



# Carers of People with Mental Illness Project

Final Report

June 2000

The Mental Health Council of Australia in partnership with the  
Carers Association of Australia

*Promoting the mental health of all Australians*

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## ABBREVIATION LIST

ACTCOSS	ACT Council of Social Services
ACTMHS	ACT Mental Health Services
AHMAC NMHWG	Australia Health Ministers Advisory Committee National Mental Health Working Group
AIHW	Australian Institute of Health and Welfare
AMHCN	Australian Mental Health Consumer Network
ARAFMI	Association of Relatives and Friends of the Mentally Ill
ATSIC	Aboriginal and Torres Strait Islander Commission
CAA	Carers Association of Australia
CAG	Community Advisory Group
CAV	Carers Association Victoria
CCSP	Carer Crisis Support Program
COPEs	Carers Offering Peers Early Support
CSDA	Commonwealth/State Disability Agreement
HACC	Home and Community Care
MHCA	Mental Health Council of Australia
MHCC	Mental Health Coordinating Council
NACCHO	National Aboriginal Community Controlled Health Organisation
NEAMI	North East Alliance of the Mentally Ill
NOAC	Network of Australian Community Advisory Groups
NRCP	Commonwealth National Respite for Carers Program
OATSIH	Office of Aboriginal and Torres Strait Islander Health
OTSIA	Office of Torres Strait Islander Affairs
PDSS	Psychiatric Disability Support Services
RANZCP	Royal Australian and New Zealand College of Psychiatrists
SAAP	Supported Accommodation Assistance Program
SAMHS	South Australia Mental Health Services

SFNQ	Schizophrenia Fellowship North Queensland
SPGPPS	Strategic Planning Group for Private Psychiatric Services
TGC	Telephone Group Counselling
WAAMH	Western Australian Association for Mental Health

## EXECUTIVE SUMMARY

The *Carers of People with Mental Illness* project is an innovative partnership project funded by the Commonwealth Department of Health and Aged Care and jointly conducted by the Mental Health Council of Australia (MHCA) and the Carers Association of Australia (CAA).

The primary goal of the project was to identify priority actions to better support and recognise the roles of carers of people with mental illness across Australia. In addition, the project aimed to address the following issues:

- **The National Picture of Current Carer Support**  
A documented account of existing support arrangements and service linkages for carers of people with mental illness in all States/Territories and nationally.
- **The Education, Training and Information Service Gaps**  
A clear analysis of support that is not available for carers of people with mental illness in the fields of education, training and information services.
- **Carer Access to Mainstream Services**  
An evaluation of how well carers of people with mental illness access existing mainstream services including their participation in service planning and service delivery decisions as well as reforms which are needed to increase the support, influence and opportunities of carers.
- **Partnership Opportunities with other Carers**  
An understanding of how carers of people with mental illness can build partnerships with carers in other health and community service fields to enhance support and policy recognition of the pivotal role carers play in all service delivery sectors.
- **Carer Policy Participation**  
A full picture of how carers of people with mental illness currently participate and provide policy advice at national and State/Territory levels.
- **Action Recommendations**  
Readily implementable recommendations to improve recognition and support for carers of people with mental illness which address the responsibilities of Commonwealth and State/Territory Departments (including the Australian Health Ministers Advisory Council National Mental Health Working Group – AHMAC NMHWG) and non-Government organisations including those affiliated with MHCA and the CAA.

An Australian wide review of the needs and service support arrangements associated with the roles of carers of people with mental illness was undertaken. The report considers the findings of project field consultations conducted in all States/Territories to understand the needs, issues and support requirements confronting the roles of carers of people with mental illness. The project has developed recommendations for consideration by Government and non-Government organisations, which are designed to nationally strengthen the recognition of and support for the large group of non salaried/volunteer carers who make such a significant and sustained contribution to mental health service delivery.

## METHODOLOGY

National consultation and methodology was largely based on the use of focus groups. Respective focus groups of carers and mental health service providers/stakeholders were conducted in each State/Territory. The methodology aimed to capture the day to day caring or service delivery narratives of participants and then converting these expressions of personal experience into quantified data trends. This approach yields 'hard data' needs evidence which can be readily ranked and prioritised as well as compared on a standardised basis across localities or group types. The focus group form of evidence gathering was complemented by the conduct of interviews with each AHMAC NMHWG State/Territory departmental representative or their delegates, the Commonwealth Mental Health Branch, the Strategic Planning Group for Private Psychiatric Services (SPGPPS), the Australian Transcultural Mental Health Network, the National Aboriginal Community Controlled Health Organisation (NACCHO), Office of Aboriginal and Torres Strait Islander Health (OATSIH), and the Office of Torres Strait Islander Affairs (OTSIA).

Additional focus groups were undertaken in the Kalgoorlie/Goldfields region of Western Australia to consider carer needs in non-metropolitan and rural/remote community settings. A consultation was also conducted with Aboriginal mental health workers in the Northern Territory to gain insight into the needs of Aboriginal carers.

## FINDINGS

The following issues confronting carers have been identified through project consultations.

### *The Contribution of Carers*

Individual carers on average contribute 104 hours per week caring for a person with mental illness.

The project identified that an enormous volunteer contribution is made by carers of people with mental illness. The *National Mental Health Report (1997)* indicates that in 1996-1997, \$2.07 billion was allocated nationally to mental health service delivery. It is likely the majority of this expenditure supported salaried service provision at a mental health worker's average duty time of less than 40 hours per week.

Consequently the average individual caring time of 104 hours per week indicates that it is primarily carers who are sustaining the fabric and operational effectiveness of mental health service systems across Australia.

### *The Needs of Carers of People with Mental Illness*

Carers are experiencing undue responsibilities and pressures in their caring roles due to significant gaps or inadequate practice in formal consumer mental health service delivery. If formal service delivery for consumers operated at the quality levels expected within the *National Standards for Mental Health Services (1996)*, a range of stresses and demands currently felt by carers would be markedly reduced.

Carers require greatly improved mental health and generalist service provision to meet a variety of core needs which directly arise from the reasonable expectations of their caring role. Nationally, carers expressed extremely low levels of satisfaction with service provision in key support areas, such as accessing personal information; information, education and training provision; emotional and social support; consulted by

professionals; policy decision making; having a break; back up help; and rights and responsibilities.

Very similar assessments on these and related items were indicated by 'on the ground' mental health service providers and other stakeholders in their evaluation of current support arrangements for carers.

### ***Coordination of Education, Training and Information Development for Carers***

Results indicate that while individual organisations are dedicated to making valuable contributions and effort, the Australian mental health community develops education, training and information resources for carers in a generally fragmented manner. This effort occurs in the absence of a sector wide common or shared approach to needs analysis, educational design and learning methodologies, curriculum and resource development (including the concept of core and specific knowledge), overall standards setting and the effective monitoring of education and information service delivery. Community expertise is being harnessed at levels well below its full potential to maximise education and information benefits for carers.

Urgent action is required to promote collaboration by mental health organisations on education and information development for carers within an agreed framework of national standards. This process must practically support day to day service delivery in States/Territories and involve carers in all phases of product and resource development.

### ***Carer Access to Mainstream Support Services***

Carers of people with mental illness are being excluded from many mainstream or generic community support services which offer services such as respite assistance and practical home help. This is occurring despite the reality that without the extensive contribution of carers, many people with mental illness who have highly complex needs could not be supported to live in a family or household environment and would require more expensive alternative care.

The complexity and extent of the needs of people with mental illness and their carers is not adequately understood by a range of community support agencies and they lack sufficient professional expertise to assess and respond to these needs.

National trends from project findings suggest a range of services funded through the Home and Community Care Program (HACC), the Commonwealth/State Disability Agreement (CSDA), the Supported Accommodation Assistance Program (SAAP), and the Commonwealth National Respite for Carers Program are prone to creating service access barriers to carers of people with mental illness. Moreover in many jurisdictions, government policy arrangements for these programs seem not to encourage a sufficient targeting of mental health needs during the process of establishing and monitoring funding service agreements between government agencies and local service providers.

In the absence of significant changes which give people with mental illness and their carers improved access to generalist support services, carers will continue to experience many extreme and unjustifiable caring pressures. These pressures expose both carers and people they care for to a range of unacceptable risks, and threaten longer-term viability of a range of mental health household and community based options as alternatives to increased levels of institutional care.

Furthermore, current lack of mental health access to generalist support services is in direct contradiction to several *National Mental Health Strategy* key objectives such as:

- (a) promoting integration between mental health services and other community services; and
- (b) facilitating access by mental health consumers and their carers to mainstream services.

### ***Partnerships with Mainstream Carer Organisations***

Carers of people with mental illness and other mental health community stakeholders are cautiously willing to consider partnerships with generalist carer organisations and related generalist providers serving carer needs in the health and community service field.

The requirements of generalist carer organisations to bridge across client groups and program boundaries allows them to acquire expertise in broader health and community services sector budget planning, policy development, and service access/coordination. Mental health specific organisations are less exposed to and have limited opportunity to gain such additional knowledge because of their specialist focus in their own sector. The expertise of generalist carer agencies, applied in a careful fashion within the mental health arena does offer tangible value for carer support outcomes.

The consultation findings indicate many stakeholders in the Australian mental health community recognise genuine policy and service strengthening benefits could flow to mental health carers through collaboration with generalist carer agencies in areas of common concern. However, they also fear partnerships entered into in the wrong way could lead to a depletion of resources and specialist expertise in the mental health sector. Carers, mental health service providers and other mental health stakeholders have referred to what they see as diminution of mental health service capabilities as a result of recent reform initiatives which have placed mental health service resources under general hospitals and equivalent health bodies. In addition, consultations identified a belief that the negative effects of linking mental health specific services with other generalist health agencies have been intensified because the processes commenced in the first instance with an inadequately funded mental health resource base.

While keeping these concerns prominent and clearly visible, other conclusions drawn from project investigations reveal promising opportunities for carers in the mental health field to benefit from partnerships with generalist carer agencies including cooperation in the fields of education and information development.

If partnerships between mental health carer and generalist carer groups in target fields including education and information, are to translate into durable and effective actions, the process of doing so must safeguard against entering poorly constructed alliances and consequent negative outcomes.

### ***Policy and Planning Participation by Carers***

In all Australian jurisdictions carers of people with mental illness are represented on peak national and State/Territory consumer and carer groups which are central to and influential in the consumer and carer movement. Many of these advisory groups have formal endorsement and direct reporting powers at ministerial levels. These groups have

also been used to facilitate carer involvement in legislative changes or major service redevelopment across Australia.

However, at local service levels carer policy and planning participation is not occurring in an inclusive, methodical and effective fashion. The expectation of the *National Standards for Mental Health Services* that carers be systematically involved on a quality assured basis in planning and other decisions of local mental health services appears not to be current practice.

### ***Rural, Remote and Non-metropolitan Communities***

The physical distance which often separates carers in rural and remote settings from the generally higher concentration of potential support and services found in capital cities, may offer carers significant advantages for practical strengthening and enhancing of their caring roles. It is evident isolation can act as a catalyst to bring people together. A positive interdependence can emerge in these settings which promotes viable self help and better collaboration across service providers, carers, consumers and other mental health stakeholders within a defined locality. This observation is made not for the purpose of suggesting that carers in isolated environments do not have special needs as a consequence of their remoteness. Rather, the 'positive' aspects of isolation could be applied as an important ingredient of service models to help create better support for rural and remote carers.

### ***Aboriginal Communities***

Consultation with Aboriginal mental health workers has identified specific needs and service support requirements for carers in Aboriginal communities.

- Carer support is enormously enhanced when Aboriginal mental health workers are based in local Aboriginal communities;
- Being based in the local community helps the worker immensely to establish trust and proper accountability with community members including those experiencing mental illness and their carers;
- Indigenous mental health workers are in a position to approach their work with an orientation and expertise which can interpret mental illness in a cultural context;
- Such a culturally sensitive orientation is able to help facilitate either traditional or Western approaches being used for the support of people with mental illness and their carers; and
- It is common that within Aboriginal communities, care for a person with mental illness is provided by an extended group of carers rather than by a sole or primary carer, which is more common in Western communities.

### ***Cultural Diversity***

Approximately 40 percent of Australians were born offshore in a non-English speaking community or have at least one parent or other family member with a non-English speaking background. Therefore, it may be expected a similar proportion of people with mental illness and their carers are from families which reflect ethno-cultural diversity.

While this diversity offers many strengths for families, it may also produce significant tensions in the way families address mental illness. For instance, parents who have a non-English speaking background and are carers, may have a very different interpretation of mental illness and the role of intervention strategies to that held by a son or daughter experiencing a mental illness or the professionals treating them. Given the high incidence of families experiencing both mental illness and ethno-cultural diversity, mental health and generalist services must value skills and knowledge in ethno-cultural matters as core practice expertise if they are to effectively address the needs of this large group of consumers and carers.

## RECOMMENDATIONS

The following recommendations attempt to address the needs, issues and support requirement of carers which have been identified by this project.

### 1. *Carer Sensitive Service Delivery*<sup>1</sup>

- (a) That the Commonwealth Mental Health Branch fund a best practice demonstration project in each State/Territory which informs the Australian mental health community on ways to promote carer participation and carer responsiveness in service delivery.
- (b) That the experiences and learning from the demonstration projects be applied as guides in the context of mental health agencies being accredited against and achieving practice performance levels required by the *National Standards for Mental Health Services*.
- (c) That where possible, the demonstration projects seek to build on and consolidate existing examples of innovative practice occurring in the Australian mental health community which emphasis carer engagement in service delivery including initiatives identified in the current study.
- (d) That demonstration projects be structured to inform the Australian mental health community in the following practice areas:
  - engagement of carers in consumer assessment and care/treatment planning decisions;
  - practical and timely access by carers to consumer information necessary for the effective carriage of their caring responsibilities;
  - effective carer participation in policy and planning decisions at local mental health service/community levels including the use of carers as service consultants;
  - provision of counselling, debriefing and other emotional and social support services for carers;
  - service outreach and community development approaches in service delivery designed to link mental health care/service planning with a wide range of community supports able to sustain caring households and families; and

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<sup>1</sup> See page 26 for further detail relating to this recommendation.

- responses to families experiencing mental illness who are ethno-culturally diverse including cross generation issues between consumers and carers.
- (e) That project initiatives which review carer access to consumer information address 'on the ground' practice implications of the findings of the report *Information Sharing in Mental Health Crisis Situations* (2000).
- (f) That projects embrace public, non-Government and private mental health service providers.
- (g) That the conduct of demonstration projects occur in conjunction with the *National Standards for Mental Health Services* Implementation Working Group, the AHMAC NMHWG Consumer and Carer Participation Subcommittee, and the MHCA Consumer and Carer Subcommittee.

## 2. **Carer Education and Information Development<sup>2</sup>**

In order to promote national consistency in the development of education and information for carers two options are provided.

### *Option 1*

- (a) That the Commonwealth Mental Health Branch allocate funds on a three year pilot basis to the MHCA to establish a Carer Education and Development Unit to directly facilitate national functions.
- (b) That the Commonwealth Mental Health Branch allocates funds on a three year pilot basis to all State/Territory carer organisations to establish Carer Education and Information Development Officers to facilitate State/Territory level functions in the mental health field.
- (c) That at least in one State/Territory the role of the proposed Carer Education and Information Development Officer be focussed exclusively on the needs of carers in non-metropolitan locations and address models of cooperation within rural and remote communities.

### *Option 2*

- (a) That the Commonwealth Mental Health Branch allocate funds on a three year pilot basis to the MHCA to auspice a key centre for best practice in carers of people with mental illness education and information development.
- (b) That the key centre be accountable to the MHCA Board and be managed by a representative committee including the Association of Relatives and Friends of the Mentally Ill (ARAFMI), SANE Australia, Schizophrenia Fellowship Council of Australia, Network of Australian Community Advisory Groups (NOAC), the CAA and the MHCA.
- (c) That the key centre be responsible for addressing national functions.
- (d) That the key centre be responsible for funding the creation of carers of people with mental illness Education and Information Development Officers within all State/Territory carer organisations or other suitable auspices involving the

<sup>2</sup> See page 21 for further detail relating to this recommendation.

State/Territory carer organisations and the mental health sector, to address State/Territory level functions.

- (e) That at least in one State/Territory the role of the proposed Carer Education and Information Development Officer be focussed exclusively on the needs of carers in non-metropolitan locations and address models of cooperation within rural and remote communities.

### **3. Carer Access To Mainstream Support Services<sup>3</sup>**

- (a) That the MHCA in conjunction with the CAA conduct a study to examine access barriers to carers of people with mental illness in relation to mainstream support, services including services funded through Home And Community Care (HACC), Commonwealth/State Disability Agreement (CSDA), and the Commonwealth National Respite Carers Program, and that this study be conducted on a staged basis and reflect points (b) to (i) below.
- (b) That the study review the relationship between mental illness, the various symptoms and resulting degrees of disability, handicap and dependency experienced by people with mental illness, and the consequent pressures and demands placed on carers to sustain home and similar community living arrangements for people with mental illness.
- (c) That assessment tools currently used by HACC, CSDA, and the Commonwealth National Respite Carers Program funded agencies be evaluated against the review findings in (b) above and recommendations be made about improvements to assessment methodologies to enable mental health carer needs to be given objective recognition on a relative needs basis with other client groups in intake decisions by support services.
- (d) That the study gather, collate and analyse recorded data on the extent of access by people with mental illness and their carers to services funded by HACC, CSDA, and the Commonwealth National Respite Carers Program, including information held by the Australian Institute of Health and Welfare (AIHW) and where necessary, make recommendations on client information recording to better track the numbers of mental health consumers and carers served by these programs.
- (e) That the study build upon other project studies already undertaken on the concept of psychiatric disability and associated levels of dependency including work conducted in Victoria in conjunction with the Psychiatric Disability Support Services (PDSS) and in Queensland with the Brisbane North HACC Mental Health Access Project.
- (f) That the scope of the study be consistent with current Commonwealth directions in the HACC and CSDA programs to review procedures and mechanisms to better prioritise community needs for service.
- (g) That the study incorporates relevant findings emerging from the current Supported Accommodation Assistance Program (SAAP) Mental Health Access Project.
- (h) That at the conclusion of the activities documented above, recommendations be prepared for further staged work to enhance mental health carers access to mainstream support services including a focus on how mental health needs in the programs analysed in the first stage above can be better targeted at the levels of

<sup>3</sup> See page 24 for further detail relating to this recommendation.

policy development, provider service agreements and 'on the ground' professional skills.

- (i) That the Commonwealth Mental Health Branch funds the MHCA to conduct stage one work as outlined.

#### **4. State and Territory Issues<sup>4</sup>**

- (a) That the Chair and Chief Executive Officer of the MHCA and the State/Territory Departmental Mental Health Directors represented on the AHMAC NMHWG jointly review the project data emerging from the State/Territory focus groups and individual Departmental interviews and:

- Consider how actions arising from the project's primary recommendations can effectively complement the responsibilities of individual Departments;
- Identify ways in which the MHCA can support State/Territory Departmental strategies for support of carers of people with mental illness; and
- Address consistent concerns emerging in focus groups that day to day mental health service delivery is not engaging carers.

#### **5. Indigenous Carer Issues<sup>5</sup>**

- (a) That findings from consultations held with Aboriginal mental health workers be reviewed by the National Aboriginal Community Controlled Health Organisation (NACCHO), the Aboriginal and Torres Strait Islander Commission (ATSIC), the Office of Aboriginal and Torres Strait Islander Health (OATSIH), the Office of Torres Strait Islander Affairs (OTSIA), and the MHCA to consider how the findings may inform:

- the non-Government implementation of the *Ways Forward* (1995) and *Bringing Them Home* (1997) reports including responsibilities connected with regional training centres, social health team counselling and parenting and family support initiatives;
- decisions of State/Territory partnership forums on indigenous health;
- other mental health initiatives which may be considered by ATSIC, OATSIH, NACCHO and OTSIA; and
- protocols for future MHCA support of indigenous mental health issues.

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<sup>4</sup> See page 32 for further detail relating to this recommendation.

<sup>5</sup> See page 34 for further detail relating to this recommendation.

