

# State Carers Policy 2004

## Mental Health Carers Task Group Submission

### **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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## **Submission by Mental Health Carers Task Group**

On November 27<sup>th</sup> 2003, the Mental Health Carers Task Group held a consultation to inform input into the formulation of the State Carers Policy.

The membership of the Mental Health Carers Task Group includes carers of people with a mental illness as well as workers, paid and voluntary, from the non-Government and community sector (Details of the Mental Health Task Group are attached).

The following were identified as critical issues for Carer of people with a chronic and ongoing mental illness leading to functional impairment.

### **1. Issues particular to those caring for a family member with a mental illness**

#### Demands on Carers of People with Mental Illness

- The episodic nature of mental illness creates its own problems for Carers. It means that sometimes the consumer is well and sometimes unwell. This means that management of the illness falls on the Carer when the consumer is unwell, but at other times when the consumer is well they want to take responsibility for their own health, and its then that they may reject all offers of help, despite their often significant level of psychiatric disability and their consequent need for ongoing support and assistance.
- In an ideal world, the independence and strengths of a person with a mental illness should be maximised, with the level of support offered by the family member dependent upon the need of their kin requiring care (just as intervention in the formal service system should be based upon need).
- However, it is common for Carers of people with a mental illness to experience a lot of rejection of their caring role, not only from their family member but also from the mental health service system. The reality is often that the carer plays a pivotal role in maintaining the wellbeing of a person with a mental illness. The episodic nature and the very negative impact of a relapse on the consumer's well being, means that Carers are ever watchful of signs of ill health and relapse. This creates a balancing act between closeness and watchfulness, and distance and dependence, creating stress and tension in the Carer.
- As well, Carers often have to cover the cost of medication for their family member with a mental illness. They have a personal investment in this, that the consumer remains as well as possible. There can be reluctance on the part of the consumer to take medication because they have limited funds. Also the consumer's spending can be erratic and out of control. This often means that they do not have the funds for medication, and besides their lack of insight about the need to keep taking medication means they simply do not see this as an important expenditure for their limited funds.

- The burden that falls on carers as a result of this situation is profound. Without accommodation and psychiatric disability support services the load falls significantly on Carers. It is common for families of people with a mental illness to spend considerable resources on buying homes for their children. With increasing costs of housing this will not be such a possibility in the future.

#### Mental Health System & Recognition of Carers

- The Carers' confusion, stress and tension are exacerbated by failure of the Mental Health system in SA to develop and adopt a comprehensive policy on the role and function of carers in the support of people with a mental illness.
- This has led to the situation where carers are either ignored by mental health professionals or patronised. At worst, the reaction of the mental health system professionals towards family Carers may be hostile.
- In the absence of a sound policy, mental health professionals are free to respond to consumers and carers according to their personal attitudes and beliefs. This situation may result in carers being treated in a variety of ways within a single service: eg
  - as resources who can be given the responsibility for the on going care of the consumer;
  - as co-workers who will be supported as part of "the team";
  - as co-clients, who need to be humoured and treated as part of the "problem"; or
  - as non persons, who can be ignored as they are seen to play no useful role in the treatment process.
- These reactions can be attributed to myths or false perceptions of families on the part of MH professionals operating in a policy vacuum: eg some myths include:
  - As parents, they may be responsible for the mental illness (the 'psychogenic family')
  - Some may want to usurp the human rights of the consumer.
- The reality is that many families are highly supportive of their kin when they are suffering with a mental illness (whether acute or chronic), and are actively interested in and are willing to support their mental health and independence.
- Doctrines of confidentiality and privacy of adult patient information are often interpreted by some professionals and adhered to so strongly within that Carers are intentionally not provided with information about medication, treatment and progress. Also, they are frequently denied linkages with those treating the consumer, even though Carers are expected to support and manage the care of the consumer in the community. The reality is that care provided in the community by family members frequently occurs without recognition from the mental health system, the professionals, or the general health care and primary health care sectors.
- Carers report a decline in use of practice guidelines and protocols in the Mental Health Service System. For example in the days of SAMHS, there

was a Carers Policy, protocols for inclusion of families and Carers, and also a simple authority the consumer could sign for the release of information. These no longer exist. These were lost with the end of SAMHS.

- Carers and service providers also report a lack of acceptance or compliance by the mental health professionals of existing clinical practice guidelines, and a lack of evidence based practices. Despite the evidence that the establishment of alliances with families and carers improve outcomes, many professionals fail to include Carers in the clinical care plan and management. These attitudes perpetuate an inappropriate culture of consumer confidentiality, and privacy policy.

