Australian community in the delivery of health and other services?

Response: Not explicitly addressed.

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?

Response: This could perhaps be drawn out more strongly and clearly.

Does the SCP adequately recognise and address issues arising from CALD and Indigenous backgrounds?

Response: It is better at dealing with indigenous issues than broader cultural issues.

Family Carers as a specific group

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

and broadly and include health needs, financial
right to have a life of one's own, among

Principles, Rights & Responsibilities

- P Does the SCP contain an acceptable set of principles, on which it is based?
- P Does the SCP reflect these principles ? If not, where are the gaps?

For example, see the principles contained in the Queensland Government Carer Recognition Policy as follows:

1. **Acknowledge, respect and support** the valuable contribution made by Queensland Carers to those they care for and to the community
2. **Accept** the significance of the role of Carers, along with those receiving care and with service providers
3. **Ensure** information is provided to Carers on their rights when dealing with Government agencies
4. **Acknowledge** Carers as individuals with their own needs within and beyond the caring situation
5. **Value** the expertise and skills of Carers in relation to their caring role
6. **Acknowledge** and **identify** the diversity of Carers' individual needs, taking into consideration cultural differences, age, disability, religion, socioeconomic status, gender identification and where people live in Queensland
7. Ensure **programs** and **services** for Carers are responsive, timely, coordinated, innovative, flexible and appropriate
8. **Ensure** the appropriate **sharing of information** and decisions on care with Carers in matters that affect them or the care they provide.

Response: There are gaps in the CMAC Report's principles, particularly Queensland principles 1,2,3 and 8 above, and WA principles 2 and 3 below.

The Western Australian Carers Recognition Act has the following principles in its Carers Charter :

1. Carers must be treated with respect and dignity.
2. The role of Carers must be recognised by including Carers in the assessment, planning, delivery and review of services that impact on them and the role of Carers.
3. The views and needs of Carers must be taken into account along with the views, needs and best interests of people receiving care when decisions are made that impact on Carers and the role of Carers.
4. Complaints made by Carers in relation to services that impact on them and the role of Carers must be given due attention and consideration.

See also the separate discussion of principles in Section One above.

statement of family Carers rights?

ly spelt out. National Standards on the rights and needs of Carers should be developed and enforced in relevant programs such as HACC and Disability Services Program.

- 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?

Response: Refer discussion above and in Section Two. The Association acknowledges that the Minister for Families and Communities has foreshadowed the development of a Carers charter elsewhere.

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

Response: The CMAC Report does not mention legislation although the Association acknowledges that the Minister for Families and Communities has foreshadowed this elsewhere.

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?

Response: The CMAC document does not specifically address this. There could be a separate principle setting out Carers 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)
- Does the SCP acknowledge and provide for family Carer responsibilities in managing care recipient finances with regard to access to, and payment for, services?

on 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.

the provision of adequate information (as defined

Response : There is a fairly weak statement about service providers “giving consideration” to overcoming rigid adherence to privacy and confidentiality but the document does not propose amending those guidelines to address Carers’ issues and needs.

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)

Response: The CMAC document says independent complaints and grievance mechanism should be available but doesn’t define their scope.

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?

Response: See above re: Information.

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?

Response: The needs of Carers are alluded to several times but there is no specific right to an assessment for the Carer. It is vital that family Carers have the right for a personal assessment of their own needs

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.

the delivery of services to the care recipient where
ed as unable to care?

Response: It is vital that SCP provides for delivery of services to care recipient where
the family carer is assessed as unable to care and that family Carers be able
to receive services needed.

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?

Response: The Report recognises Carer-specific supports but does not entrench
individual Carer needs through a Carer assessment.

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?

Response: There is a whole principle on children and young Carers but it does not
specifically create a right to services for people under 18 years.

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?

Response: The CMAC Report goes some way towards this.

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.

d care workers to meet OH&S standards without and strain to family Carers. There are many workers can not perform certain tasks which the family Carer is then required to do, usually with no equipment to help. The result is that the family Carer's physical health suffers but there is no workers' compensation. The damage can be permanent.

- 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?

Response: There is a broad commitment but little in the way of specifics.

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?

Response: There is limited recognition of these areas other than health needs. It is very important that the SCP acknowledges the whole of life service needs of family Carers. Government and service providers need to see that being a family Carer can affect the Carer's entire life style and can affect a whole family in many far reaching ways.