## PROJECT METHODOLOGY

A Project Advisory Group (PAG) with membership drawn from the MHCA and CAA affiliated organisations provided guidance in project implementation (Appendix A). A PAG workshop conducted soon after project commencement, aimed to develop a comprehensive workplan and methodology to proceed with the study including 16 key areas of project investigation (Appendix B, C and D).

Needs, issues and support requirements and existing support arrangements and service linkages for carers were identified through national consultations held in each State/Territory.

With coordination support from State/Territory generalist carer organisations together with State/Territory mental health agencies affiliated with the MHCA, 19 focus groups were conducted with carers of people with mental illness and mental health stakeholders/service providers respectively, in all States/Territories. Carer and stakeholder/service provider focus groups were also conducted in the WA Goldfields to address rural/remote carers issues. A consultation was also conducted with Aboriginal mental health workers covering the Darwin and Top End regions of the Northern Territory. A total of 76 carers and 75 mental health stakeholders/service providers participated in the focus groups (Appendix E).

Focus groups were conducted using standardised methodology, which involved participants:

- on a group basis, discussing their experiences, priority issues and needs in relation to mental health carer support;
- on an individual basis, ranking their level of agreement on a 0-10 scale with maximum disagreement at 0 and maximum agreement at 10, to best practice propositions about mental health carer support, which were based on the project objectives, the PAG areas of investigation and relevant prior research;
- on a group basis, developing priority action statements designed to enhance mental health carer support;
- on an individual basis, ranking the level of importance on a 0-10 scale with the least important being 0 and the most important being 10, to the priority action statements developed by the group; and
- on an individual basis, providing written qualitative responses about the project objectives and directions.

While carers and mental health service providers/stakeholders addressed a number of similar propositional items, a range of items were specific to each group in order to address variations in role or orientation between groups.

Carers were asked to identify the average number of hours of care they contributed in a week. This assessment included times they believed they were 'on call' during the night and other periods, as well as non face to face consumer care activities such as following up consumer financial issues or negotiating with service providers or commercial organisations. Items presented at carer focus groups are presented in Appendix F.

Stakeholders/service providers were asked to prepare a 'roadmap' of how services for carer support operated in their own field of activity. Items presented at stakeholder/service provider focus groups are presented in Appendix G. The average time for the conduct of each carer focus group and each stakeholder/service provider focus group was approximately three hours and two and a half hours respectively.

In addition to focus groups with carers and stakeholders/service providers, the following groups were also consulted:

- AHMAC NMHWG representatives or their delegates;
- the Strategic Planning Group for Private Psychiatric Services (SPGPPS);
- the Australian Transcultural Mental Health Network;
- National Aboriginal Community Controlled Health Organisation (NACCHO);
- Office of Aboriginal and Torres Strait Islander Health (OATSIH);
- Office of Torres Strait Islander Affairs (OTSIA)
- Commonwealth units responsible for HACC, the CSDA and the Commonwealth National Respite Carers Program;
- a project presentation was made to the National Executive of the Schizophrenia Fellowship Council of Australia; and
- informal data gathering occurred with a range of mental health and generalist service representatives.

An open ended group process was employed for the Aboriginal mental health workers consultation.

AHMAC NMHWG departmental representatives were interviewed with a standardised schedule of questions directed towards their responsibilities (Appendix I).

# PROJECT FINDINGS AND ANALYSIS

## The National Picture of Current Carer Support

### CARER NEEDS

Carers and other mental health stakeholders believe carers face a range of undue responsibilities and pressures in their caring roles due to significant gaps or inadequate practice in formal mental health service delivery. If formal service delivery for consumers operated at the level expected within the *National Standards for Mental Health Services* many of carers current needs would be addressed.

Carers require improved direct service provision to address needs associated with the reasonable expectations of their caring role. Priority areas include access to respite care and home care services; clearly defined access points to gain mental health information/education; access to counselling, debriefing, emotional and social support to sustain their caring capacities; support for their roles in helping to assist consumer medication programs; and a variety of improvements in professional mental health practice that directly impact on their effectiveness, including timely and practical access to consumer information and engagement in consumer assessment and treatment/care planning decisions.

### CARE TIME CONTRIBUTION AND SERVICE SATISFACTION LEVELS

The average number of hours individual carers involved in the consultations believe they provide care for is 104 hours per week. For many carers this time includes periods they are 'on call' or alert for problems arising with the person they care for.

This significant caring effort needs to be contrasted with other data from consultations regarding level of satisfaction both carers and mental health stakeholders/service providers have reported about the levels and adequacy of available supports to carers. National trends suggest carers have low levels of agreement on all key carer support items (Appendix F), with scores ranging from less than 1 to a little over 4 on a 0-10 scale where 0 indicates disagreement.

Results indicate there is a major gap between carers' support needs and the available support levels and service arrangements to address these needs, despite the huge contribution carers make towards mental health service delivery.

Consultations identified a strong perception that carers often fill a void in consumer care and treatment due to poor practice in the professional/formal delivery of mental health services. In addition, without the sustained contribution of carers, the consumer service system would be placed in great jeopardy.

Information attained at each consultation including carer support services and responses on focus group items in each State/Territory, are presented in Appendix H. A service profile for mental health carer support in each State/Territory is also provided which illustrates an outline of carer service provision and planning in each jurisdiction. Each profile is based on project consultations. Profiles do not purport to be a complete description of all mental health carer services or developments in each jurisdictions.

## POSITIVE PRACTICE

In addition to identifying problems with service provision and support for carers, the project also identified examples of positive practice which offer inspiration to the Australian mental health community to achieve extended service reform in this field.

- *Skills for Carers*. This program operated by the Canberra Institute of Technology, has been extremely active in provision of education and training for carers of people with mental illness. The program utilises adult learning and community development principles as important foundations of educational delivery.
- *The Blueprint Guide to Carer Education and Training*. This initiative undertaken by SANE Australia, provides an important systemic framework for service providers to utilise in planning carer education strategies and approaches. The *Blueprint Guide* also gives a methodical overview of national and international best practice examples in carer education.
- *The South Australian Mental Health Carers Task Group*. The task group auspiced by the Carers Association of South Australia convened two statewide conferences for mental health carers, and is active in the development and advocacy surrounding the South Australian Mental Health carer policy. It produced a detailed implementation plan for introduction of the policy into local services.
- *Carers Offering Peers Early Support (COPES)*. This is a program of direct support by carers for family members and friends of people with mental illness receiving services from Maroondah Area Mental Health Service Adult Inpatient Unit and Murnong Community Mental Health Service in outer eastern Melbourne.
- *Schizophrenia Clinical Guidelines*. The Schizophrenia Fellowship of NSW in partnership with the mental health community, developed clinical practice guidelines for schizophrenia treatment and care response. The guidelines, awaiting release from the NSW Government, involved extensive carer input and reflect a strong carer focus in specifications for mental health service delivery and practice.
- *Jerendine*. This is an innovative mental health respite care family support program auspiced by the Association of the Relatives and Friends of the Mentally Ill (ARAFMI) in Brisbane and jointly funded by Queensland Health and Disability Services.
- *Western Australian Association for Mental Health (WAAMH)*. This is the State peak mental health body, which auspices a carers issues committee. It recently conducted a sector forum on carers of people with mental illness and developed a carers position paper.
- *Schizophrenia Fellowship of Victoria*. This organisation delivers carer services on a statewide and metropolitan basis. Family education is based on two frameworks: 'The Journey of Hope' and 'The 14 Principles for coping with Schizophrenia'. Extensive consultation with carers/family members, mental health service providers and GPs experienced in providing service to carers is currently being undertaken via the 'Maps to Care' project.
- *Building the Links for Better Mental Health*. This South Australian project is active in the State's mid north, where carers are involved in piloting continuity of care between home, the community and the hospital.
- *North East Alliance of the Mentally Ill (NEAMI)*. This organisation, developed in the north eastern suburbs of Melbourne, provides a strong specialist capability for carer support

with non-English speaking background communities using both group and individual support models based upon bilingual outreach.

- *Family Sensitive Training.* This is an extensive initiative funded by the Victorian Department of Human Services and delivered by Bouverie Family Center which recently targeted Victorian public mental health clinical staff and disability support workers. The training aims building a strong family orientation in mental health service delivery practice.
- *The McFarlane Program.* This is a model of education and treatment support involving the whole family and is delivered in the clinical setting. The model engages the person with mental illness, the carer and the mental health professional. The approach seeks to give the person with mental illness and the family control over their circumstances and to draw upon their own strengths. It was developed by William McFarlane and operates in several locations in NSW and Victoria.
- *Help for Rural Care Givers of the Mentally Ill.* This program is provided by the Schizophrenia Fellowship of North Queensland (SFNQ) and is a rural access, support and education/information outreach program for mental health carers operating in 29 remote localities, and in Townsville, Mossman, Mount Isa, Longreach and Mackay.
- *Bilingual Case Management Program.* This is a pilot initiative of the Victorian Transcultural Psychiatry Unit and the public mental health services in the western region of Melbourne. This program has addressed a range of carer matters, including cross-generational factors associated with mental health service delivery to people with a non-English speaking background who have a mental illness and their families.
- *Telephone Group Counselling (TGC).* The Carers Association of NSW is piloting the training of mental health providers in the use of this counselling mode as a model of emotional support for carers. The desired result after completion of the training is that the Carers Association of NSW will co-facilitate the first TGC program with these providers who then continue this program of carer support.
- *Victorian Regional Carer Consultation and Planning.* CarerLinks North and the Carers Association of Victoria (CAV) have recently released consultative studies at regional levels dealing with carer access to support services, carer engagement in professional service delivery and the development of support strategies. The CarerLinks North study exclusively addresses mental health carer needs in the northern suburbs of Melbourne while the CAV study covers a range of carer groups including mental health carers in the southern metropolitan and Grampians regions.
- *ARAFMI Northern Territory (ARAFMI NT).* This organisation has a strong presence in the Top End and Darwin regions of the Northern Territory. ARAFMI NT has developed close working arrangements with Territory Health Services - Mental Health Services. Its operations provide a good model of a non-Government carer agency working successfully in partnership with public mental health services to advance the recognition and support of carers in service system decision making.
- *Goldfields Mental Health Community.* This community is a positive example of an active and growing local partnership between consumers, carers, and government and non-Government mental health and generalist service providers in service development activities. The Goldfields Mental Health Action Group in conjunction with the Western Australian Mental Health Division Regional Office and Centercare have been important catalysts in this process.

## Review of Education and Information Satisfaction and Provision Gaps

In response to the statement *"When the need arises, I can readily draw upon information, education or training resources to provide essential knowledge or skills involved in my caring role"* carers indicate low agreement nationally with an average score of 3.5 on a 0-10 scale with 0 indicating disagreement.

Service providers and stakeholders were asked to *"indicate the availability and suitability of information, education and training resources for carers of people with mental illness including gaps in provision."* Results indicate a consistent trend of acknowledging the occurrence of some very limited positive carer education and information developments within the service environments in which they work, while emphasising that overall provision is extremely inadequate and fragmented.

These trends were consistent with 'group view points' from both carers and service providers/stakeholders about barriers and other problems with education and information provision. The obstacles appear to fall into two key areas:

- Carers are having great difficulty in accessing helpful mental health education and information at the onset of mental illness in the person they care for, which may facilitate action for early professional diagnosis/assessment and treatment/care intervention and also reduce carer anxiety arising from not knowing the cause of their family member's or friend's unfamiliar behaviour; and
- Carers are not able to access effective mental health education and information during the ongoing processes of treatment and care in order to be informed about their caring role, help them work productively with mental health teams, and provide them with anticipatory knowledge and responses about behaviour patterns of the person they care for resulting from mental illness.

Consultations have consistently identified narratives which depict:

- (a) enormous delays in carers gaining initial knowledge about the mental illness experienced by the person they care for;
- (b) carers identifying by chance the symptoms of mental illness of their family member or friend from reading magazine articles or viewing television news stories; and
- (c) carers receiving knowledge and information from professional sources in a form unintelligible to a lay person.

Project results reinforce recent studies by SANE Australia which portray many examples of excellent practice in carer education and information development and delivery which exist in the Australian mental health community. However, the reason such practice excellence is not widely transferred to day to day service delivery, appears connected to the fragmented way in which the Australian mental health sector addresses planning, standards development and expertise sharing surrounding carer education and information activities.

The development of resources has generally occurred on an individual agency or diagnostic category specific basis.

Carer needs analysis, the specification of carer core and specific knowledge fields, educational design, resource development, product delivery, product evaluation and carer engagement in these functions is not systematically facilitated, coordinated or monitored within the mental health sector. This lack of coordination extends across government, non-Government and private service providers as well as within the relationships between national and State/Territory responsibilities.

In addition, there are few State/Territory level planning structures which systematically link generic carer agencies and mental health organisations to support education and information development for carers of people with mental illness (although in several States/Territories the system wide foundations do exist for this to occur).

It is evident that a framework of national and State/Territory level cooperation for achieving consistency in carer and information development is not in place. The absence of such a framework is a major deficit, which is impeding efforts by the Australian mental health community to provide adequate carer education and information.

In recognition of this deficit, the framework should reflect:

- (a) an accountability to various stakeholders in the Australian mental health community including carer organisations and government, non-Government and private providers;
- (b) a capability to work within the *National Mental Health Strategy* and promote national standards and facilitation tools for carer education and information development which can be translated into practical support for day to day delivery in the practice settings of States/Territories;
- (c) effective coordination systems within States/Territories for agencies within the mental health sector to cooperate on carer education and information initiatives; and
- (d) a capability to promote reciprocal linkages between mental health and relevant generalist carer providers in the planning and delivery of mental health carer education and information activities.

The implementation of such a framework should assist in significantly rectifying the currently disparate and poorly integrated way much carer education and information development occurs within the Australian mental health community and help deliver strengthened quality assurance for carers in this important support area.

Described below are objectives and functions which the framework would seek to address at national level and at the level of service delivery in States/Territories.

#### **NATIONAL OBJECTIVES AND FUNCTIONS**

National functions and objectives for achieving mental health sector wide consistency and collaboration in education and information goals for carers of people with mental illness:

- establish a national clearing house which resources and informs the Australian mental health community about all carer education and information initiatives occurring within the community and related national and international research activities in this field;

- develop specifications about core and specific knowledge fields for carers which are endorsed and regularly reviewed by the Australian mental health community;
- develop standards and benchmarks for the creation of knowledge products/resources and associated learning methodologies designed for carers which are endorsed and regularly reviewed by the Australian mental health community;
- develop national consistency in development and use of tools to effectively evaluate carer education and information products and services;
- develop national consistency in tools and methodologies used to conduct carer education and information needs analysis;
- develop best practice principles and guides, endorsed by the Australian mental health community for the participation of carers in the planning, development, delivery and evaluation of education and information products and resources;
- develop best practice principles and guides, endorsed by the Australian mental health community, to promote innovative mental health inter agency collaboration and individual agency responses in carer education and information matters;
- identify prevailing areas where collaboration with generalist carer organisations on common interests can be anticipated to add value to carer education and information product and resource development in the mental health field;
- initiate policy development on the roles and support requirements of carers of people with mental illness;
- develop specialist competency standards to guide professional development in mental health agencies for building staff expertise in engagement of carers and families in service delivery;
- convene regular national forums of carers of people with mental illness to address education and information issues;
- ensure functions and objectives described above are designed to support carers and service providers in the public, non-Government and private areas of the mental health sector;
- ensure functions and objectives described above are focussed upon practically supporting carer education and information strategies within States/Territories; and
- ensure functions and objectives described above are grounded on the *National Standards for Mental Health Services*.

#### **STATE/TERRITORY OBJECTIVES AND FUNCTIONS**

Objectives at State/Territory level which can be supported by national level planning and collaboration on education and information development for carers of people with mental illness include:

- enable national clearing house reports data and research on current carer education and information initiatives to be readily available and interpreted for service providers at State/Territory and local levels;

- enable the standards, benchmarks, tools and methodologies developed at national level about carer education and information to be translated into practical operational support for mental health agencies at State/Territory and local levels;
- establish or strengthen State/Territory and regional mental health sector networks and forums of carers and public, non-Government, and private service providers to collaborate and plan carer education and information initiatives and related activities to support carers;
- help put in place or strengthen systems of contact points for carers of people with mental illness to seek education and information advice at State/Territory and local levels;
- foster partnerships, pooling of expertise and similar joint efforts on common issues with carers in other fields to address education, information and related goals providing these actions will add tangible value for carers in the mental health field;
- provide consultancy advice to mental health agencies or generalist support providers regarding mental health carer education and information matters;
- encourage mental health service organisations to take active responsibility for provision of education and information to carers in the processes of day to day service delivery;
- ensure the above functions and roles complement support strategies for carers of people with mental illness initiated through State/Territory government funding and resourcing; and
- ensure the above functions and roles complement support strategies for carers of people with mental illness funded through other Commonwealth, non-Government and private sector sources.

## RECOMMENDATION

Outlined below are recommendations to achieve the implementation of the framework and national and State/Territory objectives and functions. The recommendations also address conclusions from the project that there is value in mental health organisations with responsibilities for carers of people with mental illness entering into partnerships with generalist carers organisations. The recommendations are made with an awareness firstly of the strongly held view from many mental health organisations that only where the interests of the mental health field can be demonstrably protected and advanced should such alliances proceed, and secondly of the already significant role national and State/Territory carer associations have played in promoting mental health sector collaboration on carer issues.

The MHCA has a pivotal role in progressing these recommendations, which arise from project observations that individual mental health organisations may be reluctant to participate in the creation or consolidation of sector wide planning and collaboration due to a lack of consensus about the accountability and representative foundations upon which such bodies should be based. The MHCA, through its representative structure has accountabilities directly to national non-Government mental health organisations (including a range of State/Territory affiliates) and other non-Government and private provider organisations. Through mandated reporting linkages, the MHCA also has accountabilities directly to the Commonwealth Government and Minister via the Commonwealth Mental Health Branch and to all Australian Governments via participation

on the AHMAC NMHWG. Consequently, the MHCA is suitably positioned to assume a leading role in promoting national collaboration on carer education and information issues.

The recommendations are presented in the form of two options which are designed to create facilitating structures for the previously discussed carer education and information planning goals to be attained.

### ***Option 1***

- (a) That the Commonwealth Mental Health Branch allocate funds on a three year pilot basis to the MHCA to establish a carer education and development unit to directly facilitate the national functions.
- (b) That the Commonwealth Mental Health Branch allocates funds on a three year pilot basis to all State/Territory carer organisations to establish carers of people with mental illness Education and Information Development Officers to facilitate the State/Territory functions.
- (c) That in at least one State/Territory the role of the proposed Carer Education and Information Development Officer be focussed exclusively on the needs of carers in non-metropolitan locations and address models of cooperation within rural and remote communities.

### ***Option 2***

- (d) That the Commonwealth Mental Health Branch allocate funds on a three year pilot basis the MHCA to auspice a key centre for best practice in carers of people with mental illness education and information development.
- (e) That the key centre be accountable to the MHCA Board and be managed by a representative committee including ARAFMI, SANE Australia, SFCA, NOAC, CAA and the MHCA.
- (f) That the key centre be responsible for addressing national functions.
- (g) That the key centre be responsible for outpostting or funding the creation of carers of people with mental illness Education and Information Development Officers within all State/Territory carer organisations or other suitable auspice involving the State/Territory carers organisation and the mental health sector to address the State/Territory functions.
- (h) That in at least one State/Territory, the role of the proposed Carer Education and Information Development Officer be focussed exclusively on the needs of carers in non-metropolitan locations and address models of cooperation within rural and remote communities.

## Access to Mainstream Support Services and Carer Engagement in Mental Health Services

### MAINSTREAM SERVICES

The mainstream program areas offering support for carers of people with mental illness which the project initially intended to assess, were the Home and Community Care Program (HACC), the Commonwealth/State Disability Agreement (CSDA), and the Supported Accommodation Assistance Program (SAAP).

These programs were targeted for analysis due to their strong Commonwealth/State axis and involve planning processes that are similar to and can link with Commonwealth/State decision making reflected in the *National Mental Health Strategy* and related work of the AHMAC NMHWG. However, as field consultations proceeded, questions relating to mental health carer access to the Commonwealth National Respite for Carers Program (NRCP) emerged and consequently this program is also considered in the review of issues discussed below.