#### Carers and the General Community

- The lack of mental health literacy in our community impacts not only on consumers but also Carers and families. The perpetuation of the many myths of mental illness and the lack of access to accurate information often results in the illness being hidden within the close family and difficult for relatives and close friends to understand. As a consequence there is not the same level of support that is offered to those families where there is a physical or an acute illness with a clearly articulated medical basis. It is harder for families to speak out about either the experience of caring or the impact of the illness on the Carer, the family, and the consumer. Whilst many people with family members with a chronic mental illness are not full-time Carers, or do not want to be labelled as a Carer (just like people with a mental illness do not want to be defined in terms of their illness), disclosure of periodic traumatic experiences of mental illness is difficult due to stigma and misconceptions in the wider community.

#### The Statewide Mental Health Service System

- There is a chronic lack of psychiatric disability support services in SA. On a per capita basis, there is clear evidence that the mental health sector is significantly worse than other groups within the disability sector.
  - MH specific disability support services are very poorly funded in SA (2.5% of MH budget versus 5% nationally)
  - Only 0.3% of the SA mental health budget is spent on supported accommodation (compared with 6% nationally).
- As well, people affected by mental illness do not have access to services funded through mainstream funding programs for people with disability:
  - the CSTDA (Commonwealth State Disability Agreement). We are the only state/territory which does not provide disability funding to people with psychiatric disability.
  - Carers and consumers of people with mental illness have not been classed as eligible for local HACC Community Care programs (eg Respite, home help, personal care, transport) that are delivered outside of the specialist mental health system. Although Carers are able to participate in Carer Support

programs, in general other HACC programs target the frail and elderly and those with chronic physical illness, but not people with a mental illness.

- These failures of the system to respond to the needs of people with mental illness were identified by the Parliament of South Australia Social Development Committee's 2003 report, based on extensive consultations, that although there was a lack of appropriate supported accommodation for people with disabilities as a whole, the issue was particularly disturbing for people with psychiatric disabilities.
- The National Mental Health Strategy, including the Rights and Responsibilities document, highlights the need to recognise the role of Carers and provide services to meet their needs. The National Mental Health Standards and National Mental Health Practice Standards spell out how services are to recognise and incorporate the role and needs of Carers. The Mental Health Council of Australia's independent consultations and subsequent report 'Out of Hospital, Out of Mind' 2003, identified that insufficient had been done to support and recognise the role of family Carers as required by the 2<sup>nd</sup> National Mental Health Plan towards the national Mental Health Strategy. This finding is painfully accurate of South Australia where there has been no visible progress to improve the experience of families. More than this has been the lack of ongoing communication with the Carers Association or the community sector and families about what is to be done to fulfil the requirements in relation to Carers.

#### Legal Authority of a Carer

- There is a lack of acceptance by the Mental Health System of the Carers legal authority where Enduring Power of Guardianship is held by the Carer. This relates to many of the issues previously highlighted but also relates to:
  - The legal authority needing to be triggered by the incapacity of the consumer and this can be hard to define, assess and/or diagnose.
  - There is no central registration of legal orders such as Enduring Power of Guardianship/Attorney, so therefore the orders are not viewed as valid by professionals.
  - Consumers when unwell can verbally discredit the legal authority held by the Carer, making their legal standing ineffective.
  - Although Carers are mentioned in the Mental Health Legislation it is not elaborated upon and they are therefore not afforded rights within in the Mental Health System despite the fact that of much of the care in the community (in the area of mental health) is provided by families.

## **2. Issues experienced by Carers of people with a mental illness that are similar to those of other Carers**

The following are issues commonly experienced by all Carers including Carers of people with a mental illness; however, it is important to note that the Carer's experience may be exacerbated due to lack of adequate and appropriate services in the mental health sector.