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?

Active human service organisations need to develop
policies.

- 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?

is to ensure that relevant funding legislation and provisions to fund organisations to support family

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?

Response: The CMAC Report does not mention legislation although the Association acknowledges that the Minister for Families and Communities has foreshadowed this elsewhere. Legislation that recognises the role, rights, needs and contributions of family Carers in South Australia would provide the SCP with teeth.'

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?

able implementation process for state wide policies

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?

N/A 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.

plans targeting employers to recognise the skills
gained 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?

Response: Carer Comment: The SCP must have an 'Employment and Caring' component. The listed Key elements are vital to allow Carers to have the choice to be involved in the paid work force. The Government needs to be made aware that living on a Carers Pension, especially over a long period of time does not provide sufficient income for the Carer and family. Children of Carers can miss out on many opportunities due to ongoing low household income and the Carer can be under extra stress due to the worry of inability to pay bills and provide a good standard of life in a financial sense. Also there is often a feeling of no hope. The unemployed person says 'When I get a job...' but a Carer can be in a position where he/she can't dream of that day. Carers who are not in the paid workforce are not respected enough by Government or the community because our society puts so much value on a person's 'job' (paid work). Employment allows a person to fulfil many other needs than the need for money. Carers need to be given a choice. Also many Carers have so many skills which would benefit the workforce but the carers themselves often don't realise this and can suffer low self-esteem.

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.

- 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?

Response: Carer comment: All the points listed here need to be addressed in the SCP. I found the Certificate III and IV courses in Disability Work I did through TAFE helped me in my role as a family Carer and I see many issues differently now (how much 'help' to provide the person I care for, the right for her to make decisions and mistakes, her right to deal with certain issues without my interference etc-the right to complain is really important as a Carer can be afraid a complaint will have bad repercussions on the person receiving services and maybe even withdrawal of those services.

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?

Response: There is recognition of a need for a complaints and grievance mechanism but this is not elaborated.

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),

as, people with limited literacy and/or other
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?

Response: Right to Advocacy: Carers need access to advocates for family Carers as the Carer may lack the confidence, time, knowledge, energy to complain, chase up services that are not provided.

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?

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?

... provide for an acceptable consultation process with
... 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?

Response: This is not specifically mentioned but there is a statement that joint planning involving all concerned parties will have the best outcomes for everyone.

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?

refers to the broad impact of policies and 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?

Response: Carer Comment: Institutional Admission and Discharge Policies-all these points were really important. It is only when one has had experience with hospitals and a care recipient that one realise how little doctors and hospital staff understand the situation!

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?

Response: The CMAC document refers to staff and Carers needing training in respect of caring for the person cared for.

e:
on 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?

Response - The SCP must be reviewed on an annual basis.

Carer Recognition and Support: State Budget Submission 2005 – 2006

Introduction

The Carers Association of SA Inc. was established in 1989 by a 'grass roots' movement of Carers. The Association is recognised as the peak organisation for family Carers in South Australia.

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

In South Australia there are 235,000 family Carers (Australian Welfare 2003), including 46,126 primary Carers, looking after a parent, child, partner or friend. Family Carers come from all cultural and social backgrounds and range greatly in age. Some provide care twenty-four hours a day, every day; others give care for a few hours a week.

Association submissions and responses are developed utilising documented research, previous submissions prepared by the Association, surveys of members, discussions by the Association Policy Subcommittee and Policy working groups, focus groups of Carers and service providers and miscellaneous input from Association members.

Carer Recognition and Support

The Carers Association of SA acknowledges the Government's release during Carers Week 2004 of the SA Carers Report and the announcement of the development of a Carers Charter and Carer Recognition Bill. These are long awaited initiatives.

The Association notes and welcomes the recognition of the situation and needs of South Australian family Carers, in particular the encouragement of government agencies and non government service providers to adopt a more consistent approach to responding to Carer needs, 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 family Carers by the wider community.

In order to achieve a consistent approach the Association has called for a strategically driven whole of government approach that recognises the across portfolio nature of the caring role and the need for each government agency to develop its own family Carer policies and programs within a central framework.

the good work to date may be dissipated if the
currently devoted to the development of Carers policies
through an across portfolio approach.