Combined data from carers, stakeholders/service providers and AHMAC NMHWG respondents indicate a low level of access and other barriers are experienced by carers of people with mental illness when seeking support from services funded through these programs.

Carer focus group participants rated on the 0-10 scale, where 0 indicates disagreement, the following national average scores for items investigating access to mainstream support:

- 2.00 for *"When I want a break from my caring role (like a short holiday, a weekend off or just getting out for a few hours) affordable or free of charge respite services are readily available to give me this break"*.
- 1.5 for *"When I want practical backup for my caring role (like assistance for in home cleaning, meal preparation, shopping, transport etc) affordable or free of charge back up services are readily available to me"*.

Similarly, service providers/stakeholders provided the following scores on related items:

- 2.5 for *"Carers of people with mental illness can readily and without facing unreasonable eligibility criteria, draw on community services and supports which are funded through the Home and Community Care Program"*.
- 2.4 for *"Carers of people with mental illness can readily and without facing unreasonable eligibility criteria, draw on community services and supports which are funded through Commonwealth/State Disability Program arrangements"*.
- 3.3 for *"Carers of people with mental illness can readily and without facing unreasonable eligibility criteria, draw on community services and supports which are funded through the Supported Accommodation and Assistance (SAAP) program"*.

Focus group discussions in relation to these programs identified a number of access barriers which include:

- funding agreements with service providers not giving a priority focus to mental health needs;
- mental health client areas needs being 'overwhelmed' by needs from other client areas including aged care and general disability; and
- lack of skills, expertise and practice support tools within community agencies to effectively address mental health needs including those of carers.

These barriers can also operate to prevent carers of people with mental illness from effectively participating in service delivery decision making and service planning for services resourced from HACC, SAAP, the CSDA, and NRCP.

The national picture indicates current assessment methodologies and expertise of many service providers are predominantly not able to:

- (a) identify the extent of disability, handicap and life skill dependency of the consumer as a result of mental illness and its symptoms;
- (b) identify the impact of such disability, handicap and dependency on the responsibilities, demands and pressures of the role of a carer of a person with mental illness; and
- (c) identify objectively on a case by case basis, relative needs of individual people with mental illness and their carers for support services compared with needs of individual consumers with other forms of disability (including the frail aged and those with intellectual and physical disability) and their carers for these services.

In addition, services often do not have sufficient skills to sensitively respond in a home based setting to a person with a mental illness and their carer and set up practical supports which offer genuine assistance towards every day living tasks.

Based on interviews with government mental health representatives associated with the AHMAC NMHWG, it is apparent that in some jurisdictions, inter and intra departmental linkages between mental health service planning and paralleled service planning for HACC, SAAP and the CSDA require strengthening. The focus of strengthened linkages should include the capacity to effectively prioritise, quantify, and monitor the extent to which the mental health field including carers is or should be accessing these mainstream support program resources.

Evidence suggests slippage of the mental health sector including carers for access to these programs is occurring at some or all of the following three levels:

- Commonwealth/State Program Agreements;
- departmental service agreements with 'on the ground' providers; and
- 'on the ground' service provider practices.

## RECOMMENDATION

In view of these identified issues, it is therefore recommended:

- (a) That the MHCA in conjunction with the CAA conduct a study to examine access barriers to carers of people with mental illness in relation to mainstream support services including services funded through HACC, the CSDA, and the Commonwealth National Respite Carers Program, and that this study be conducted on a staged basis and reflect points (b) to (i) below.
- (b) That the study review the relationship between mental illness, its various symptoms and resulting degrees of disability, handicap and dependency experienced by people with mental illness, and the consequent pressures and demands placed on carers to sustain home and similar community living arrangements for people with mental illness.
- (c) That assessment tools currently used by HACC, CSDA and the Commonwealth National Respite Carers Program funded agencies be evaluated against the review findings in (b) above and recommendations be made about improvements to assessment methodologies to enable mental health carer needs to be given objective recognition on a relative needs basis with other client groups in intake decisions by support services.
- (d) That the study gather, collate and analyse recorded data on the extent of access by people with mental illness and their carers to services funded by HACC, the CSDA, and the Commonwealth National Respite Carers Program including information held by the Australian Institute of Health and Welfare (AIHW) and where necessary, make recommendations on client information recording to better track the numbers of mental health consumers and carers served by these programs.
- (e) That the study build upon other project studies already undertaken on the concept of psychiatric disability and associated levels of dependency including work conducted in Victoria in conjunction with the Psychiatric Disability Support Services (PDSS) and in Queensland with the Brisbane North HACC Mental Health Access Project.
- (f) That the scope of the study be consistent with current Commonwealth directions in the HACC and CSDA programs to review procedures and mechanisms to better prioritise community needs for service.
- (g) That the study incorporate relevant findings emerging from the current SAAP Mental Health Access Project.
- (h) That at the conclusion of the activities documented above, recommendations be prepared for further staged work to enhance mental health carers access to mainstream support services including a focus on how mental health needs in the programs analysed in the first stage above can be better targeted at the levels of policy development, provider service agreements and on the ground professional skills.
- (i) That the Commonwealth Mental Health Branch fund the MHCA to conduct stage one work as outlined.

## Mental Health Service Delivery

Carers are consistently reporting negative experiences in their engagement with mental health professional service delivery, especially regarding public system services. Carers expressed the view they are not seen by the service provider/professional as a partner with the consumer and service provider in the service delivery process. Carers report they are excluded or the recognition of their role is minimised in professional service delivery functions regarding consumer assessment, care/treatment planning and implementation and case review. These views have been supported by responses from mental health service providers and stakeholders.

Carers have rated the following average national scores on a 0-10 scale where 0 indicates disagreement, for items dealing with their engagement in mental health service delivery:

- 4.1 for *"When mental health professionals plan and take actions about the person I care for, they routinely and frequently consult me and encourage my participation in decision making (this could involve things like conducting a mental health assessment or developing a treatment plan for the person, arranging a voluntary or involuntary admission to a psychiatric facility, arranging for discharge from psychiatric care or reviewing the type of care or treatment that has been provided)"* .
- 3.4 for *"When I want personal support or advice in response to emotional, social or other needs arising from my caring role, this support is readily available to me from mental health or other health and community service agencies (for example, counselling in response to stressful events I am managing or perhaps an indepth discussion on how I should handle challenging behaviour by the person I care for)"* .
- 2.6 for *"When mental health professionals plan and take actions about the person I care for, they routinely and frequently consult with me and encourage my participation in decision making (this could involve things like conducting a mental health assessment or developing a treatment plan for the person, arranging a voluntary or involuntary admission to a psychiatric facility, arranging for discharge from psychiatric care or reviewing the type of care or treatment that has been provided)"* .
- 1.5 for *"I have been clearly and fully informed about my rights and responsibilities as a carer of a person with mental illness including rights and responsibilities set out in government or non-Government policy or legislation"* .

Service providers and stakeholders gave the following average scores on a 0-10 scale where 0 indicates disagreement, for items dealing with carer sensitive mental health service delivery.

- 3.7 for *"When carers of people with mental illness want personal support or advice regarding emotional, social or other needs arising from their caring role, this support is readily available from mental health or other health and community service agencies (for example, debriefing or counselling in response to stressful events they are managing or an indepth discussion on how they should handle challenging behaviour)"* .
- 2.9 for *"The professional practice and case management standards of the service system and their day to day operation, enable carers to be consulted and involved in assessment, service planning and treatment/care decisions which impact on the effective conduct of their"*

*caring role. This includes access to relevant case information providing that consumer consent has been given and appropriate confidentiality safeguards are maintained".*

- 2.3 for "*The professional practice and case management standards of the service system and their day to day operation, enable carers to be appropriately engaged in admission, in care and discharge decisions when the person they are caring for is placed within or withdrawn from a psychiatric facility on a voluntary or involuntary basis*".
- 2.5 for "*The rights and responsibilities of carers of people with mental illness are set down in service system legislation, appropriately expressed in service system practice and adequately communicated to carers*".

Many of the group statements and qualitative comments derived from carers and service providers/stakeholders have concentrated on solutions to improve direct mental health consumer service delivery. A very clear national consensus has emerged from the focus groups that carers are filling gaps in many facets of direct consumer service delivery which are not being provided by mental health agencies. Consequently, pressures upon carers are intensified as they respond to the very considerable demands of their own caring roles as well as additional responsibilities due to inadequacies in service delivery.

Actions to resolve these problems are linked to improving professional mental health practice within the context of the *National Standards for Mental Health Services* such as:

- better engagement of carers in mental health service delivery; and
- ensuring mental health treatment and care planning more effectively incorporates and connects with mainstream community supports to address the needs of consumers and carers.

## RECOMMENDATION

It is therefore recommended:

- (a) That the Commonwealth Mental Health Branch fund a best practice demonstration project in each State/Territory which informs the Australian mental health community on ways to promote carer participation and carer responsiveness in service delivery.
- (b) That the experiences and learnings from the demonstration projects be applied as guides in the context of mental health agencies being accredited against and achieving practice performance levels required by the *National Standards for Mental Health Services*.
- (c) That where possible, the demonstration projects seek to build on and consolidate existing examples of innovative practice occurring in the Australian mental health community which emphasis carer engagement in service delivery including initiatives identified through the current study.
- (d) That the demonstration projects be structured to especially inform the Australian mental health community in the following practice areas:
  - engagement of carers in consumer assessment and care/treatment planning decisions;

- practical and timely access by carers to consumer information necessary for the effective carriage of their caring responsibilities;
  - effective carer participation in policy and planning decisions at local mental health service/community levels including the use of carers as service consultants;
  - provision of counselling, debriefing and other emotional and social support services for carers;
  - service outreach and community development approaches in service delivery designed to link mental health care/service planning with a wide range of community supports able to sustain caring households and families; and
  - responses to families experiencing mental illness who are ethno-culturally diverse including cross generation issues between consumers and carers.
- (e) That project initiatives which review carer access to consumer information address 'on the ground' practice implications of the findings of the report *Information Sharing in Mental Health Crisis Situations* (2000).
- (f) That the projects embrace public, non-Government and private mental health service providers.
- (g) That the conduct of demonstration projects occur in conjunction with the *National Standards for Mental Health Services* Implementation Working Group, the AHMAC NMHWG Consumer and Carer Participation Subcommittee, and the MHCA Consumer and Carer Subcommittee.

## Carer Services Resource Flow and Carer Access Strategies

Project findings indicate national and State/Territory budget resources flows supporting service for carers in the mental health field are complex. The dominant program sources are:

- The Commonwealth National Respite for Carers program;
- State/Territory mental health budget allocation; and
- the very variable accessing of other health and welfare program funds mainly allocated through State/Territory departments and including HACC and the CSDA.

Depending on the jurisdiction and region, some agencies and services may gain funding from all of these sources or only some. Funding resources are generally given to:

- generalist carer agencies;
- generalist community support agencies;
- mental health agencies with both carer and consumer service responsibilities; or
- mental health agencies with a dominant carer focus.

The service products yielded to carers through these agencies are diverse and include in-home and out-of-home respite; home help; transport; advocacy support; counselling, emotional, social support; emergency financial/material assistance; and education/training and information provision. Additional information on State/Territory service system profiles are presented in Appendix H.

AHMAC NMHWG representatives indicated carers were eligible to receive debriefing and counselling assistance and other forms of support from public mental health services, although focus group consultations suggest this assistance is not readily available.

Carer strategies to access support include:

- Referrals by professionals/clinical services for carers to access support services;
- Carers coming in contact with support agencies through targeted community information/promotion initiatives conducted by support agencies;
- Carers contacting established help lines and information points from both generalist carer and mental health specific agencies with initial leads often coming from telephone and municipal/local community directories; and
- Carers making 'by chance' and 'stumbling upon' links with support agencies through television programs and magazines, social contacts and the like.

While a range of agencies have systematic information strategies in place, the experiences of carers suggest that a considerable amount of service contact/access is still occurring on a randomised or ad hoc basis.

## Carer Partnerships

Carers gave the following national averages on a 0-10 scale where 0 indicates total disagreement:

- 8.00 for *"The needs of people with mental illness and their carers can best be addressed by both groups working in partnership to gain improvements and desired changes in mental health policy or service delivery"*.
- 6.00 for *"The recognition and support given to carers of people with mental illness by government and service providers would be strengthened if they joined forces with carers in other health or community service fields to take action on common issues"*.

Similarly, service providers and stakeholders have the following national averages using the same scale on similar items:

- 6.10 for *"Future strategies for strengthening the recognition and support given to mental health carers should significantly rely on partnerships between mental health sector agencies and agencies with generic carer responsibilities or carer linked responsibilities in other health and community service fields. In this way carer organisations can come together to take action on common issues such as securing for carers, funding from the health and community service sector budget or improving the overall service access to generic community services for carers"*.
- 4.30 for *"People with mental illness and their carers as respected stakeholder groups in the service system, have a good understanding of each other's needs and are cooperatively working together to achieve desired policy and service delivery improvements"*.

These responses suggest that both carers and service providers/stakeholders in the Australian mental health community are prepared to consider partnerships with organisations having generalist carer responsibilities in order to advance common carer objectives.

The responses also suggest that mental health carers are very keen to collaborate on a strategic basis with consumers of mental health services to pursue mental health policy and service system improvements. However, mental health service providers/stakeholders believe current collaboration between people with mental illness and their carers to achieve policy and service improvements is not working well.

Project findings suggest a major reason why service providers and stakeholders have given a low evaluative rating to current partnership collaboration between carers and consumers may result from the frustrations arising for many carers when they are denied consumer information from mental health services. The report has previously recommended the issue of carer access to consumer information be addressed via the conduct of best practice demonstration projects which can offer guidance to the Australian mental health community on the practical and timely transfer of relevant information to carers. The development of best practice in this field may assist in reducing tensions on this issue between carers and consumers, and may also offer valuable experience on how both parties may work in partnership within a problem solving exercise.

Project investigations have carefully examined the scope and potential for the mental health sector to collaborate with generalist carer organisations to advance the recognition and support of carers of people with mental illness. Project findings indicate that carers and others in the Australian mental health community generally acknowledge this form of partnership can add genuine value to initiatives seeking to strengthen policy, program and advocacy outcome impacts for carers in the mental health field.

There is a recognition that mental health carers will be heard when their voices are joined with those of carers in other sectors to work together on matters of common concern. However carers of people with mental illness and other mental health community stakeholders also fear that if partnerships with generalist carers organisations are poorly structured, resources could be diverted away from the mental health sector to other client groups, and specialist skills and expertise required to address carers needs in the mental health domain could be depleted.

The report has observed the already significant service coordination and planning role generalist carer agencies are exercising towards recognition and support of carers of people with mental illness in a number of Australian jurisdictions. As generalist carer agencies invariably cross a range of health and welfare program boundaries, they appear to acquire an extensive understanding of policy development, budget allocation and service planning on a generally broader spectrum than that gathered by mental health specialist agencies. This expertise and knowledge can be beneficially harvested by the mental health sector to strengthen assistance for mental health carers.

These observations suggest if partnership arrangements can effectively construct safeguards to address the unease of mental health carers and stakeholders, then collaboration between the Australian mental health community and national and State/Territory generalist carer organisations will produce positive outcomes for carers in the sector. These benefits can be expected to include significantly enhanced mental health carer access to mainstream support resources and extended opportunities for carers of people with mental illness to influence policy and service development decisions.

In summary, carers and stakeholders in the mental health sector have indicated a cautious preparedness to consider partnerships with generalist carer organisations providing that safeguards are in place to:

- prevent priority service resources for mental health carers' support being diverted to other client groups; and
- ensure that specialist mental health skills and expertise are not dissipated in the process of partnerships and linkages with generalist carer agencies and mainstream support providers.

## **RECOMMENDATION**

As stated previously<sup>6</sup>, a national framework to enable coordinated, systematic and quality assured carer education and information development to proceed within the Australian mental health community should be put in place. This framework would yield best value to the mental health sector if it is based upon a partnership platform between the MHCA and CAA and their respective affiliated bodies at national and State/Territory levels.

The implementation of this proposal which is recommended on a three year pilot basis will give the Australian mental health community the opportunity to monitor the effectiveness of a significant national strategic partnership with the generalist carer service network.

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<sup>6</sup> See page 21

## Carer Policy Participation

One avenue for carer participation in policy activities is the AHMAC NMHWG Consumer and Carer Participation Subcommittee, which has been established to review the current status of consumer and carer participation in Australian's mental health service delivery. The terms of reference for the group are:

- To create an opportunity to share current developments and perspectives;
- To identify and disseminate innovative best practice models and approaches;
- To identify applied research and evaluation opportunities, which could contribute to further development of service innovation and improvement; and
- To identify and develop initiatives where a national approach is considered to be a mutual benefit.

The Subcommittee is currently developing a policy on consumer and carer participation, which will act as an 'ideal' consumer and carer participation policy template for States/Territories to aim towards. In addition, the MHCA is establishing a Consumer and Carer Subcommittee which will ensure consumers and carers have a single forum for support and discussion.

Project information from AHMAC NMHWG consultations suggest the dominant policy and planning participation channels available to carers are currently via the Consumer Advisory Group (CAG) structures and in some State/Territories, differently titled bodies with equivalent or similar status.

The CAG and related bodies are reporting and appointed advisory groups, often convened under ministerial auspice and comprise of both mental health consumers and carers.

CAGs and related bodies also provide advice on a range of mental health issues including changes to legislation and service redevelopment/deinstitutionalisation. The CAGs interests can address public, non-Government, and private sector mental health issues although project data suggests the majority of CAG advice deals with the public system.

At levels under the central and Ministerially endorsed CAG arrangements, the national picture of carer policy participation is extremely variable. Arrangements regarding the extent of local level involvement of carer, appears to be a function of discretionary decision making by public, non-Government, and private services. In some situations, carer policy participation is extensive, while in other situations it is non-existent.

Carers believe they do not have a high level of participation in policy activities as indicated by their rating on a 0-10 scale where 0 indicates disagreement, of 2.3 for the item *"User friendly and effective channels are readily available to me as a carer and my carer colleagues to participate in policy decision making of relevant government or non-Government agencies on matters which are important to carers of people with mental illness"*.

Similarly, service providers and stakeholders had a rating of 2.7 for *"User friendly and effective channels are readily available for service providers and carers of people with mental illness to participate in policy decision making about intersectoral (ie government and non-Government) system wide matters which are important to carers of people with mental illness"*.

These responses which were attained from participants who could be classified as 'grass roots carers and service providers' suggest there is a considerable lack of carer policy participation opportunity at local levels.

## RECOMMENDATION

The directions for strengthening carer policy participation at the local level in service provision are linked to:

- the work of the AHMAC NMHWG Consumer and Carer Participation Subcommittee;
- the proposed MHCA Consumer and Carer Subcommittee; and
- implementation initiatives regarding the roll out of the *National Standards for Mental Health Services* and especially how 'carer involvement' aspects of the Standards are expressed in individual services.

This could be achieved through the Chair and Chief Executive Officer of the MHCA and the State/Territory Departmental Mental Health Directors represented on the AHMAC NMHWG jointly reviewing the project data emerging from the State/Territory focus groups and individual Departmental interviews and:

- Consider how actions arising from the project's primary recommendations can effectively complement the responsibilities of individual Departments;
- Identify ways in which the MHCA can support State/Territory Departmental strategies for support of carers of people with mental illness; and
- Address consistent concerns emerging in focus groups that day to day mental health service delivery is not engaging carers.

## Indigenous Issues

Previous research undertaken within the framework of the *National Mental Health Strategy* and elsewhere cautions strongly against readily applying to other Aboriginal communities, findings arising from studies or consultations undertaken in a particular Aboriginal community or group of Aboriginal communities. Aboriginal communities reflect a diversity of geographical contexts including rural, remote, provincial, urban, inland, coastal or island environments. Moreover, each community expresses its own unique pattern of affiliations, cultural values and traditions, aspects of which may be in common with other communities. Consequently, evidence gathered by the project must be regarded as one window to view this topic. The project consultations were conducted with Aboriginal mental health workers in the Darwin and Top End regions of the Northern Territory. The workers were auspiced via Territory Health Services and were working in partnership with local Aboriginal communities and organisations.