### Similar Issues to Other Carers

- There are few training or education opportunities to assist Carers in:
  - Understanding their family member's illness.
  - Understand the family dynamics arising from the illness of a family member and the impact on family functioning and survival.
  - Managing the illness and resultant behaviours.
  - Developing problem solving skills
  - Coping with their stress levels and health and personal wellbeing.
- There is a lack of recognition of the respite needs of Carers of people with mental illness:
  - Respite needs to be tailored in a way that is useful to the consumer and encourages their resilience.
  - There is a lack of intake assessment of the complete family situation.
  - The need for Carers to take a break, receive support and renew their batteries is less obvious.
- Counselling for Carers:
  - Carers need counselling about their own issues, particularly the grief and loss arising out of role changes or loss of expectations.
  - They also need counselling about a range of issues related to managing the illness and the mental health system.
- Advocacy:
  - There is a critical need for advocacy for Carers. There is no personal advocacy service for Carers of people with a mental illness. The disability advocacy services do not include psychiatric disability and advocate for the consumer only and not the Carer. Aged Rights Advocacy advocates for older people.
- Complaints and Feedback:
  - Carers have fear of retribution if they complain about a mental health service to that mental health service. Complaints and feedback about services generally do not occur because of fear of retribution.
  - There is no general complaints service or system in the mental health system in this state for Carers that satisfies the requirements for a transparent, professional and fair process.
  - Mental Health services do not know how to respond to Carers. It is not part of their history, culture or training to incorporate families in their recovery and treatment approach.

- There are misunderstandings and a lack of protocols around the rights, responsibilities and needs of Carers that differentiate them from the needs of consumers. There is unresolved tension between the rights of consumers and Carers felt by all parties involved in the clinical process. This need to be resolved by the establishment of Clinical processes and practices.
- Carer Assessment
  - There is a need for a Carer Assessment Tool for use across all Carer systems, including the mental health system. This would ensure the inclusion of families in the admission process and the assessment of both the consumer and the family's need for information and support regarding the illness, and the treatment and recovery. This does not happen at present in any of the community or residential care systems, either acute or long-term.
  - There is a need to address the concerns of older Carers of older children related to guaranteeing care when the Carer dies, or is no longer able to care. This applies equally to Carers of people with a mental illness and Carers of those with a disability.

#### Work of Mental Health Carers Task Group – Roles & Relationships

It was considered by the Mental Health Carers Task Group that the Mental Health System in South Australia has failed to recognise the needs of Carers or to implement the changes required both under the National Mental Health Strategy. The opinion was that there had been a backward step in that a previous Carers Policy that had been endorsed by SAMHS was "lost" with the change in structure.

The requirements outlined by the Mental Health Carers Task Group in its position document *Progressing the Needs of Carers in the Mental Health System – The Next Steps (1999)* have not been met. (Details about the Mental Health Carers Task Group are attached).

Liaison between the Mental Health Carers Task Group and the Mental Health System commenced more than 9 years ago. Despite some promising relationships at the time of the establishment of the Mental Health Carers Task Group by Minister Armitage in 1996, the contact with the Carers Association has generally been non-existent or reactive, despite us having as many as 30% of Carers in our networks reporting they care for someone with a mental illness.

There has been a failure by DHS – Mental Health Service System to recognise that supporting and informing the network of Carers with information and training and support services would be one immediate way of improving the community response to mental illness. The Mental Health Carers Task Group is amazed that the DHS mental health system has failed to recognise this potential.

## Summary

In summary, the Mental Health Carers Task Group considered that any vision or commitment by the SA Government to improve the circumstances of Carers of people with a mental illness is contingent upon the resolution of a number of critical elements.

We consider that the first priority is to acknowledge that the Mental Health system in South Australia is in a state of chaos. It has such fundamental deficiencies that need to be resolved before it can truly become a system that responds to the needs to both Consumer and Carers. For example:

- There is no formal, accountable planning framework or process that encourages the participation of carers and consumers in policy and service development and evaluation;
- There are no structures in place that encourage such a partnership of all stakeholders: eg
  - ❖ The DHS Mental Health Unit has to date failed to forge a relationship with organisations mandated to advocate for constituencies such as carers or consumers;
  - ❖ Their current approach of appointing one or two Carers and consumers in an advisory capacity fails to provide the linkages or partnerships with key peak organisations, such as the Carers Association and other non government organisation and groups in the community sector
- Previous attempts at policy development have been ‘lost’ and buried;
- A proper purchasing framework based on promoting appropriate service delivery does not exist. We have no vision of an array of evidence based services of proven effectiveness;
- Similarly, there is no, and probably has never been, a transparent process for the allocation of new and existing resources. Without that, there can never be evidence of equitable and accessible service delivery;
- In the absence of recognition by the SA Government people affected with a psychiatric disability need a comprehensive range of services orientated to their biological, psychological and social needs, it is unlikely that the needs of consumers and carers will ever be satisfied.

The Mental Health Carers Task Group supports the reform process and wants to work together with others to improve the outcomes for consumers and their families and Carers affected by mental illness.

Please contact Rosemary Warmington, Chair of the Mental Health Carers Task Group for queries about this submission.

## Mental Health Carers Task Group