The Association has called for, and welcomed, the announcement of the Carer Recognition Bill.

Recommendation

That further funds be set aside for the development of operational policies and the implementation of priorities that arise from the principles enunciated in the SA Carers Report, the proposed Carer Recognition Bill and any associated consultation with Carers, their families and service providers.

Recommendation

That there be a continuation of the Carers Ministerial Advisory Council, or similar body.

The Association recognises the importance of developing policy platforms across individual departments for the operational implementation of the SA Carers Report seven core principles. Nevertheless there are a number of areas in which action should be taking place, even while these platforms are being prepared. These include:

1. Community Recognition

Raising community awareness and acceptance of family Carers' role in society will assist in the validation and self identification for Carers themselves.

Recommendation

That a community education program on family Carers, with appropriate resources, be developed.

2. Carer Assessment

Recognition is but a first step. Each family Carer has his or her own needs separate from the care recipient, for the family Carer is not only providing care but struggling to maintain their own capacity and well being. In particular, family Carers often find it hard to voice their own needs when attempting to secure adequate and appropriate care for the care recipient.

The Association is concerned that current policies and practices appear to be that the care recipient has to be in receipt of services prior to any recognition of the needs of the family Carer. The family Carer not only has the right to be assessed but also the right to have the results of the assessment taken into account when services are provided. This will offer a protection to family Carers when services are provided as their needs will also have to be taken into account. It would also provide for a re-assessment when circumstances change, including receiving greater assistance.

Carer assessment, then, is an important component in determining and in developing appropriate services for the family Carer themselves. Such assessment should cover

ents, financial impact, training needs, respite needs
impacts.

A model assessment tool, such as developed by the Carers Association, would be a useful resource in the development of a common Carer Assessment tool for use across services.

Recommendation

That an assessment tool for the assessment of family Carers be introduced for use across government and non government services, with associated training resources for services in the use of such an assessment tool.

3. Cost of Living

Family Carers on a limited income struggle to meet the daily costs with the additional burden of the expenses related to the caring role. State Governments can play a valuable role by maintaining and strengthening a regime of concessions and subsidies.

Whilst acknowledging the concessions and subsidies the Government does provide, nevertheless over the years these have developed in an ad hoc fashion, with an inequitable criteria and decreasing face value.

Recommendation

That a review of all South Australian concessions takes place to ensure that assistance is well targeted and that eligibility criteria ensure concessions are targeted to, and can be easily accessed by, those most in need. Issues for family Carers in such a review include:

- Recognition of the additional burden on family Carers of the energy costs in meeting the needs of care recipients.
- Determination of strategies for the equitable inclusion in government assistance schemes of family Carers who need assistance with household expenses, such as electricity, gas and water rates; and housing, transport and education services.
- Recognition of the Carers Allowance as a basis for eligibility for concessions and subsidies for household costs.
- Development of a strategic program of education on entitlements to concessions and subsidies.
- Provision of an improved fee waiver system for the Home and Community Care Program.
- Provision for subsidised incontinence products across all age groups.

4. Children and Young People as Carers

The Association acknowledges the recognition of the special needs of young Carers in the SA Carers Report and the efforts of the working group that prepared the Children and Young People as Carers Background Paper which informed it.

ia attending the First National Summit on Young
Australia in August 2004, outlined their priority needs as
children and young people as Carers, whole of family
and age appropriate respite, information about available services and support in
schools.

Recommendation

That a policy framework for young Carers be prepared, including development of appropriate assessment procedures and the identification of whole of family approaches.

Recommendation

That a special program for young Carers be developed within the Department for Education to assist young Carers in the primary and secondary school years including the introduction of flexible education options including use of technology for distance education and other external options, peer support, mentoring and home tutoring that support the young Carers and their families, and recognition of the skills that are learnt through the caring role.

Recommendation

That a program be established to provide state wide coordination of information and referral that enables the identification of young Carers, including self identification and that provides young Carers with age appropriate information and connects them with the services that can support them in their caring role.

The Association acknowledges the announcement during Carers Week 2004 by the Minister for Families and Communities of special packages of assistance to specific families in which there is a child with a disability and an identified young person in a caring role.

Recommendation

That there be further development of special packages of assistance for families of children and young people in a caring role.