Despite the restricted nature of the consultation, the consultation with Aboriginal mental health workers has identified some significant needs and service support requirements for carers in Aboriginal communities. These are listed in greater detail in Appendix H. Important findings include:

- Carer support is enormously enhanced when Aboriginal mental health workers are based in local Aboriginal communities;
- Being based in the local community helps the worker immensely to establish trust and proper accountability with community members including those experiencing mental illness and their carers;
- Indigenous mental health workers are in a position to approach their work with an orientation and expertise which can interpret mental illness in a cultural context;
- Such a culturally sensitive orientation is able to help facilitate either traditional or Western approaches being used for the support of people with mental illness and their carers; and
- It is often the case that within Aboriginal communities, care for a person with mental illness is provided by an extended group of carers rather than by a sole or dominant primary carer, which is often the case in many Western communities.

Application of both the detailed and summary findings of consultations to future indigenous mental health service development should be placed in the current policy implementation framework for indigenous health. This has several facets which include the work of the Office of Aboriginal and Torres Strait Islander Health (OATSIH) in supporting developments in the community controlled sector, and associated linkages with the National Aboriginal Community Controlled Health Organisation (NACCHO), related work of the Aboriginal and Torres Strait Islander Commission (ATSIC) and the Office of Torres Strait Islander Affairs (OTSIA), and initiatives through State/Territory Departments involving services which they directly administer or fund in the community sector. Significant program directions for 'on the ground' service implementation have derived principally from the *Ways Forward* (1995) report and the *Bringing Them Home* (1997) report. On a combined basis these two reports have provided the non-Government foundations for indigenous mental health service planning.

Within this framework, OATSIH has supported community-based developments for the facilitation of regional training centres to improve skills and provide services in social and emotional health responses for indigenous communities including parenting and family support.

The Commonwealth and State/Territory Governments in cooperation with indigenous communities have also established an indigenous health partnerships forum in each local jurisdiction to coordinate and plan service responses on a multi-sectoral basis. The partnership forums include relevant government departments and services, ATSIC, OATSIH, and also NACCHO affiliated organisations.

The project believes findings from Aboriginal consultations should be referred initially to key stakeholders in the framework outlined above. This will enable the insights from the consultation to effectively inform indigenous mental health service developments. The project also believes a protocol should be established between the MHCA and the stakeholders discussed to enable the Council in the future to optimally support indigenous mental health policy and service development.

## RECOMMENDATION

It is therefore recommended:

- (a) That the findings from the project's Aboriginal mental health worker consultations be reviewed by NACCHO, ATSIC, OATSIH, the Office of Torres Strait Islander Affairs (OTSIA), and the MHCA to consider how the findings may inform:
  - the non-Government implementation of the *Ways Forward* and *Bringing Them Home* reports including responsibilities connected with regional training centres, social health team counselling and parenting and family support initiatives;
  - decisions of State/Territory partnership forums on indigenous health;
  - other mental health initiatives which may be considered by ATSIC, OATSIH; and the OTSIA; and
  - protocols for future MHCA support of indigenous mental health issues.

## Rural and Remote Issues

The project undertook focus groups at Kalgoorlie on the Western Australian Goldfields to gain an understanding of mental health carer support issues in a non-metropolitan and rural/remote location. The carer and service provider focus groups occurred within a backdrop of partnership activity by the Goldfields Mental Health Action group and related local service providers to pursue enhanced supports for consumers and carers. This partnership approach seems to have created an environment of generally positive relationships between carers, consumers and mental health service providers and seems to have influenced the way focus group participants responded to the project investigation items.

The viewpoints and results emerging from both the carer and service provider/stakeholder focus groups suggest that despite the relative isolation of this area from metropolitan Perth, the local mental health support system has partly been able to address some of the barriers and obstacles often associated with remoteness. On all the common support items rated by the Goldfields service providers/stakeholders their scores were higher than the national averages. Carer scores for *"getting essential personal information and consulted by professionals"* were significantly higher than the national averages (Goldfields 6.60, National 4.10; and Goldfields 5.70, National 2.60 respectively). The Goldfields carer focus group also rated an average agreement score of 6.00 for the item *"carers of people with mental illness who reside in the Kalgoorlie/Goldfields district and surrounding areas do not have lower levels of support and back up than carers of people with mental illness living in Perth"*. The Goldfields service providers/stakeholders focus group rated an average agreement score of 3.60 for the Goldfields item *"The local service system of which my organisation is part, receives adequate recognition in funding arrangements for the demands involved in effectively responding to the needs of carers of people who reside in non-metropolitan and remote locations"*.

Useful cooperation between public and non-Government mental health service providers and other generalist service providers was evident from service provider/stakeholder focus group discussions although there was a perception that structured coordination for carer support objectives was not as strong as most participants would prefer. While both sets of focus group scores indicate overall that service conditions and assistance levels for carers were at low performance levels and not achieving the practice expectations of the *National Mental Health Strategy*. The results suggest recognition and support for carers in this region was not worse, but often better than conditions found in other locations.

It is likely the distance which often separates carers in rural, remote and non-metropolitan settings from the generally higher concentration of potential supports and services found in capital cities, may offer carers important advantages for the practical strengthening and enhancing of their caring roles. It is evident that isolation can act as a catalyst to bring people together. A positive interdependence can emerge in these settings which promotes viable self-help and better collaboration across service providers, carers, consumers and other mental health stakeholders within a defined locality. This observation is made not for the purpose of suggesting that carers in isolated environments do not have special needs as a consequence of their remoteness. Rather the 'positive' aspects of isolation could be applied as an important ingredient of service models to help create better support for rural and remote carers.

In contrast, the Rural and Remote Mental Health Unit of South Australian Mental Health Services (SAMHS) suggests there are exacerbated caring stresses being placed upon carers in remote locations arising from their isolation from supports. Furthermore,

SAMHS also referred to intense stigma and prejudice about mental illness which can be experienced by some carers living in small remote communities. Similar sentiments were conveyed by the Schizophrenia Fellowship of North Queensland's 'Help for Rural Care Givers of the Mentally Ill' program. This program is supporting remote carers in 29 isolated locations in North and Western Queensland.

## **RECOMMENDATION**

It is recommended a thorough study of rural and remote mental health carer needs be undertaken by the MHCA, as an extensive examination of this issue may result in a clearer assessment of needs and the development of more informed recommendations for action.

At this point, the project has confined its recommendations regarding support for rural and remote mental health carers to an action documented in an earlier section of this report dealing with education and information development for carers<sup>7</sup>. This action refers to the creation on a three year pilot basis in at least one State/Territory, of a Carer Education and Information Development Officer focussed exclusively on the needs of carers in non-metropolitan locations and who would address models of cooperation within rural and remote communities.

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<sup>7</sup> See page 21

## Cultural Diversity

While it was not possible to extensively investigate carer issues associated with non-English speaking background communities due to time constraints, consultation with the Transcultural Mental Health Network did occur. Field contacts were also made with the North East Alliance for the Mentally Ill regarding the ethno-cultural outreach program in Northern Melbourne, and with the Schizophrenia Fellowship of NSW regarding the Greek and Italian carer groups the Fellowship facilitates in Sydney.

Approximately 40 percent of Australians were either born overseas or have at least one parent who is from a non-English speaking background. Twenty percent of the Australia population was born in a non-English speaking country. In many regions of Australia the proportion of the local population that is of non-English speaking background is considerably higher. For example, one in three people in the Western and Northern regions of Melbourne are from a non-English speaking background.

The prevalence of mental illness among immigrants varies considerably according to country of birth, with the overall rate not significantly different to that among people who are born in Australia. Despite this similar overall prevalence, mental health services (community-based and inpatient) are significantly under-utilised by non-English speaking background communities. Such under-utilisation is due to a complex range of factors, including:

- high levels of stigma associated with mental illness and psychiatric treatment among non-English speaking background communities;
- lack of information about services and how to gain access to them;
- the general lack of culturally appropriate services; and
- great shortages in the availability of interpreters and of bilingual and bicultural mental health professionals in the service system.

This under-utilisation has important implications for families and particularly for carers, and suggests a significant proportion of people from non-English speaking backgrounds with a mental illness are receiving either no treatment or inadequate treatment.

People who do not speak fluent English who do get access to mental health services do not have access to the wide range of mental health services that rely on effective communication, such as psychotherapy, family therapy, psycho-educational and rehabilitation programs. In addition, services received are frequently culturally inappropriate.

A major deficiency is the lack of family, carer support and education programs that are delivered in the preferred language of families and carers, and that take into consideration the particular beliefs that members of cultural minority communities have about mental illness and treatment. Many ethno-specific welfare agencies attempt to run such programs despite lack of resources and qualified personnel. A number of State-funded transcultural psychiatry units offer such programs, but their reach is very limited due to insufficient resources.

Given the peak incidence of the most serious mental disorders occurs in young adulthood, an issue of particular importance for non-English speaking background communities with children who were born or grew up in Australia, is the cultural and sometime linguistic divide between the consumer and his/her carer. Although interpreters are not required to communicate with the consumer, they are frequently required if the family is to be a full participant in the diagnostic treatment and rehabilitation process, and for the purposes of family and carer education and support.

Given the large number of Australian families of non-English speaking background with a family member who has a mental illness, mental health and generalist services must develop the necessary skills and knowledge in ethno-cultural matters as core practice expertise if they are to effectively address the needs of this large group of consumers and carers. Mental health services must also develop effective means of communicating with non-English speaking background communities in their area (including the development of collaborations with the ethnic print and electronic media) in order to carry out mental health promotion activities, to inform them of available services and how to gain access to them, and to encourage the development of community-based family and carer support programs.

## RECOMMENDATION

In an attempt to address these important aspects of carer linked mental health service delivery, it is recommended that funding be allocated to a range of best practice demonstration projects associated with the implementation of the *National Standards for Mental Health Services*<sup>8</sup> and that several projects focus in part or exclusively on promoting carer sensitive mental health service delivery for ethno-culturally diverse families.

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<sup>8</sup> See page 26

## Private Sector Issues

To gain an understanding of private sector issues, the Strategic Planning Group for Private Psychiatric Services (SPGPPS) was consulted. The SPGPPS which represents private sector mental health practitioners and private hospitals, is in the initial stages of reviewing its approach to carer recognition and support in mental health service delivery. The SPGPPS is shortly to embark on its own project to review carer needs. As a result of the limited work to date undertaken by SPGPPS on carer matters, it was not possible to gain a comprehensive understanding of priority issues which the project should address to support those carers involved in caring for people with mental illness receiving private mental health services. However a significant issue which has emerged is that both people with mental illness and carers involved in private service delivery may be experiencing intensified access barriers to generalist community support services. It is possible that because people with mental illness are paying for professional mental health services, publicly funded generalist support services regard the carers of these people as having a lower eligibility to receive support.

## A Summary of Benchmark Issues

In recognition of carer needs, issues, and support requirements identified in this report, the following best practice benchmarks are suggested:

- ensure mental health consumer service delivery operates at the level required by the *National Standards for Mental Health Services* in order to prevent undue responsibilities being placed on carer roles caused by carers compensating for gaps and deficiencies in appropriate professional treatment and care for the consumer;
- ensure carers have timely and practical access to consumer information to support their essential caring tasks;
- ensure carers are regarded as valued members of the mental health service delivery team;
- ensure carers have early access to mental health information/education to help them understand the mental illness confronting the person they care for, and to practically assist in timely referral, assessment and treatment/care for the person they care for;
- ensure carers have timely access to adequate respite (in home/out of home) and home help services;
- ensure carers have timely access to adequate counselling, emotional, social, and debriefing support services;
- ensure carers are provided with clear information about their rights and responsibilities;
- ensure forward planned strategies are in place to address consumer care when family members or friends are no longer able to provide care to a person with mental illness; and
- ensure carers have access to education/information and 24 hour professional advisory arrangements to support consumer medication programs.

# EVALUATION REPORT

Contract specifications require a project evaluation be undertaken which addressed how the project progressed against time lines; objectives and agreed performance indicators; major achievements; major problems encountered and steps undertaken to overcome them; and any anticipated future activities.

## *General time lines*

The project proceeded in a timely manner. Contract finalisation and project commencement occurred two weeks later than originally intended. A decision was also made to send a draft version of the final project report to selected stakeholders for comment. This step added another week to the project duration. Given these adjustments the project held closely to the initially estimated completion date of early to mid June 2000.

## *Progress Against Objectives and Agreed Performance Indicators*

The project has promptly addressed feedback from the Commonwealth Mental Health Branch, the MHCA, the CAA and the PAG about adjustments to submitted reports in order to ensure all objectives and performance indicators have been met in a comprehensive manner. This has included requirements for more detail on the profiles of services supporting carers in each state and territory and a strengthened documentation of good service practice in response to carers needs. The original expectations of the study have been realised.

## *Major achievements*

The study has been able to undertake a comprehensive investigation of carer needs, the structure and pattern of current carer support arrangements, and future actions to enhance carers support. This analysis has yielded qualitative and quantitative evidence collected from a cross section of Australian carers, local service providers, other mental health community stakeholders and government agencies. Feedback received about the draft final project report from a range of Australian mental health community and generic carer organisation stakeholders indicates the study reflects a rigorous and thorough investigation and its findings are an accurate assessment of needs and preferred responses. It is also important to acknowledge some members of the Australian mental health community could retain reservations about aspects of the project recommendations which support partnership proposals between mental health and generic carer organisations (additional comment on this issue is outlined below).

The intensive consultative orientation of the study has in most instances encouraged strong participant "ownership" of the project and its outcomes. Feedback received indicates participants see a direct relationship between their involvement, the views they expressed and the documented project results.

## *Major problems encountered and steps undertaken to overcome them*

(a) Protective attitudes by some mental health stakeholders

During project consultations many participants referred to stigma, prejudice and ignorance existing in the wider community about mental illness. Carers and service providers also discussed their struggles in gaining effective recognition and adequate resources to address service and support needs for both people with mental illness and their carers.

This background of striving in response to discriminatory attitudes and inadequate resources has built an intense commitment of many mental health stakeholders towards achieving effective service provision. However this same background environment has often caused stakeholders to hold strongly protective viewpoints about the realm of mental health and be very reluctant to place confidence in organisations who are seen as being outside the mental health sector.

These protective attitudes produced at times, some passionate discussion by focus group participants when project consultations considered questions of partnership between mental health carer organisations and generic carer groups and related issues of access by carers to mainstream support services.

The focus group methodology was designed to enable a sensitive exploration of these questions with participants. The feedback from participants at the conclusion of each group indicated that participants felt complex issues had been addressed thoroughly, the 'pros and cons' of various questions fully examined and viewpoints accurately recorded. The one exception to this trend was a service provider/stakeholder group in Victoria where three participants complained to the MHCA that the consultative process used was in effect imposing pre-emptive views and outcomes. The MHCA Chief Executive Officer in response, agreed that the participants concerned would have an opportunity to consider and comment upon the draft final project report in order to ensure their views were validly represented.

The project has received feedback from one of these participants, who concurred with the report summary and findings analysis. This participant felt the quantification of consultation viewpoints as applied in the methodology was "problematic". The feedback also indicated the service system summaries in the report were valuable.

The problem of protective mental health attitudes within the consultative methodology has been suitably addresses.

#### (b) State/Territory Carer Data Bases

Strategic planning in the mental health sector to address care issues is underdeveloped. This is reflected in limited management information reporting systems on carer issues being in place in Sate/Territory Government Department Mental Health Divisions. While the project gained excellent cooperation from the Departmental members of the AHMAC NMHWG, information sought was often not readily available. This ranged through numbers of mental health carers in each jurisdiction, funding and budget information, advice on case management systems, duty of care issues, numbers of mental health clients and carers serviced from other support programs administered by the same or a colleague department in the same jurisdiction and other matters.

Consequently the project spent considerable time "chasing" this information. As such, it has not been possible to present the departmental information returns with the same summarised rigour as found in the focus group results.

### *Rural and Remote, Indigenous and non-English Speaking Background Carer Issues*

The original project brief did not focus special attention on data gathering about carer needs in rural, remote and non-English speaking background communities. The PAG workshop however requested that coverage be given to these fields within the context of an already extensive project plan and objectives. The project report documents activities undertaken to understand carer needs in these communities. While some extremely valuable insights and conclusions were established by the project in these fields, the findings are of an essentially provisional nature and additional future investigation on a in depth basis is strongly recommended.

The project in particular wishes to thank the Transcultural Mental Health Network for its contribution to this area of the project.

### *Anticipated Future Activities*

This evaluation report has already indicated the need for follow up work on rural and remote, indigenous and non-English speaking background communities' carer issues.

Carers are an indispensable group within the Australian mental health community. Without their contribution, formal mental health service systems would collapse. The project's recommendations must be considered for implemented on a priority basis if essential recognition and support of carers is to be achieved. Without this recognition and support, quality assurance for primary consumer service delivery in the mental health sector will remain inadequately recognised.

## APPENDIX A

### Project Advisory Group (PAG) Membership

Mr John McGrath (Chair)	Mental Health Council of Australia (MHCA)
Mr Des Graham	Mental Health Council of Australia (MHCA)
Ms Irene Gibbons	Carers Association of Australia (CAA)
Ms Helen Conner	Australian Mental Health Consumer Network (AMHCN)
Ms Maria Bohan	State/Territory based Carers Association
Ms Judy Hardy	Network of Australian Community Advisory Groups (NOAC)
Ms Barbara Hocking	SANE Australia
Mr John Skelton	Associations of Relatives and Friends of the Mentally Ill (ARAFMI)
Mr Bob Burgell	Burgell Consulting
Mr Rob Ramjam	Assistant to consultant (Schizophrenia Fellowship NSW)



## APPENDIX B

### A Review of Findings against Investigation Objectives identified by the Project Advisory Group (PAG) Workshop

The Project Advisory Group established 16 investigation areas for the project. Outlined below is a review in relation to findings within these areas (descriptions of the investigation areas were frequently phrased in the form of affirmative practice statements about carer recognition and support).

1. *Ensuring that the values and principles of partnership between people with mental illness and their carers which are reflected in the National Mental Health Plan become everyday realities in mental health service delivery.*

Project findings indicate carer groups are extremely conscious of maintaining close and effective relationships with consumers. However there are occasions when carers could be best served by taking separate actions to address their needs (eg. in relation to seeking improved carer respite access from some mainstream support agencies).

2. *Assessing whether the level of support provided by mental health service providers and governments to mental health carers is in balance with the enormous resource and time investment provided by carers.*

Project findings suggest carers are contributing on average 104 hours per week of care. The project has gathered aggregate data about the size of mental health budgets. Follow up work is required to provide helpful perspectives on the balance of resource investments and contributions by unpaid carers and salaried staff.

3. *Ensuring the inclusion or strengthening of the legislative recognition of the rights and responsibilities of mental health carers in all Australian government jurisdiction.*

Carer rights are not codified or are codified in a very limited manner in State/Territory legislation.

4. *Ensuring that mental health case management policy and practice frameworks at State/Territory level incorporate carers roles and carer participation/consultation in consumer assessment, service planning and case review activities.*

All State/Territory jurisdictions express a commitment to case management in public mental health service delivery. Project evidence indicates that four jurisdictions have system wide frameworks, but further study is required to assess the role of carers in these frameworks.

5. *Assessing service gaps and strengthening access to mainstream and mental health specific respite and related support services for mental health carers.*

Provision is generally poor.

6. *Reviewing the adequacy of carer allowances and out of pocket expense reimbursement arrangements for the carers of people with mental illness in relation to episodes of care where carers are subject to extreme pressures.*

Several consultations have strongly indicated that carer allowances and payments do not compensate for income loss from carers giving up work to care. A number of carers also report that they are personally paying for consumer medication which they believe should be either freely available or better subsidised.

7. *Reviewing the roles of carers in relation to involuntary admissions to, care within and discharge from psychiatric facilities for people with mental illness.*

Project data indicates that carer participation in consumer admission, discharge and related decisions is being poorly addressed by public mental health services.

8. *Ensuring that duty of care principles, practices and frameworks within mental health service delivery systems address the role of carers.*

Duty of care frameworks in most State/Territory jurisdictions are poorly articulated. Carer dimensions in duty of care criteria are absent or very inadequately developed.

9. *Ensuring that privacy, confidentiality and personal consent arrangements and practices governing the transfer of mental health consumer information to other parties, enables carers to be adequately informed about essential information they require to effectively perform their caring roles.*

Carers almost universally report they cannot get essential and timely information about consumers in order to effectively carry out their caring roles.

10. *Ensuring that carers have effective tools and supports to assist people with mental illness to administer home based programs of medication.*

Tools and supports to assist in the administration of consumer home based medication are generally not available for carers.

11. *Ensuring that training programs offered by mental health service delivery agencies are not confined to employed professionals but give adequate access to carers.*

The extension of training options from salaried staff to carers is limited.

12. *Ensuring that resource investment decisions by TAFE and higher education institutions gives just access to mental health carers for targeted accredited training which addresses their specific skill and knowledge needs.*

Carers are not accessing these resources. There is also ambivalence in the Australian mental health community about doing so.

*13. Documenting gaps in mental health carers access to education, training and information resources.*

The biggest gap is in the area of systematic and coordinated planning for and provision of these services.

*14. Reviewing arrangements that will strengthen the inclusion of carers in the development, implementation and evaluation of mental health policy by mental health service providers and governments.*

Effective inclusion of carers in policy participation is not generally occurring at local levels. Solutions are linked to the adequate roll out of the *National Standards for Mental Health Services* and the impetus the Standards should offer to encourage local services to engage carers in service planning and delivery.

*15. Within the constraints of the project, review literature in relation to the mental health carer special needs groups.*

Helpful perspectives on rural/remote, Aboriginal, Torres Strait Islander, and non-English speaking background carer issues have been gathered.

*16. Review service gaps and services available in relation to the emotional and social support needs of mental health carers.*

Service provision is often very limited especially in relation to responses by public mental health providers.



## APPENDIX C

### Priority Ranking the PAG gave to Key Questions for Investigation

Statement	Group Average Score	Ranking
Reviewing arrangements that will strengthen the inclusion of carers in the development, implementation and evaluation of <i>National Mental Health Policy</i> by mental health service providers and governments.	9.1	1
Assessing whether the level of support provided by mental health service providers and governments to mental health carers is in balance with the enormous resource and time investment provided by carers.	9	2
Ensuring that privacy, confidentiality and personal consent arrangements and practices governing the transfer of mental health consumer information to other parties, enables carers to be adequately informed about essential information they require to effectively perform their caring roles.	8.8	3
Ensuring that the values and principles of partnership between people with mental illness and their carers which are reflected in the <i>National Mental Health Plan</i> become everyday realities in mental health service delivery.	8.4	=4
Reviewing the roles of carers in relation to involuntary admissions to care within and discharge from psychiatric care for people with mental illness.	8.4	=4
Ensuring that mental health case management policy and practice frameworks at State/Territory level incorporate carers roles and carer participation/consultation in consumer assessment, service planning and case review activities.	8.3	5
Assessing service gaps and strengthening access to mainstream and mental health specific respite and related support services for mental health carers.	8.1	6
Review service gaps and services available in relation to the emotional and social support needs of mental health carers.	7.7	7
Ensuring the inclusion or strengthening of the legislative recognition of the rights and responsibilities of mental health carers in all Australian government jurisdiction.	7.6	=8
Ensuring that duty of care principles, practices and frameworks within mental health service delivery systems address the role of carers.	7.6	=8
Ensuring that carers have effective tools and supports to assist people with mental illness to administer home based programs of medication.	7.1	9
Reviewing the adequacy of carer allowances and out of pocket expense reimbursement arrangements for the carers of people with mental illness in relation to episodes of care where carers are subject to extreme pressures.	6.8	=10
Documenting gaps in mental health carers access to education, training and information resources.	6.8	=10
Within the constraints of the project review literature in relation to the mental health carer special needs groups.	6.8	=10

Ensuring that training programs offered by mental health service delivery agencies are not confined to employed professionals but give adequate access to carers.	6.6	11
Ensuring that resource investment decisions by TAFE and higher education institutions gives just access to mental health carers for targeted accredited training which addresses their specific skill and knowledge needs.	5.6	12

### Field Methodology

Statement	Group Average Score	Ranking
Focus group consultation with carers of people with mental illness in all mental health service sectors in each State/Territory.	9.6	1
Field consultations in all States and Territories including rural and remote localities.	9.4	2
Ensuring that the PAG monitors and receives regular reports about the progress of the project.	9	3
Use previous research/studies which have been validated by the Australian mental health and carer communities as the project starting point.	8.4	4
Consultations which encourage participant engagement and participant ownership of eventual findings.	8.3	5
Interviews with other relevant non-Government representatives in each State/Territory.	8.1	=6
Data gathering which addresses special needs groups.	8.1	=6
Consultations orientated to getting information about solutions and actions (including building upon initiatives already started or in the 'pipeline').	8.1	=6
Surveying of key carer and other stakeholders unable to attend focus groups or field interviews.	7.8	7
Arrangements for field consultations to be coordinated through the State/Territory agencies affiliated with CAA with backup from the State/Territory network affiliates of the PAG and MHCA.	7.7	8
Interviews with relevant Departmental staff in each State/Territory.	7.4	9
Interviewing or consultations with SPGPPS to address private sector mental health carer issues.	7	10
Interviewing or surveying all Health and Community Services Industry Training Advisory Boards at State/Territory and National levels.	6.3	11

## APPENDIX D

### PAG Priorities - Results, Findings and Proposed Actions

Statement	Group Average Score	Ranking
Developing recommendations for action which have a partnerships focus including links between carers and people with a mental illness and between mental health carer networks and other carer networks in the health and community services field.	9.1	1
Ensure timely feed back to consultation participants of the documented results of their participation.	8.7	=2
Ensure that State/Territory level findings are assessed by PAG representatives to promote nationally consistent decisions in the context of the <i>National Mental Health Strategy</i> and related policies.	8.7	=2
Structuring results, findings and recommendations to target the Commonwealth Department of Health and Aged Care.	8.4	=3
Structuring results, findings and recommendations to target State/Territory Departments via AHMAC NMHWG and the private sector via SPGPPS.	8.4	=3
Structuring findings to formulate best practice benchmarks for carers in mental health and which give implementation guidance to the sections of the <i>National Standards for Mental Health Services</i> dealing with carer issues.	8.4	=3
Structuring results, findings and recommendations to target non-Government organisations in the Australian mental health and carer communities.	8	4
Developing recommendations which enable mental health carers to have access to mainstream training and support services including resources allocated through the Australian National Training Authority and also the HACC and SAAP programs.	7.8	5

## APPENDIX E

### Number of Focus Group Participants in each State/Territory

State/Territory	Carers	Stakeholders
Northern Territory: Darwin	9	(General )4 (Aboriginal mental health workers) 8
South Australia	7	9
Western Australia: Kalgoorlie	9	10
Western Australia: Perth	9	9
Australian Capital Territory	7	8
Tasmania	9	6
New South Wales	7	6
Victoria	11	8
Queensland	8	7
<b>Total</b>	<b>76</b>	<b>75</b>
<b>Overall Total: 151 Participants</b>		

## APPENDIX F

### Carer Focus Group Items

#### **Please Indicate the Hours You Give**

I give the following hours of care in a week to a person with mental illness (please make sure to include things like undertaking necessary transport/travel and arranging or attending appointments or emergency situations etc. as well other types of support you give in the home throughout the day and night)

*Best practice attainment items common to all carers focus groups. Participants were asked to rank the items on a scale of 0-10 for their strength of agreement to the statement.*

#### **Getting Essential Personal Information**

With the agreement of the person I care for and in keeping with proper confidentiality guidelines, I can readily obtain from mental health professionals, essential information about the needs of the person whom I care for so that I can effectively perform my caring role (eg knowledge or information about their case assessment/diagnosis or treatment plan, advice about their medication program, the names of the mental health professionals involved in their care).

#### **Having a Break**

When I want a break from my caring role (like a short holiday, a weekend off or just getting out for a few hours) affordable or free of charge respite services are readily available to give me this break.

#### **Backup Help**

When I want practical backup for my caring role (like assistance for in home cleaning, meal preparation, shopping, transport etc) affordable or free of charge back up services are readily available to me.

#### **Policy Decision Making**

User friendly and effective channels are readily available to me as a carer and my carer colleagues to participate in policy decision making of relevant government or non-Government agencies on matters which are important to carers of people with mental illness.

#### **Emotional and Social Support**

When I want personal support or advice in response to emotional, social or other needs arising from my caring role, this support is readily available to me from mental health or other health and community services agencies (eg counselling in response to stressful events I am managing or perhaps an indepth discussion on how I should handle challenging behaviour by the person I care for).

### **Action with Other Carers**

The recognition and support given to carers of people with mental illness by government and service providers would be strengthened if they joined forces with carers in other health or community services fields to take action on common issues.

### **Consulted By Professionals**

When mental health professionals plan and take actions about the person I care for, they routinely and frequently consult me and encourage my participation in decision making (this could involve things like conducting a mental health assessment or developing a treatment plan for the person, arranging a voluntary or involuntary admission to a psychiatric facility, arranging for discharge from psychiatric care or reviewing the type of care or treatment that has been provided).

### **Information, Education and Training Resources**

When the need arises, I can readily draw upon information, education or training resources to provide essential knowledge or skills involved in my caring role.

### **Rights and Responsibilities**

I have been clearly and fully informed about my rights and responsibilities as a carer of a person with mental illness including rights and responsibilities set out in government or non-Government policy or legislation.

### **Carer – Consumer Partnerships**

The needs of people with mental illness and their carers can best be addressed by both groups working in partnership to gain improvements and desired changes in mental health policy or service delivery.

### **Support for Carers in Kalgoorlie/Goldfields**

Carers of people with mental illness who reside in the Kalgoorlie/Goldfields district and surrounding areas do not have lower levels of support and back up than carers of people with mental illness living in Perth.

*This group believes the following actions are needed to strengthen the recognition and support for carers of people with mental illness.*

*I would like to make the following comments about steps to strengthen the recognition and support of carers of people with mental illness.*

## APPENDIX G

### Stakeholder/Service Provider Focus Group Items

#### **Your Roadmap of the Mental Health Carers Service System**

Based on our discussion and using the navigation markers as guides, would you please set down a brief summary statement of the service system for mental health carers in your State/Territory as you understand it. This should be based on your own/your organisations experiences. You may also wish to make evaluative comments regarding the adequacy of this service system.

*Best practice attainment items common to all mental health stakeholder/service provider focus groups. Participants were asked to rank each item on a scale of 0-10 regarding their strength of agreement to the statement.*

#### **Effectiveness of Coordination Arrangements**

The service system has effective arrangements in place to coordinate effort and build partnerships between organisations for strengthening the recognition and support of carers of people with mental illness. This includes linkages between mental health agencies and agencies with generic responsibilities for carers in the health and community services field or for the generalist provision of community resources/supports.

#### **HACC Access**

Carers of people with mental illness can readily and without facing unreasonable eligibility criteria, draw on community services and supports which are funded through the Home and Community Care Program.

#### **Commonwealth/State Disability Programs Access**

Carers of people with mental illness can readily and without facing unreasonable eligibility criteria, draw on community services and supports which are funded through Commonwealth and State disability program arrangements.

#### **SAAP Access**

Carers of people with mental illness can readily and without facing unreasonable eligibility criteria, draw on community services and supports which are funded through the Supported Accommodation and Assistance (SAAP) program.

#### **TAFE/HIGHER Education Access**

Carers of people with mental illness can readily and without facing unreasonable eligibility criteria, access targeted education and training programs of TAFE's or Universities to gain skills and knowledge necessary for their caring roles.

## **Policy Participation**

User friendly and effective channels are readily available for service providers and carers of people with mental illness to participate in policy decision making about intersectoral (ie Government and non-Government) system wide matters which are important to carers of people with mental illness.

## **Emotional and Social Support**

When carers of people with mental illness want personal support or advice regarding emotional, social or other needs arising from their caring role, this support is readily available from mental health or other health and community services agencies (eg debriefing or counselling in response to stressful events they are managing or an indepth discussion on how they should handle challenging behaviour).

## **Partnerships between the Mental Health Sector and Other Carer Organisations**

Future strategies for strengthening the recognition and support given to mental health carers should significantly rely on partnerships between mental health sector agencies and agencies with generic carer responsibilities or carer linked responsibilities in other specific health and community services fields. In this way carer organisations can come together to take action on common issues such as securing, for carers, funding from the health and community services sector budget or improving the overall service access to generic community services for carers.

## **Inclusiveness of Professional Practice**

The professional practice and case management standards of the service system and their day to day operation, enable carers to be consulted and involved in assessment, service planning and treatment/care decisions which impact on the effective conduct of their caring role. This includes access to relevant case information providing that consumer consent has been given and appropriate confidentiality safeguards are maintained.

## **Psychiatric Facility Decisions**

The professional practice and case management standards of the service system and their day to day operation, enable carers to be appropriately engaged in admission, in care and discharge decisions when the person they are caring for is placed within or withdrawn from a psychiatric facility on a voluntary or involuntary basis.

## **Carer Rights and Responsibilities**

The rights and responsibilities of carers of people with mental illness are set down in service system legislation, appropriately expressed in service system practice and adequately communicated to carers.

## **Carer – Consumer Relationships**

People with mental illness and their carers as respective stakeholder groups in the service system, have a good understanding of each others needs and are cooperatively working together to achieve desired policy and service delivery improvements.

## **Service Funding**

*(Kalgoorlie/Goldfields Group only)*

The local service system of which my organisation is part, receives adequate recognition in funding arrangements for the demands involved in effectively responding to the needs of Carers of People who reside in non-metropolitan and remote locations.

*Information, Education and Training Resources.*

*Please indicate the availability and suitability of information, education and training resources for carers of people with mental illness including gaps in provision.*

*This Group believes the following actions are needed to strengthen the recognition and support of carers of people with mental illness*

*I would like to make the following comments about steps to strengthen the recognition and support of carers of people with mental illness.*



## APPENDIX H

### ACT Carers Focus Group

<b>Common Items</b>	<b>Average Score</b>	<b>Strongest Agreement to Strongest Disagreement</b>
Action with Other Carers	9.6	1
Carer and Consumer Partnerships	6.4	2
Getting Essential Personal Information	4.8	3
Emotional and Social Support	4.6	4
Information, Education and Training Resources	3.8	5
Policy Decision Making	2.7	6
Backup Help	2	7
Having a Break	1.6	8
Consulted By Professionals	0.3	9
Rights and Responsibilities	0.1	10
<b>Action Items</b>	<b>Average Score</b>	<b>Greatest Importance to Least Importance</b>
Ensure that mental health services include the carer in the development and implementation of individualised care and treatment plans	9.8	1
Ensure effective linkages between and coordination of agencies/services which provide rehabilitation to enable the consumer to progress their life skills and independence (this includes training/employment placement options, social/recreational and other activities. If these supports are in place, carers are more strongly positioned to provide optimum care).	9.4	2
Implement effective training/professional development for mental health and community support workers to strengthen skills to address dual diagnosis, challenging behaviour and carer/family support issues including effective responses to address the needs of	9.1	3

siblings of carers of people with mental illness.		
Implement timely and effective information/education services for carers to: <ul style="list-style-type: none"> <li>• understand mental illness/diagnosis categories</li> <li>• empower the carers role in service delivery eg, advocacy, understanding rights and responsibilities</li> <li>• to be informed about the operation of the service system and services available</li> </ul>	8.8	4
Ensure adequate funding/resourcing of public mental health clinical services and non-Government agencies to provide effective counselling, social and emotional support to carers when they need it	8.1	5
Implement in practice, service partnership procedures between responsible agencies to address consumer dual diagnosis needs. In order to achieve accountable and coordinated treatment care. For the consumer and support for the carer (dual diagnosis in this context means mental illness plus substance or/and alcohol abuse)	8	6
Implement effective government funding and accountability mechanisms to ensure HACC, CSDA, SAAP and other funding programs effectively target and deliver support to mental health carers and consumers.	7.3	7
Strengthen policy arrangements and funding to encourage collaboration between mental health carers groups, in the	6.8	8

delivery of information/education, advocacy and self help services		
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<b>Average number of hours per week I provide care</b>	86
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### ACT Stakeholders Focus Group

Common Items	Average Score	Strongest Agreement to Strongest Disagreement
Partnerships between the Mental Health Sector and Other Carer Organisations	7.3	1
HACC Access	4.8	2
Emotional and Social Support	4.2	3
SAAP Access	4	4
Commonwealth/State Disability Programs Access	3.1	=5
Effectiveness of Co-ordination Arrangements	3.1	=5
Carer Rights and Responsibilities	3	6
Inclusiveness of Professional Practice	2.8	7
Policy Participation	2.6	=8
TAFE/HIGHER Education access	2.6	=8
Carer and Consumer Relationships	2.6	=8
Psychiatric Facility Decisions	2.5	9
Action Items	Average Score	Greatest Importance to Least Importance
<p>In recognition of the value and needs of all carers including young carers</p> <p>a) where appropriate carers to be included in care management, discharge plans and distribution of information</p> <p>b) mental health services must recognised that carers are severely impacted upon by the Mental Illness of the consumer and consequently service resources should be allocated for carers and their needs should be addressed in assessment and other aspects of case management</p> <p>c) ensure that the needs of children in carer roles are adequately assessed and non-Government support is provided for them</p>	10	1
<p>NMHS implementation and accreditation in the ACT requires the resourcing of generalist support agencies to ensure</p> <p>a) that they are can guarantee and be accountable for, access to training by their staff on mental health carer/consumer issues</p> <p>b) that this training incorporates the articulated needs of carers and consumers</p> <p>c) that this training addresses cultural relevance and access and equity issues in service delivery</p> <p>d) that this training is non-Government</p>	9	2
<p>That ACT carers be requested to continue to update the content and review the distribution of its mental health carer resource kit/materials to ensure full targeting of relevant support agencies. That ACT carers be adequately resourced by Government for this purpose.</p>	7.8	3

## **The ACT Service System for Carers of People with Mental Illness**

### **Primary funders**

#### *Health and Community Care:*

- Territory wide public mental health services budget \$21 million pa.
- Mental health non-Government funding which includes a specific mental health carer focus.
  - *Respite Care ACT*: Mental health consumer and carer respite \$134,000 pa.
  - *Mental Health Foundation ACT*: a respite component in a total grant of \$282,000 pa.
  - *Barnardos*: Respite for children with parents who have a mental illness or parents with children with a mental illness.
  - *ACT Post Natal Depression Support Group*: to receive support funding of \$80,000 pa.
  - *ACTCOSS*: funding for the implementation of the NMHS in non-Government services one off \$75,000.
  - Mental health resource for information and referral services \$ 60,000 pa.
- HACC
  - Carers Association of the ACT
  - CIT Skills for Carers Program \$66,900 pa.

#### *ACT Mental Health Services:*

- Funding to CIT Skills for Carers in partnership with ACT Carers for the conduct of the ACT Mental Health Carers Project.

#### *Commonwealth National Respite for Carers Program (NRCP):*

- Funding to ACT Carers for the ACT Carer Resource Centre and Respite Care Centre. Provision of generalist carer services involving information, referral, education and also access to respite.
- Funding to CIT Skills for Carers \$30,000 pa (approx.). This includes a targeted mental health component.

### **Carers Service Initiatives**

- *Schizophrenia Fellowship ACT* provides general support and information to carers of people with mental illness.
- Targeted mental health respite services covering carer needs are delivered by *Respite Care ACT*, *Mental Health Foundation ACT* and *Barnardos*.
- *ACTCOSS* is working with non-Government organisations in the ACT to address implementation issues associated with agencies conforming to *National Standards for Mental Health Services* requirements. This project has a significant focus on carer engagement in service delivery.

- *CIT Skills for Carers*: This program has been extremely active in the provision of education and training for carers of people with mental illness.
- *ACT Carers*: The agency's Carer Resource Centre operates a one-stop shop for advice, information and referral for carers and service providers including carers and providers in the mental health field.
- *Calvary Hospital*: conducts a mental health carers support group.