5. Health Care

5a. Caring is a Public Health Issue

The Association acknowledges the progress of the health reform agenda in South Australia. In particular the Association notes the intent of greater consumer participation in the processes of health care in this state.

Participation and partnership are at the core of the family Carers' interface with the health system. This interface occurs in two significant ways.

1. Family Carers continue to be a high risk population group due to the physical, mental and emotional stresses of the caring role.
2. Family Carers are partners in the delivery of health care as they accompany the care recipient to medical appointments and take responsibility for the health care needs of the care recipient at all other times.

These appropriate mechanisms be developed for the participation of family Carers, in conjunction with the Carers Association of SA as peak body, in the health care of those they care for. Such mechanisms would include:

- Development of strategies, including education campaigns, within the health system on the role of family Carers and the part that they can play in care programs.
- Development of guidelines that provide for family 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 family Carers, care recipients and service providers.
- Development of injury minimisation programs for family Carers including training resources and priority of access to back care treatment within the health system.
- More quality, affordable and flexible respite of all kinds including in home, out of home, emergency, long term and residential, with an emphasis on family Carers having access to adequate planned respite through the year.

5b. Mental Health

The Association remains concerned at the paucity of state resources to community based care of the mentally ill in South Australia. This has grave impacts on family Carers whose needs are still largely unrecognised and ignored by the mental health system and its practitioners.

Recommendation

That a support and development program for family Carers of people with a mental illness be established. Such a program would include:

- The implementation of the National Mental Health Strategy as it relates to family Carers.
- Recognition of the needs of family Carers by the mental health system.
- Development of information, training and support for family Carers.
- Recognised eligibility for local HACC Community Care programs (respite, home help, personal care, transport).
- Greater psychiatric disability support services including housing and provision of medication to lighten the load on family Carers.

6. Employment and Care

Research indicates that whilst family Carers move in and out of the workforce they are less likely than others in the community to be in the workforce, they are less likely to be in fulltime employment and they need special assistance to return to paid jobs after a period of caring.

assistance program for family Carers be developed

- A scholarship program to enable attendance at secondary and tertiary institutions for family Carers, particularly young Carers, including provision for respite.
- The development and utilisation of Public Service Employment and Care policies and practice as a model for the business and community sectors, accompanied by training resources to assist them.

7. Transport

The provision of low cost accessible transport options has a vital role to play in the accessing of services and reduced social isolation for care recipient and Carer alike, particularly in the case of young Carers. It provides significant relief to the family Carer who otherwise would be responsible for providing the transport needs for the care recipient.

The Association acknowledges the work of the former Public Transport Board, now the Office of Public Transport, in pursuing public transport options, particularly in rural areas. The Association believes that there is scope for greater promotion of routes and times of wheelchair accessible buses, as well as further consideration of ways of supporting alternative transport options in areas where, or at times when, accessible transport is not available.

The Association acknowledges that some consideration has been given to changes to the South Australian Transport Subsidy Scheme.

Recommendation

That there be greater flexibility in the use of the South Australian Transport Subsidy Scheme, particularly in rural areas, including the widening of the eligibility criteria using a definition based on the DDA; the allocation of vouchers based on need rather than quotas and the development of secure anti-fraud measures to enable greater flexibility.

8. Advocacy

The Association welcomes the passing of the Health and Community Services Complaints Bill. However, the Association remains concerned that there will continue to be limited resources to adequately support the advocacy needs of family Carers, currently not being met through existing aged and disability advocacy services.

Recommendation

That a state wide advocate for family Carers be appointed, either independent to, or placed within, the office of the Health and Community Services Commissioner.

This would serve to underpin the proposed changes to the Equal Opportunity Act that seek to include family Carers within the anti-discriminatory ambit and that seek to provide for adequate and appropriate resourcing of complainants.

ng Role

Whilst there is some education and training for family Carers in the skills necessary for undertaking the caring role this remains ad hoc and uncoordinated and very limited in scope. Issues include the family Carer's role, disabilities and illnesses, personal care, negotiation and advocacy and the health and community services system where it provides support to family Carers and the care recipients.

Recommendation

That a state wide framework be developed, with associated resources, for the training of Carers through innovative training strategies, for example family Carer training within the home to be included as part of care packages.

Development of training at state level needs to be linked with a nationally recognised curriculum, including accreditation for other study.