### **Carer Policy and Planning Participation**

- The ACT Mental Health Act and related mental health policies have recently been reviewed. The review has involved ACT Health and Community Care and ACT Mental Health Services (ACTMHS) in extensive consultations with the Territory's mental health community. Initiatives which have occurred in this context include:
  - Development of a comprehensive consumer and carer policy for participation in mental health services.
  - Formation of a new Ministerial Mental Health Advisory Council which includes carer representatives.
  - A project funded by ACTMHS and conducted by ACT Skills for Carers and the ACT Carers of People with Mental Illness Network (auspiced by ACT Carers). The project is developing a protocol between ACTMHS and Territory carers.
  - An audit of carer involvement in ACTMHS case planning.

### **Carer Service Coordination**

- The ACT Carers auspiced Mental Health Carers Network is the primary coordination structure for mental health carer support. ACT Skills for Cares has a major facilitating role in many Territory carer initiatives and was active in the formation of the Network. Additional coordination support comes from the Mental Health Providers Network auspiced by ACTCOSS.

**NSW Carers Focus Group**

<b>Common Items</b>	<b>Average Score</b>	<b>Strongest Agreement to Strongest Disagreement</b>
Carer – Consumer Partnerships	7.7	1
Information, Education and Training Resources.	7.1	2
Action with Other Carers	5.6	3
Getting Essential Personal Information.	5	4
Emotional and Social Support	4.6	5
Policy Decision Making.	3.4	6
Consulted By Professionals	3.3	7
Rights and Responsibilities	2.8	8
Backup Help.	0.6	9
Having a Break	0.3	10
<b>Action Items</b>	<b>Average Score</b>	<b>Greatest Importance to Least Importance</b>
Ensure that the NSW Mental Health Service has in place highly responsive and timely crisis intervention teams which respond effectively to consumer and carer needs in home based and community settings	9	=1
Review and monitor budget allocation in the NSW Mental Health Service to ensure the bulk of resources go into frontline community based responses which address the needs of consumers and carers. Implement clear budget and accounting identification of management and academic unit expenditure as these items are believed to be on the increase compared to actual service delivery expenditure	9	=1
Implement a Statewide information strategy based on all media forms and accessible local community access points to enable carers and consumers to get necessary knowledge and first level advice about mental illness	8.7	2
All efforts should be made to reduce and eliminate the stigma associated with mental illness including strategies of school based education	8.4	3
Carers should be involved as full partners in the process of mental health assessment, case planning, treatment and rehabilitation	8.3	4
NSW Mental Health Services must operate at best practice standard guided by <i>National Standards for Mental Health Services</i> to ensure that: <ul style="list-style-type: none"> <li>• inappropriate caring responsibilities or pressures are not placed on carers</li> <li>• Carers can perform their optimum caring role</li> </ul>	8	5
Develop and implement an effective case management framework for mental health professionals in NSW including: <ul style="list-style-type: none"> <li>• Training of professionals</li> <li>• Staffing arrangements to ensure continuity of care</li> </ul>	7.8	6
Ensure adequate counselling and debriefing services are established/accessible to carers	7	7
Ensure mental health professionals consult amongst	6.7	8

themselves and with consumers on medication decisions and encourage carers and consumers to be actively engaged in the monitoring of medication programs		
Strengthen the capacity for GP's as a support for carers and consumers through professional education and training and improved linkages with mental health services	6.6	9

<b>Average number of hours per week I provide care</b>	51.6
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**NSW Stakeholders Focus Group**

<b>Common Items</b>	<b>Average Score</b>	<b>Strongest Agreement to Strongest Disagreement</b>
Partnerships between the Mental Health Sector and Other Carer Organisations	5.1	1
Emotional and Social Support: Combined Government and non-Government organisations score. (Government score: 0.8, non-Government score: 6.5)	3.6	=2
Carer – Consumer Relationships	3.6	=2
Policy Participation	2.8	3
Effectiveness of Co-ordination Arrangements	2.1	4
Inclusiveness of Professional Practice	2	5
Commonwealth/State Disability Programs Access	1.6	=6
SAAP Access	1.6	=6
Carer Rights and Responsibilities	1.6	=6
Psychiatric Facility Decisions	1.4	7
HACC Access	1.3	8
TAFE/HIGHER Education access	1.2	9
<b>Action Items</b>	<b>Average Score</b>	<b>Greatest Importance to Least Importance</b>
Ensure that carer recognition, support and participation as identified in the <i>National Standards for Mental Health Services</i> is implemented by the allocation of effective funding/resourcing at the local service and community level for non-Government, public and private mental health services.	8	=1
Develop local/regional forums which are adequately resourced and coordinated to identify carer support needs at the local and regional level	8	=1
Ensure adequate education to carers, consumers and service providers about the content, intent and philosophy and policy implications of the <i>National Mental Health Strategy</i>	7.1	2
Ensure the carers role is recognised at an equal level to that of the consumer	7	3

## The NSW Service System for Carers of People with Mental Illness

### Primary funders

#### *NSW Health:*

- Statewide public mental health services budget \$475 million pa.
- \$5 million pa allocated to consumers and carers support in predominantly non-Government services.
- Central and area funding to mental health Statewide peak bodies with carer responsibilities including ARAFMI NSW, Schizophrenia Fellowship NSW and NSW CAG.

#### *Community Services, Ageing and Disability Services:*

- HACC: funding to generalist agencies for respite and personal support.
- Disability services funding for respite (variably accessible by mental health carers).

#### *Government Wide:*

- The NSW government has recently announced a new Carers Policy and Strategy, which involves \$12.9 million over 4 years with \$1 million pa allocated to mental health in the first 3 years for a total of \$3 million. Community funding submissions are currently being considered. In developing the framework for NSW and through consultations with the NSW carer community, approximately 70 responses to the Carers Statement were received from individuals and organisations. As well, specific consultation meetings were conducted with ARAFMI membership and through the Mental Health Coordinating Council (MHCC). An additional 300 responses were collected and collated by the Carers Association of NSW. Respondents most frequently identified the needs of carers as follows: personal and emotional support, service system responsiveness, income support and the capacity to return to work. It was also found that the need for education, training and information by carers was primarily required at the outset of the caring experience.

#### *Commonwealth National Respite for Carers Program:*

- *NSW Carer Resource Centre* within Carers NSW: The resource centre provides of advice, information and referral for all carers including those caring for people with mental illness.
- *Regional Carer Respite Centres*: A network of respite care contact points for carer information and referral and provision of respite services for all carers including mental health carers.

## **Carers Service Initiatives**

- *Schizophrenia Fellowship NSW (SF NSW)*: It conducts a range of carers support groups, carer education and information initiatives, contact line advice information and referral, and targeted advocacy. SF NSW operates 'Siblink', an education and support program for siblings of people with mental illness. The organisation also facilitates both a Greek and Italian Carers of People with Mental Illness support programs. SF NSW is engaged in extensive anti stigma education.
- *ARAFMI*: It offers a span of education, information, referral and advocacy services for carers, including support groups. The agency also offers services and support to siblings and children of people with mental illness through its Young ARAFMI program.
- *Carers Association NSW*: The organisation is piloting training of mental health providers in the use of Telephone Group Counselling (TGC) as a model of emotional support to carers. The desired result after the completion of the training is that Carers NSW co-facilitates the first TCC program with these providers who then continue this program of carer support.
- *Schizophrenia Clinical Guidelines*: SF NSW in partnership with the mental health community has developed clinical practice guidelines for schizophrenia treatment and care response. The guidelines, which are awaiting release from the NSW Government have involved extensive carer input and reflect a strong carer focus in specifications for mental health service delivery and practice.
- *Banks House Supporters Group*: This is a comprehensive Metal Health Family Education Program based at Bankstown Hospital.
- *NSW Institute of Psychiatry*: It has developed and delivered in association with ARAFMI, SF NSW, Carers NSW and other organisations a number of accredited courses with a focus on carer issues.
- *Area Mental Health Services*: are offering some local level targeted supports to carers. Carers are eligible to receive emotional and social support from clinical staff.

## **Carer Policy and Planning Participation**

The NSW CAG offers advice on mental health issues to the NSW Centre for Mental Health and other sections of government. The group has carer representation. Guidelines have been prepared for area mental health services for consumer, carer and other forms of community involvement and consultation. These guidelines are being applied at uneven rates statewide. Localities where carers involvement is advanced includes Northern Rivers and the Mid North Coast.

## **Carer Service Coordination**

In NSW the project has found little evidence of a collaborative mental health sector wide body addressing service coordination and planning for carers of people with mental illness.

**Victorian Carers Focus Group**

<b>Common Items</b>	<b>Average Score</b>	<b>Strongest Agreement to Strongest Disagreement</b>
Carer and Consumer Partnerships	9.9	1
Having a Break	7.3	2
Emotional and Social Support	6	3
Action with Other Carers	5.3	4
Policy Decision Making	3.8	5
Information, Education and Training Resources	3.6	6
Backup Help	3.4	7
Getting Essential Personal Information	2.9	8
Consulted By Professionals	2.7	9
Rights and Responsibilities	1.6	10
<b>Action Items</b>	<b>Average Score</b>	<b>Greatest Importance to Least Importance</b>
<b>Night Respite</b> Ensure respite is available to enable the mental health carer to have at least 3 full nights sleep per week including regular nights away from the caring home	9.8	1
<b>Medication Support</b> Strengthen the provision of support, information and training kits to effectively address home based medication programs	9.6	2
<b>After Hours Mental Health Service Support</b> Ensure mental health carers have ready access to emergency/crisis after hours support from mental health services especially to manage consumer challenging behaviour at night	9.4	=3
<b>Mental Health Service Support to Family Members</b> Ensure mental health services provide knowledge and professional support/education to all family members of the consumer about mental illness that the consumer is experiencing	9.4	=3
<b>Engagement by Professionals</b> Ensure that mental health professionals frequently consult and engage mental health carers in consumer assessment, service planning, discharge and case review decisions including the provision of case information.	9.2	4
<b>Transport Provision</b> Ensure transport is available for caring role tasks including attendance at	8.3	5

consumer medical or mental health appointments		
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<b>Average number of hours per week I provide care</b>	160.2
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**Victorian Stakeholders Focus Group**

<b>Common Items</b>	<b>Average Score</b>	<b>Strongest Agreement to Strongest Disagreement</b>
Partnerships between the Mental Health Sector and Other Carer Organisations	7.1	1
Carer and Consumer Responsibilities	4.3	2
Commonwealth/State Disability Programs Access	3.6	3
HACC Access	3.5	4
Effectiveness of Coordination Arrangements	3.4	=5
Policy Participation	3.4	=5
SAAP Access	2.8	6
TAFE/HIGHER Education access	2.7	=7
Carer Rights and Responsibilities	2.7	=7
Emotional and Social Support	2.5	=8
Inclusiveness of Professional Practice	2.5	=8
Psychiatric Facility Decisions	2.4	9
<b>Action Items</b>	<b>Average Score</b>	<b>Greatest Importance to Least Importance</b>
<p><b>Generic and Mental Health Specialist Carer Organisations</b> State and Commonwealth carer support funds should be allocated/distributed through both mental health specialists carer sensitive service providers and through generic carer organisations (providing that generic auspices preserves the focus and resource levels devoted to mental health carer support)</p>	9.3	1
<p><b>Challenging Behavior Support</b> Ensure mental health carers are provided with early intervention practical professional support (including problem solving skills) to address challenging behaviour of consumers</p>	8.7	2
<p><b>Carers of People with Anxiety Disorders</b> Victorian Carers of People with Anxiety Disorders should be eligible to receive publicly funded resources/services which are targeted for the support of carers of people with a mental illness. (This group of carers should be seen as legitimate members of the Victorian carer community in relation to government and non-Government mental health policy program decision making. Moreover carer service eligibility should be changed from that based on mental health diagnosis to consideration of the burden off care and the impact of disability upon the carer).</p>	8.6	=3
<p><b>National Consistency</b> Develop national consistency in legislation and service standards/practices for consumers and carers in the mental health field.</p>	8.6	=3
<p><b>Access to Public Counselling Services</b> Ensure that carers of people with mental illness have access to publicly funded face to face, one to one non-</p>	8.5	=4

Government counselling and related services (along the lines of services available to family members/carers of the primary client in programs such as support for victims of crime, sexual assault and people with AIDS)		
<b>Rural/Remote Carer Needs</b> Ensure the needs of rural/remote carers of people with Mental Illness are adequately recognised including appropriate funding of accessible services.	8.5	=4
<b>CCSP Coverage for Private System Carers</b> Extend the eligibility of Victorian Government Carer Crisis Support Program (CCSP) funds and services to cover consumers and their carers under private system mental health care.	8.3	5
<b>Duty of Care</b> The framework for applying professional duty of care in the mental health field should effectively address the role of carers as part of the treatment team including a focus on their best interests, their safety, their stress limits, their reasonable workload limits and the direct responsibility the mental health services system has towards carers as individual people. Professional staff training, case management/practice standards and service funding levels should be directed to ensuring that this framework is effectively implemented in service delivery	8.2	6

## The Victorian Service System for Carers of People with Mental Illness

### Primary funders

#### *Human Services:*

- Statewide mental health services budget \$387.73 million pa
- Targeted funding for mental health carer support \$ 5.79 million pa
  - *Mutual Support and Self Help*: \$1 million pa for non-Government organisations, and an emphasis on information, advocacy support and also carer support group facilitation. Funded groups include ARAFMI VIC, SFV, and Obsessive Compulsive Disorders Foundation.
  - *Carer Crisis Support Program*: \$3.1 million pa; provides individualised support to carers of consumers eligible to access public mental health services – purchases goods and services to promote the caring relationship.
  - *Planned Respite*: \$1 million pa, respite to mental health carers via provision of meaningful activities to the consumer eg at home, day activities, overnight and holiday camps, also some emergency respite is available. Allocation of support linked to the long term care plan.
  - *Mental Health Carers Support Workers Program*: \$ 0.3 million pa, funds workers located in Commonwealth funded Respite Care Centres to provide information, support and advocacy to mental health carers and facilitate their access to respite and other services.
  - *Koorie Mental Health Carers Support Program*: \$0.39 million pa, supports family and community members caring for a person with mental illness, includes strengthening family networks and service access.
- *Psychiatric Disability Support Services (PDSS)*: a CSDA program, it funds non-Government organisations for psychiatric disability support services with a focus upon consumer support allocated via an individual program plan. Carer engagement is encouraged. Education and community development are included in service strategies. Carers needs are often addressed through consumer respite and home based outreach assistance.
- *HACC*: This program funds a range of generalist services which mental health carers variably access. The HACC 'Service System Resourcing' sub category funds the Carers Association of Victoria for generic carer service coordination and planning.

#### *Commonwealth National Respite for Carers Program (NRCP):*

- Funding to the Carers Association of Victoria for a statewide Carers Resource Centre for generalist information, education and development services for all carers including those in the mental health field.
- Funding to Regional Respite Centres for funding of generalist carer services including information, referral, and service access including respite.

### Carers Service Initiatives

- *Carers Offering Peers Early Support (COPES)* - A program of direct support by carers for family members and friends of people with mental illness receiving services from

Maroondah Area Mental Health Service Adult Inpatient Unit and Murnong Community Mental Health Service in Outer Eastern Melbourne.

- *Bilingual Case Management Program* - A pilot initiative of the Victorian Transcultural Psychiatry Unit and the public mental health services in the Western Region of Melbourne. This program has addressed a range of carer matters, including cross generational factors, associated with mental health service delivery to NESB people with mental illness and their families.
- *Schizophrenia Fellowship Victoria (SFV)* - It delivers carer services on a statewide and metropolitan basis and in Hume, Gippsland, Barwon and Peninsula. Based on professional and peer support models, services include face to face counselling, telephone support (SFV HELPLINE), community education, library services, support group facilitation throughout the State, specialised support and information programs for partners, siblings and children of people with mental illness, on grief and loss, forensic issues and families who have experienced suicide. Family Education is based on two frameworks, 'The Journey of Hope' and 'The 14 Principles for coping with Schizophrenia'. Extensive consultation about carers/family members, mental health service providers and GPs experience in providing service to carers is currently being undertaken in the 'Maps to Care' Project.
- *ARAFMI VIC* - The organisation offers counselling, library, publications, telephone support, education and support group facilitation services to carers. It also provides mental health promotion/awareness services to the wider community regarding mental health carer issues. ARAFMI operates four open (non-Government) support groups and other closed groups (time limited/education specific). Service outlets are in Melbourne and Bendigo.
- *Regional Respite Services* - Those centres which contain DHS funded mental health access workers, generate a strong focus on mental health carers accessing NRCP, HACC based and similar generalist support services.
- *North East Alliance of the Mentally Ill (NEAMI)* - It has developed, in Melbourne's north east suburbs, a strong specialist capability for carer support with NESB communities using both group and individual support models based upon bilingual outreach.
- *Obsessive Compulsive and Anxiety Disorders Foundation* - Provides information, referral, telephone support and group support to carers of people with obsessive compulsive and anxiety disorders.
- *Anorexia and Bulimia Nervosa Foundation Association* - Provides information, referral, telephone support and group support to carers of people experiencing eating disorders.
- *Waiora Parents and Friends Support Group* - The group is an example of a range of voluntary based initiatives around the State offering carer advocacy and support.
- *Family Sensitive Training* - An extensive initiative funded by DHS and delivered by Bouverie Family Center which recently targeted all Victorian public mental health clinical staff and disability support workers. The training was aimed at building a strong family orientation in mental health service delivery practice. About one third of all Victorian staff eligible to participate in the program attended.

- *Quality Incentive Strategy* - Victorian public clinical services have implemented a consumer and carers service satisfaction measure. Services are rewarded for receiving a high rating on the measure.

### **Carer Policy and Planning Participation**

- *VICCAG* - is the Victorian ministerial consumer and carer advisory group.
- *Mental Health Ministerial Advisory Committee*: This group includes carer representation.
- The DHS Mental Health Branch meets bi-monthly with the Carers of People with Mental Illness Network (see below).
- These bodies provide good central level opportunities for mental health carer policy and planning participation. Carers are appointed to most reference groups dealing with major policy and service developments.
- *'In Partnership'* - This is the Victorian Policy guideline addressing carer participation and involvement in mental health service delivery. It specifies a comprehensive range of requirements for carer engagement in case management and other aspects of service provision.

### **Carer Service Coordination**

- *Carers of People with Mental Illness Network*- This involves participants from the mental health carer sector (Mutual Support and Self Help), generalist carer sector including the Carers Association of Victoria and mental health resource positions at regional/local level, carer support groups, Anorexia and Bulimia Association and Anxiety and O&CD Association. The Network has a strong advocacy and policy focus, liaises with government and shares information. A feature of the work of the network has been convening State conferences for carers, the 4<sup>th</sup> of which recently attracted 480 delegates from across the State of Victoria. The Victorian Department of Human Services regards the network as having a significant sector wide collaborative planning role in the development of improved supports and services for carers of people with mental illness.

Consultations held in Victoria also indicated the following preferred actions, which would practically assist agencies to strengthen the recognition of and support for carers of people with mental illness:

1. Greater links and advocacy at Commonwealth level to ensure people with a mental illness and their carers receive appropriate access to Commonwealth funded programs. Where target groups are broad the Commonwealth should develop monitoring systems to ensure that people with a mental illness and their carers are not discriminated against in their access to these services.
2. Considerations of where the needs of people with a mental illness conflict with their carers and how these can best be resolved. This should include an analysis/identification of priorities for carers. For example, is the priority increased services for the consumer or increased services for the carer.

3. Identification of where carer support should be focused and who should be providing it. It would seem that many carers need assistance in everyday activities (ie. at home in the community). It raises questions about the considerable focus on the role of clinical services, as opposed to disability support and home help services which can provide assistance to both the carer and the person with the mental illness in their own environment.
4. Better understanding of when and how carers should be engaged. This includes consideration of timing issues (ie. when is the best time to provide information) as well as terminology. People either need to know that Governments call them carers or Governments need to change their language (conceptualisation of carers) so that it matches what people call themselves (ie. parent, child, sibling, friend). A strategy or guidelines regarding use of the word 'carer' in the engagement of carers would be useful.
5. Competencies or guidelines for accreditation agencies regarding measuring carer participation against the standards.
6. Research on outcomes on consumer and carer wellbeing of providing carer support.
7. Ideas for better linking with General Practice Division and private psychiatrists. Carers often comment that when a person they care for is receiving treatment from a GP or private psychiatrist they lose access to case coordination and other services offered by the mental health service. How can GPs/private psychiatrists be encouraged to offer better services, refer appropriately etc – or how can our mental health services continue to provide this additional level of service even if not providing treatment?
8. Explore whether carers should have the right to assessment enshrined in legislation as is the case (or is being considered) in the United Kingdom.
9. Carers Association Australia and State Carers Associations to include carers of people with a mental illness as an integral part of whatever they do.

**Darwin Carers Focus Group**

<b>Common Items</b>	<b>Average Score</b>	<b>Strongest Agreement to Strongest Disagreement</b>
Carer and Consumer Partnerships	7.5	1
Action with Other Carers	5.2	2
Getting Essential Personal Information.	3.7	3
Information, Education and Training Resources.	3	4
Policy Decision Making.	2.2	5
Consulted By Professionals	2	=6
Rights and Responsibilities	2	=6
Backup Help.	1	7
Having a Break	0.4	=8
Emotional and Social Support	0.4	=8
<b>Action Items</b>	<b>Average Score</b>	<b>Greatest Importance to Least Importance</b>
Ensure that mental health case management frameworks/practice recognise the total role of carers and treat carers as equal partners in service provision, including carers having access to essential information they require to conduct the caring role	9	1
Ensure that mental health services exercise a responsibility to the consumer's carer and family members by providing counselling, debriefing, education skills training and other practical assistance to the carer and family members	8.2	2
Governments should recognise and take action to address the additional financial burdens of effectively caring for a person with mental illness (including the provision of material support for carers from mental health services)	8.1	3
Ensure public guardianship, advocacy and trustee services provide financial security to the consumer when carers become too old	7.8	4

to effectively provide care		
Ensure respite services are available to give carers a break including alternative care resources being in place for carers to take effective holidays with or without the consumer	7.7	5
Ensure that generalist HACC, disability and other generalist community services provide day to day personal back up for carers of people with mental illness.	7.4	6
<b>Average number of hours per week I provide care</b>	40.7	

**Darwin Stakeholders Focus Group**

<b>Common Items</b>	<b>Average Score</b>	<b>Strongest Agreement to Strongest Disagreement</b>
Carer and Consumer Relationships	8.5	1
SAAP Access	7.6	2
Emotional and Social Support	6.2	3
Partnerships between the Mental Health Sector and Other Carer Organisations	6	=4
Inclusiveness of Professional Practice	6	=4
Policy Participation	5	5
Psychiatric Facility Decisions	4.7	=6
Carer Rights and Responsibilities	4.7	=6
Effectiveness of Co-ordination Arrangements	4	7
HACC Access	2.5	8
Commonwealth/State Disability Programs Access	2.2	9
TAFE/HIGHER Education access	0.2	10
<b>Action Items</b>	<b>Average Score</b>	<b>Greatest Importance to Least Importance</b>
Ensure effective carer participation in the in service training of mental health professionals so that carer needs are addressed in mental health professional practice and service delivery	9	=1
Ensure that TAFE/Higher Education pre-service professional training/education for mental health professionals (including doctors) addresses the needs of carers.	9	=1
Ensure that resources and budgets of mental health community teams/services are sufficient to support professional practice and service delivery for carer needs at the standards required by Territory legislation and the NMHS.	9	=1
Recognise and support with	7.6	2

adequate and secure budget provision and policy development the skills expertise and contributions of mental health specific carer organisations.		
Ensure that mental health service delivery is progressively audited and monitored to guarantee that the NMHS and the requirements of Territory legislation are being effectively implemented in practice	7	3

## **Aboriginal Mental Health Carer Issues for Darwin and the Top End**

- Respite for local communities and their carers is not available.
- There is no halfway house service between in patient care and local community discharge.
- Carers/families and people with mental illness do not trust the mainstream mental health services, are not comfortable with them, experience an increased sense of shame when they contact them and are reluctant to access them. These responses are often intensified for people from remote communities.
- Mainstream mental health and other generalist services misunderstand the nature of mental illness for aboriginal communities, and do not recognise that they create cultural barriers to service access and are insensitive to different cultural values.
- Aboriginal Communities are reluctant to give information to mental health workers especially non-indigenous workers.
- The project must speak with carers in local communities and Aboriginal mental health workers need time to assist the project to get the right picture and evidence – this will improve quality of findings, and should proceed over stages.
- Aboriginal mental health workers is a new program which has come from service reforms, at this point there are only a small number of positions located across the Territory.
- Accommodation is needed for families when they come to town to be with the person with mental illness.
- Overcrowding of accommodation in local communities does not give space for healing.
- Local mental health workers are under much stress and workloads (inpatient admissions to Darwin came from 25 diverse local communities in 1999).
- The bottom line for carer support is to have Aboriginal mental health workers based in local communities plus respite services at regional/district level.
- Many admissions to Darwin inpatient could have been avoided if a local worker had been available to talk with the person and the family in their own community and thereby prevent the journey to town.
- Make available mental health promotion/prevention resources at the local community level so that carers get information /knowledge at an early stage to prevent or reduce the likelihood of mental illness within families.
- Depending on circumstances, resources for carers in local communities should be allocated to the community as a whole rather than as payments or resources to individuals.
- It is important to recognize existing strengths of local communities in caring for people with a mental illness.

- In Aboriginal communities/families a network of carers work for the support of a person with mental illness – there is not just *one* carer.
- This project must work with the RANZCP ATSI Mental Health committee to work towards getting Aboriginal mental health workers and other resources to local communities.
- There is a need to improve ways of communicating with local communities about their mental health needs.
- More understanding is needed by mental health services of how local communities understand in a cultural sense, the causes of mental illness so that effective support for the person with mental illness and carers can be provided.

## **The Northern Territory Service System for Carers of People with Mental Illness**

### **Primary funders**

#### *Territory Health Services:*

- Territory wide public mental health services budget \$13.5 million pa.
- Targeted mental health non-Government organisations funding of \$56,000 to ARAFMI NT (additional funding to expand the agency's Central Australian operations is being considered).
- *Mental Health Association of Central Australia:* some of this allocation goes towards carer support.
- Aboriginal mental health workers are employed by Territory Health Services and in partnership, by several Aboriginal community organisations. These workers have a significant carer facilitation roles in many Aboriginal local communities and in episodes of inpatient admission and discharge. This program initiative is only a few years old and still developing a best practice model of service delivery.
- HACC is funding a range of generalist support services which some mental health carers have been able to access.

#### *Commonwealth National Respite for Carers Program:*

- Funds NT Carers for a Carers Resource Centre and respite services.

### **Carers Service Initiatives**

- *ARAFMI NT* - Is extremely active in mental health carer advocacy, education, information and referral. The Agency has a strong presence in the Top End and Darwin and a more limited capacity in Central Australia through a base in Alice Springs. ARAFMI has developed close working arrangements with Territory Health Services - Mental Health Services.
- *Carers Association of the Northern Territory* - Is working collaboratively with ARAFMI to develop mental health carer access to generalist services including respite. Both organisations report that in practice, respite options are not available for carers of people with mental illness.

### **Carer Policy and Planning Participation**

Opportunities exist within several forums for carer representation in the policy, planning and management of mental health services including:

- Ministerial Consumer Advisory Group on Mental Health.
- Local service delivery planning and management meeting representation.
- Discharge, Care and Treatment Planning and Case review.
- Territory Health – Mental Health Services (in conjunction with ARAFMI) These services are involving carers in Top End service planning and service development decisions.

Formal provisions relating to Carers rights are specified under the NT Mental Health and Related Services Act 1998, section 12, Principles Relating To Rights Of Carers.

### **Carer Service Coordination**

- No clearly designated structure exists for mental health carer service coordination in the NT.
- The work of NTCAG on mental health and other sectoral stakeholders currently working on linkage projects will advance many of the issues of carers of people with mental illness.

**Queensland Carers Focus Group**

<b>Common Items</b>	<b>Average Score</b>	<b>Strongest Agreement to Strongest Disagreement</b>
Carer and Consumer Partnerships	9	1
Information, Education and Training Resources.	5.4	2
Getting Essential Personal Information.	4.8	3
Emotional and Social Support	4.6	4
Consulted By Professionals	4.4	5
Rights and Responsibilities	3.1	6
Having a Break.	2.7	7
Policy Decision Making.	2.6	8
Action with Other Carers	2.2	9
Backup Help.	0.7	10
<b>Action Items</b>	<b>Average Score</b>	<b>Greatest Importance to Least Importance</b>
Ensure that the <i>National Standards for Mental Health Services</i> especially those dealing with carers be fully implemented in all jurisdictions	9.5	1
Ensure carer access to adequate and flexible respite care including community based options	9.2	2
Ensure that carers are fully engaged and are equal partners in the mental health team including those functions dealing with the consumer that address assessment, diagnosis, service planning, care and treatment and discharge planning	9.2	3
Mental health service system confidentiality guidelines should ensure that carers have access to consumer case information in order that carers can effectively perform their caring roles	9.1	4
Carers need non-Government access on a 24 hour basis to mental health counselling and crisis debriefing services.	9	5
Strengthen 24 hours	8.5	6

emergency and early intervention mental health services for the consumer including mobile services and ensure these services effectively engage the carer.		
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<b>Average number of hours per week I provide care</b>	164
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**Queensland Stakeholders Focus Group**

<b>Common Items</b>	<b>Average Score</b>	<b>Strongest Agreement to Strongest Disagreement</b>
Partnerships between the Mental Health Sector and Other Carer Organisations	6	1
Carer and Consumer Relationships	4.7	2
Emotional and Social Support	3.3	3
Effectiveness of Co-ordination Arrangements	3	=4
Carer Rights and Responsibilities	3	=4
SAAP Access	2.8	5
Inclusiveness of Professional Practice	2.7	6
Commonwealth/State Disability Programs Access	2.5	7
HACC Access	2.4	8
Policy Participation	2.1	=9
TAFE/HIGHER Education access	2.1	=9
Psychiatric Facility Decisions	2.1	=9
<b>Action Items</b>	<b>Average Score</b>	<b>Greatest Importance to Least Importance</b>
The <i>National Standards for Mental Health Services</i> should be effectively implemented in all States and Territories by allocating adequate resources to enable the practice levels set by these standards to be achieved (including those matters concerning carer support.)	9.7	1
The recent recognition given by Government to carers of people with mental illness should be backed up by adequate funding and resources.	9.3	2
The development of the Queensland Disability Plan including the psychiatric disability service sections must address the role of carers.	9	=3
Rural and remote carers of people with mental illness should have the same level	9	=3

of service access to that available in urban locations.		
The <i>National Mental Health Plan</i> and the Queensland Health including those items dealing with carer support should be fully implemented	8.7	4
Government responsibilities dealing with service coordination arrangements for the support of carers of people with mental illness should be made clearly visible and strengthened.	7.6	5

## **The Queensland Service System for Carers of People with Mental Illness**

### **Primary funders**

#### *Queensland Health:*

- Statewide public mental health services budget \$ NA pa
- HACC - respite funding and personal support funding to generalist agencies involving variable service access by mental health carers. HACC also funds the Queensland Council of Carers Community Development Program.
- Queensland Health provides funding to a range of non-Government organisations targeting the needs of people with mental illness and/or their carers. Funding is provided to ARAFMI Brisbane, Schizophrenia Fellowship of South Queensland, Schizophrenia Fellowship of North Queensland to provide services to carers (Budget \$532,165). Other services such as the Eating Disorders Association Queensland, Post Natal Disorders Support Groups, Ethnic Mental Health Program and Croatian Mental Health Program have components of their services which target carers (Budget approximately \$ 190,080).

#### *Disability Services Queensland:*

- *Project 300:* A targeted psychiatric disability personalised community support program with an exclusive focus on transferring consumers from inpatient to community settings. The program has supported some home and equivalent based carers.
- *Adult and Family Flexible Lifestyle:* packages for high needs people with disability. The program's clientele includes a small proportion who are psychiatric disability consumers and carers.
- Funds ARAFMI for mental health education with disability support workers.
- DSQ is developing a Queensland strategic planning framework for Psychiatric Disability services and support including extensive consultation at local levels across the State.

#### *Commonwealth National Respite for Carers Program:*

- *Queensland Carer Resource Centre* within the Queensland Council of Carers (QCC): Provision of general advice, information and referral for all carers including those caring for mental health consumers.
- Regional Carer Respite Centres including (6) operated by the Queensland Council of Carers and (7) by Blue Care - A network of respite care contact points for carer information and referral and provision of respite services.

#### *Family Services Queensland*

- It funds components of QCC's Respite Carers Centres.

## **Carers Service Initiatives**

- *Jerendine* - a Queensland Health and Disability Services Queensland jointly funded mental health respite care family support program auspiced by ARAFMI Brisbane.
- *Other ARAFMI Brisbane Services* include mental health carers support group facilitation on a Statewide basis, development and delivery of a variety of carer education and information packages, a 24 hour telephone support service for carers and non-Government carers information referral and advice activities.
- *South East Queensland Schizophrenia Fellowship* - It offers carer information, advice, referral and advocacy services, facilitation of carers support groups, carer education with activities outreaching into South East Queensland.
- *North Queensland Schizophrenia Fellowship* - The organisation's 'Help for Rural Care Givers of the Mentally Ill' is a rural access, support and education/information outreach program for mental health carers extending through Townsville, Mossman, MT Isa, Longreach and Mackay and covering 29 remote localities.
- *Queensland Council of Carers (QCC)* - operates a community development program in 7 locations across Queensland to build community supports and enhance service access for all carers including carers of people with mental illness. QCC also provides mental health carers advice information and referral services as part of its overall carer responsibilities.
- *Brisbane North HACC Region* - The region is commencing a pilot initiative to increase mental health consumer and carers access to HACC services based on the findings of the recent Brisbane North mental health HACC study.

## **Carer Policy and Planning Participation**

*The Queensland Mental Health Consumer and Carer Advisory Group (QCAG)* - with reporting lines to the Queensland Health Minister and reflecting a 60/40 representation of mental health consumers and carers is providing central level planning and policy advice concerning policy and legislative development, implementation and evaluation. Carers policy and planning participation at local service levels is extremely variable across the State but is largely through local consumer and carer advisory groups (there are over 35 across the State). However, these mechanisms are subject to a range of local influences impacting on each service including staff continuity and staff orientation.

## **Carer Service Coordination**

There is no mental health sector wide body addressing service coordination and planning for mental health carers. QCC Respite Carers Centres have responsibilities for promoting coordination of generic carers services at the local level. Queensland Health and Disability Services Queensland have recently funded the Queensland Alliance of Mental Illness and Psychiatric Disability Groups Inc which was initially formed in 1995. This organisation is a peak body which represents the interests of non-Government organisations, consumer and carer groups and aims to promote the development of the same. It is intended to have a broad advocacy, policy development, partnership and coordination role in the Queensland mental health and psychiatric disability fields.

**South Australian Carers Focus Group**

<b>Common Items</b>	<b>Average Score</b>	<b>Strongest Agreement to Strongest Disagreement</b>
Action with Other Carers	7.3	=1
Carer and Consumer Partnerships	7.3	=1
Getting Essential Personal Information.	5.3	2
Having a Break	3.1	3
Emotional and Social Support	2.1	=4
Consulted By Professionals	2.1	=4
Information, Education and Training Resources.	2	5
Policy Decision Making.	1.7	6
Backup Help.	1.6	7
Rights and Responsibilities	0.8	8
<b>Action Items</b>	<b>Average Score</b>	<b>Greatest Importance to Least Importance</b>
Ensure an adequately resourced and trained public and non-Government mental health service systems for consumers in order to reduce the inappropriate workloads on carers and enable family carers to make the most effective caring contribution.	9.1	1
Ensure that early mental health service intervention/diagnosis occurs to increase the effectiveness of services to the consumer and in turn support the carer and reduce unnecessary pressures upon them.	8.8	2
Ensure mental health professionals give due recognition to the role of carers as partners in care	8.7	3
Ensure that: (a) the costs/responsibilities of public and non-Government mental health services for consumer and carer support are adequately defined and (b) include carers and consumers in the process of defining these	8.3	=4

costs and responsibilities.		
Ensure children as carers can still be children while being effectively supported in their caring roles including being provided with clear and early information about Mental Illness, personal counselling, support in practical living tasks, support in the school setting, support in dealing with stigma and social/recreational opportunities outside the family	8.3	=4
Ensure mental health services effectively respond to consumers/carers in all stages of service delivery and especially in relation to the non-Government maintenance management services	8.1	5
Ensure that carers have ready access to adequate respite care and personal backup services	8.1	5
Ensure that carers have ready access to relevant and targeted information including information in improved and simplified presentation formats	7.1	=6
Ensure that carers have access to counselling, social and emotional support services when needed	7.1	=6
Ensure effective education of all government agencies and services about mental illness to prevent these organisations from expressing stigma and insensitivity to people with mental illness and their carers when they transact business and provide services.	6.6	7
<b>Average number of hours per week I provide care</b>	98.1	

**South Australian Stakeholders Focus Group**

<b>Common Items</b>	<b>Average Score</b>	<b>Strongest Agreement to Strongest Disagreement</b>
Partnerships between the Mental Health Sector and Other Carer Organisations	6.4	1
Carer and Consumer Relationships	4.8	2
Emotional and Social Support	3.4	3
TAFE/HIGHER Education access	3.3	4
Inclusiveness of Professional Practice	2.5	5
HACC Access	2.4	6
Effectiveness of Co-ordination Arrangements	2.3	=7
SAAP Access	2.3	=7
Policy Participation	2.3	=7
Psychiatric Facility Decisions	2.1	8
Commonwealth/State Disability Programs Access	1.7	=9
Carer Rights and Responsibilities	1.7	=9
<b>Action Items</b>	<b>Average Score</b>	<b>Greatest Importance to Least Importance</b>
Develop a State Government Mental Health Carers Policy which is clearly communicated to the mental health sector and community in general and implemented as a best practice guide in clinical service activity and addressed in funding service agreements	8.8	1
Develop clear national criteria which equitably and adequately resource non-Government organisations for variable carer support services including services which give carers a break	8.4	2
Ensure that funding criteria/budget allocation for mental health clinical services (a) acknowledges that these services must recognise and support the roles of families and carers and (b) provides adequate professional training and professional support to staff to effectively meet the needs of carers and families.	8.1	3
Resource and implement mental health service models which recognise and support the roles of families and children who are supporting carers of people with mental illness	7.8	=4
Ensure State/Territory and	7.8	=4

Commonwealth governments transparently report annual funding allocations and future planning projections for mental health services at all levels in the service system		
Implement an independent national survey/audit of State/Territory adherence to the carer focused <i>National Standards for Mental Health Services</i> with results being made public	7	5

## **The South Australian Service System for Carers of People with Mental Illness**

### **Primary funders**

#### *South Australia Human Services:*

- Statewide public mental health services budget \$113 million pa.
- \$2 million pa allocated to mental health non-Government services for consumers and carers support.
- Non-Government organisations receiving funding include SA ARAFMI (the only exclusive carer organisation funded), Schizophrenia Fellowship SA (SF SA), Mood Disorders Society (MDS), Panic Anxiety Disorders Association (PADA) and Recreational Links. Funding is directed towards information, education, self help, referral and advocacy including support group development.
- HACC funds the Carers Association of SA for a variety of generalist carer support functions. HACC also funds generalist carer support group in most HACC regions.

#### *Commonwealth National Respite for Carers Program:*

- It funds the SA Carer Resource Centre within the Carers Association of SA for provision of advice, information and referral for all carers including those caring for people with mental illness.
- It funds Regional Carer Respite Centres. A network of respite care contact points for carer information and referral and provision of respite services for all carers including mental health carers.

### **Carers Service Initiatives**

- *South Australian Mental Health Services (SAMHS)* - SAHMS has developed a carers policy to guide and facilitate statewide and local mental health services on issues of carer engagement. Some local services including North West Metropolitan are offering education and support services to carers.
- *Schizophrenia Fellowship SA* - It provides an education development program (this includes trained carers talking to mental health and generalist health and welfare staff, schools and community groups about mental illness), telephone and face to face counselling for carers, five metropolitan support groups for carers, liaison/and back up for a number of rural carers support groups, carer library services, carer orientated mental health promotion displays in public places/public gatherings and some carer advocacy.
- *ARAFMI SA* - It conducts several education, information, referral and advocacy services for carers. including support groups and is active in conjunction with the Carers Association of SA on policy and service advocacy issues.
- *MDS SA* - It provides some education and information to carers and support group activity.

- *PADA SA* - It offers informal and formal education, referral service and self-help group activity.
- *Carers Respite Centres* - In addition to core responsibilities for generalist information, referral and education provision and respite access for all carers, some centres including the North and West Metropolitan Centre have developed a more targeted approach to the delivery of these services for carers of people with mental illness.
- *Carers Association of SA* - has convened two statewide carers of people with mental illness conferences (1996, 1999). Carers SA has been active in the development and advocacy surrounding SAMHS'S carer policy and has also produced a detailed implementation plan for the introduction of the policy into local services. These activities have occurred via the Mental Health Carers Task Group, a mental health sector wide group auspiced by Carers SA.
- *Rural and Remote Mental Health Unit of SAMHS* - carer education and support outreach facilitated by the rural and remote unit is functioning well in some rural/remote localities. This includes the Mid North, where carers are involved in the 'Building the Links for Better Mental Health' project, which is piloting continuity of care between home, the community and the hospital".

### **Carer Policy and Planning Participation**

- *SA CAG* - members are ministerially appointed and include three carer representatives. Through SA CAG, carer participation in some significant central level policy initiatives has occurred. Carers have been involved on the high level SAMHS Strategic Implementation Committee for statewide service planning and redevelopment. Carers have had advisory and consultative roles in the SA Review of Mental Health (which is drawing to a conclusion). The Statewide Division of SA Human Services and SAMHS are reviewing implementation requirements to adequately operationalise within local mental health services, the SA Mental Health Carers Policy.

### **Carer Service Coordination**

Carers Association of SA and the Mental Health Carers Task Group it auspices, represent the prevailing mechanism for mental health sector wide planning and co-ordination for carers of people with mental illness. The South Australian Council of Social Service is engaged in a project to address future peak structures for Mental Health in SA.

**Tasmanian Carers Focus Group**

<b>Common Items</b>	<b>Average Score</b>	<b>Strongest Agreement to Strongest Disagreement</b>
Carer and Consumer Partnerships	6.6	1
Action with Other Carers	6.1	2
Policy Decision Making.	2.7	3
Getting Essential Personal Information.	2.2	4
Consulted By Professionals	2.1	5
Information, Education and Training Resources.	1.8	6
Emotional and Social Support	1.3	7
Backup Help.	1.2	8
Rights and Responsibilities	0.6	9
Having a Break	0.3	10
<b>Action Items</b>	<b>Average Score</b>	<b>Greatest Importance to Least Importance</b>
Ensure carers have access to full knowledge of the range of mental health and other services which can assist their caring role	8.7	1
Ensure full eligibility and service accessibility carers for counselling, emotional and social support in response to the pressures of the caring role including challenging behaviour	8.5	2
Document clearly and put into practice the rights of carers, which include their influence on mental health professional decisions including assessment and discharge	8.4	3
Ensure effective pre service and in service training on mental illness for GP's, mental health professionals and community support agency workers in the context of the <i>National Standards for Mental Health Services</i>	8.1	=4
(a) Ensure the carers pension replaces the loss of employment income for carers who are forced to withdraw from or reduce their workforce	8.1	=4

engagement, and (b) covers the full cost of the caring role		
Ensure the availability of accessible community information and education for carers about mental illness.	7.8	=5
Increase the supply of in- home support and respite care for carers and ensure these services are delivered by workers who are adequately skilled and knowledgeable about mental health issues.	7.8	=5
Adequately resource inpatient capacities to prevent premature discharge and readmission of consumers and the burdens this places on carers as well as preventing the additional costs incurred through this cycle.	7.8	=5
Ensure carers have ready access to (a) professionals treating the persons with mental illness, and (b) other services which can assist their caring role.	7.6	6
Implement a program of mental health education for the wider family members and community to reduce stigma, increase tolerance and consequently help the carers role.	7.1	7
<b>Average number of hours per week I provide care</b>	168	

**Tasmanian Stakeholders Focus Group**

<b>Common Items</b>	<b>Average Score</b>	<b>Strongest Agreement to Strongest Disagreement</b>
Partnerships between the Mental Health Sector and Other Carer Organisations	4.75	1
Effectiveness of Co-ordination Arrangements	3.4	2
Carer and Consumer Relationships	3.2	3
Inclusiveness of Professional Practice	2.8	4
Commonwealth/State Disability Programs Access	2.6	=5
Emotional and Social Support	2.6	=5
Carer Rights and Responsibilities	2.5	6
SAAP Access	2.3	7
TAFE/HIGHER Education access	2.2	8
HACC Access	2.0	9
Policy Participation	1.6	=10
Psychiatric Facility Decisions	1.6	=10
<b>Action Items</b>	<b>Average Score</b>	<b>Greatest Importance to Least Importance</b>
Ensure mental health service assessment/diagnosis and care planning is comprehensive and addresses client medical, psychological and social needs as well as the interacting pattern of needs occurring between the person with mental illness and carer and also directly includes the carer in this process.	9.3	1
Ensure timely, affordable, flexible and sufficient planned and crisis respite is available to meet the needs of both the person with mental illness and the carer without the requirement for continual reassessment of the person with mental illness or the carer as each new occasion for respite arises.	9	2

Ensure the needs and support arrangements for carers who are young people or children are recognized and addressed including adequate respite care.	8.1	
Ensure that: (a) dual and multiple diagnoses clients and their carers are not the subject of responsibility shifting between service/agencies; (b) services are coordinated to enable these carers and consumers are supported in the community and to prevent dual and multiple diagnosis consumers from inappropriately using and being over represented in inpatient services	8.1	3
Mental health services must review the demographic profile of consumers/carers to ensure planned response to meet the circumstances of aging carers who cannot in the future sustain a household/community caring arrangement for the consumer.	8	4
Ensure effective support for carers of persons with mental illness to avoid the caring pressures and burnout from eroding family relationships and family stability, resulting in many persons with mental illness being left without family care givers	7.6	5
Ensure that agency/service accreditation against <i>National Standards for Mental Health Services</i> is accompanied with effective resourcing	7.5	6

## **The Tasmanian Service System for Carers of People with Mental Illness**

### **Primary funders**

#### *Health and Human Services:*

- Statewide public mental health services budget \$31.9 million pa
- Mental Health Services community funding to non-Government organisations for carer support is \$10,000 pa approx. This involves ARAFMI North \$5000, ARAFMI South \$1750, and other allocations to organisations with a carer service or development component in their operations (eg TASCAG, and the Tasmanian Mental Health Association).
- HACC funds the Tasmanian Carers Association

#### *Commonwealth National Respite for Carers Program:*

- It funds the Tasmanian Carers Association for the operation of the State Carer Resource Centre which offers a range of educational, information and referral services to all carer categories in Tasmania including the mental health field.
- It funds several carer respite centres for respite access for all carers.

### **Carers Service Initiatives**

- *ARAFMI* - Information referral, education and support services are conducted by the two Tasmanian ARAFMI groups within the limits of current resourcing. ARAFMI receives considerable carer referrals from Mental Health Services Tasmania.
- Seven respite beds are available in the *Mental Health Services Tasmania* system.
- Both the *Hobart Clinic* and the *Peacock Centre* have developed a mental health practice approach which is orientated to the effective engagement of carers in service delivery decisions.
- The Red Cross *MATES* program is responding to mental health carers via the provision of a range of support initiatives.
- There is limited access by mental health carers to generalist support services.

### **Carer Policy and Planning Participation**

- *Mental Health Services Tasmania* has developed guidelines for consumer and carer participation in mental health services.
- *TASCAG* has consumer representatives. *TASCAG* is formed through ministerial appointment and has developed an operational handbook for its work. *TASCAG* representatives sit on the Mental Health Services Tasmania State management group.

- Through TASCAG and other channels carers have been engaged in significant projects including the redevelopment of Royal Derwent Hospital.
- The north and south sections of Mental Health Services Tasmania also have carer and consumer representatives on their internal management groups.
- Mental Health Services Tasmania's Strategic Plan for 1999-2002 contains goal statements which include reducing the impact of mental illness on carers and promoting carer involvement in service planning and delivery.

### **Carer Service Coordination**

- Although active mental health sector wide coordination structures for the development of carer support services are not developed in Tasmania, the Carers Association in Tasmania is exercising significant responsibility in this field.

### Kalgoorlie Goldfields Carers Focus Group

Common Items	Average Score	Strongest Agreement to Strongest Disagreement
Carer and Consumer Partnerships	8.8	1
Getting Essential Personal Information.	6.6	2
Support for Carers in Kalgoorlie/Goldfields	6	3
Consulted By Professionals	5.7	4
Action with Other Carers	5.2	5
Emotional and Social Support	5.1	6
Rights and Responsibilities	2.2	7
Information, Education and Training Resources.	2	8
Backup Help.	1	9
Having a Break	0.7	10
Policy Decision Making.	0.1	11
Action Items	Average Score	Greatest Importance to Least Importance
Information and training services/resources including financial management must be available to carers so that carers have the knowledge/skills to effectively care.	9.1	=1
Ensure that mental health and other services liaise and work closely together to maximise benefits to carers of people with mental illness in non-metropolitan areas such as is occurring in Kalgoorlie/Boulder.	9.1	=1
Mental health professional services should provide emotional and social support services to carers (eg. counselling, debriefing etc).	8.8	2
Ensure a carer's support group is set up in Kalgoorlie/Boulder with professional backing and assistance.	8.7	3
Ensure that respite services are provided for carers of people with mental illness in Kalgoorlie/Boulder, which addresses the specialist needs of dealing with mental illness.	8.3	4
Maintain and increase media advertising and general awareness/education of mental illness: (a) in the community at large (b) and for those who need advice about who to contacts to seek help	8.2	5
Ensure that the WA Health Department and Mental Health	8.1	6

Division implements and monitors practice guidelines for professionals so they develop positive relationships with carers, give carers full/early knowledge of what is wrong with the consumer and prepare treatment plans which effectively involve carers		
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<b>Average number of hours per week I provide care</b>	93
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### Kalgoorlie Goldfields Stakeholders Focus Group

<b>Common Items</b>	<b>Average Score</b>	<b>Strongest Agreement to Strongest Disagreement</b>
Partnerships between the Mental Health Sector and Other Carer Organisations	6.3	1
Carer and Consumer Relationships	5.1	2
Emotional and Social Support	4.6	=3
Inclusiveness of Professional Practice	4.6	=3
Effectiveness of Co-ordination Arrangements	4.4	4
SAAP Access	4.2	5
TAFE/HIGHER Education access	4	=6
Psychiatric Facility Decisions	4	=6
Policy Participation	3.6	=7
Remote Service funding	3.6	=7
Commonwealth/State Disability Programs Access	3.4	8
HACC Access	3	=9
Carer Rights and Responsibilities	3	=9
<b>Action Items</b>	<b>Average Score</b>	<b>Greatest Importance to Least Importance</b>
Ensure far better cross service information channels amongst service providers regarding service coverage and eligibility.	9	1
Prepare and target educational/information for mental health carers/consumers dealing with their entitlements including financial and social support back up etc.	8.3	=2
Strengthen home based respite provision for mental health carers and consumers.	8.3	=2
Develop a pilot project for rural/remote communities to enhance service information and service access for mental health carers with an emphasis on seeking support at an early intervention/diagnosis and non-Government basis.	8.2	3

Extend the range of professional/service providers who are entitled to assess mental health carers and consumers for respite care eg Silver Chain, counselling and other support services.	7.8	4
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**Perth Carers Focus Group**

<b>Common Items</b>	<b>Average Score</b>	<b>Strongest Agreement to Strongest Disagreement</b>
Carer and Consumer Partnerships	9.6	1
Action with Other Carers	8	2
Information, Education and Training Resources.	3	3
Emotional and Social Support	2.5	4
Backup Help.	2.3	5
Getting Essential Personal Information.	2.2	6
Policy Decision Making.	1.8	7
Having a Break	1.7	8
Rights and Responsibilities	0.8	9
Consulted By Professionals	0.7	10
<b>Action Items</b>	<b>Average Score</b>	<b>Greatest Importance to Least Importance</b>
Develop and implement in practice for the mental health system, (both public and private), professional case management standards which treat carers as equal partners while recognising the confidentiality rights of the consumer and the carer and take account of carers/families roles in assessment, treatment/care planning, home based medication and case review	9.2	=1
Employment options including education to inform employees about mental illness must be available to mental health consumers and by doing this reduce income support problems, improve consumers self respect, enable consumer engagement outside the home during the day and thereby reduce the load on carers	9.2	=1
In order to reduce pressures on carers, reform is needed for allowances and income security arrangements for both mental health consumers and carers to: (a) ensure carer allowances address real family expenses if the carer is not working, and (b) provides free medication to consumers in hostels and the community extend cut off limits for allowances to give greater incentive for consumers to become employed.	9.2	=1
Carers must have the right to receive	8.7	2

from mental health professional services (counselling, debriefing, financial and social support) immediately as they want it in order to that they may effectively perform their caring roles.		
Mental health carers should have priority access to general community support including transport, accommodation and home care back up and this access should include services provided/funded by HACC SAAP and Commonwealth/State Disability agreements.	8.6	=3
Mental health service system standards and their implementation must encourage full access for NESB carers including the requirement of being fully sensitive to the carers cultural background.	8.6	=3
Consumers with anxiety/eating disorders must be formally recognised by the public mental health system and by private mental health providers to ensure: (a) adequate service support access for carers of these consumers (b) funding for mutual support and self help for these carers (c) improvement in the competence of professionals to address these issues.	8.4	=4
The mental health system must provide adequate training/knowledge to carers so they can fully: (a) understand the diagnosis of the consumer (b) support home based medication (c) encourage consumer compliance with the treatment plan.	8.4	=4
The WA mental health service system must involve carers in practical service planning and service development decisions, including giving carers support to do this.	8.1	5
Utilise a paid family advocate to prevent children becoming carers or support them in their caring role and to avoid unnecessary separation of children from parents.	8	6
Mental health professionals must not blame carers for the needs/difficulties of consumers	7.7	7

<b>Average hours/week I provide care</b>	<b>77</b>
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**Perth Stakeholders Focus Group**

<b>Common Items</b>	<b>Average Score</b>	<b>Strongest Agreement to Strongest Disagreement</b>
Partnerships between the Mental Health Sector and Other Carer Organisations	6.3	1
Emotional and Social Support	2.9	2
Effectiveness of Co-ordination Arrangements	2.7	3
Carer and Consumer Relationships	2.5	4
SAAP Access	2	5
Policy Participation	1.4	6
HACC Access	1	7
Commonwealth/State Disability Programs Access	0.9	=8
Carer Rights and Responsibilities	0.9	=8
TAFE/HIGHER Education access	0.6	=9
Inclusiveness of Professional Practice	0.6	=9
Psychiatric Facility Decisions	0.5	10
<b>Action Items</b>	<b>Average Score</b>	<b>Greatest Importance to Least Importance</b>
Implement of mental health practice standards for government and non-Government professional and other staff that, effectively involve carers in assessment, service delivery, discharge planning and case review and reconcile the needs of carers and consumers including confidentiality issues	9	=1
Western Australia and Commonwealth agencies must ensure adequate funding and service delivery arrangements for mental health carer support, information and advocacy services including delivery of these services at a local community level across the State	9	=1
Implement practical procedures for carer	8.8	=2

involvement in mental health service delivery including carer contact on patient admission and designated carer liaison officers in public agencies		
Service delivery in Western Australia must be sensitive and relevant to the cultural background of the mental health carer	8.8	=2
The Commonwealth and Western Australia State Government must be transparent and consistent in the allocation of funds including HACC, SAAP and Commonwealth State Disability Services monies to ensure the mental health sector and mental health carers get effective target access to services funded from these sources	8.7	=3
Mental health public and non-Government services should be adequately resourced to meet the necessary emotional and social support needs of the carer and/or carer's extended family/household unit	8.7	=3
Western Australia and Commonwealth mental health policy must in practice recognise the central role of carers in achieving service effectiveness and quality outcomes for all parties	8.4	4
Mental health professional services should: (a) extend their eligibility coverage to ensure essential clinical and/or advisory services are available for carers (b) ensure consumer treatment plans and other consumer service activity, including medication administration can be effectively supported by	8	5

carers		
The Commonwealth and the Western Australia Government should monitor and where necessary enhance consultative and planning procedures with TAFE, higher education and the associated professions to ensure mental health carer issues are reflected in clinical and support staff pre service and continuing education	7.7	6

## **The Western Australian Service System for Carers of People with Mental Illness**

### **Primary funders**

#### *WA Health Department:*

- Statewide public mental health services budget \$176.4 million pa
- Mental Health Division; community funding to non-Government organisations for carer support is \$0.463 million pa, including WA ARAFMI, SF WA, SF Albany, WACAG, WA Association of Mental Health and an allocation of \$5000 to contribute towards participation fees for mental health sector carers involved in planning and policy activities (ARAFMI WA is the fund holder for the sector).
- HACC: respite funding and personal support funding to generalist agencies, HACC partially funds Carers WA.
- CSDA: There is an allocation of some funds through WA Disability Services Commission to MHD for specific disability-support including funding for a support worker for SF Albany.

#### *WA Disability Services Commission (WADSC):*

- Funding of disability support services, accompanied by a system of local support coordinators. Psychiatric disability consumers and carers are eligible for level one assistance ie advocacy, information and referral (4% of WADSC clients are in the psychiatric disability category).

#### *Commonwealth National Respite for Carers Program:*

- It funds Carers WA for the State Carers Resource Centre for generic carers' services including information, referral and education. It funds Carer Respite Centres in 12 locations for generic services for carers including respite (Red Cross is the most frequent auspice agency).

### **Carers Service Initiatives**

- *ARAFMI WA* - It has recently established a co-located service with the Peel MHD Metal Health Service (Mandurah). ARAFMI WA services include family counselling and family support, respite, education, information and referral and advocacy and support groups.
- *SF WA* - It provides a range of carers services which are; a telephone information and support line (covering rural/country and metropolitan), individual and systematic advocacy (State and National), support groups, education and some recreation/social activities.
- *Centrecare, Goldfields (Kalgoorlie)* - It provides targeted mental health support service delivery with carer counselling and education services.

- *SF Albany*- It operates carer recreational support, a carer suite at Albany hospital and a disability support worker service with responsibilities for outreach which includes carers.
- *Goldfields Mental Health Community*- Focussed around the Goldfields Mental Health Action Group, this community reflects a good example of an active and growing local partnership between consumers, carers and government and non-Government mental health and generalist service providers.
- *Generalist Support*- this occurs mainly via regional NRCP respite centres and HACC services (Silver Chain is the main HACC home help provider). Access for mental health cares is extremely variable.

### **Carer Policy and Planning Participation**

- Policy - WA MHD has developed policy guidelines for consumer and carer participation in service planning, implementation and evaluation. Central level carer participation on policy and program issues is occurring in conjunction with the WA MHD directorate with carer representation drawn from several sources including WA CAG, WAAMH, ARAFMI and SFWA.

### **Carer Service Coordination**

- *WAAMH* - Is the peak mental health sector body in WA. It auspices a carers issues committee. The group includes representation from sector carers, ARAFMI, SF WA, WA CAG and Carers WA. It has conducted a sector forum on carers of people with mental illness and developed a carers position paper.
- *Carers Association WA*- It is active in partnership with WAAMH on policy, resource and information co-ordination for mental health carers including access of mental health carers to the generalist support system.
- WAAMH and Carers WA point to an uneven distribution of targeted assistance for mental health carers statewide, with a concentration of limited resources around the Perth.

## APPENDIX I

### Summary of AHMAC NMHWG Responses to Project Interview Questions

The following questions seek some background understanding of your agency's current program responses which relate to the role of carers of people with mental illness.

1. *If your agency directly provides or funds other organisations to provide services to support the role of carers of people with mental illness please outline these initiatives. In your response please distinguish between services for which carers of people with mental illness are the only carers eligible to receive assistance and services which target a wider group of carers including carers in the mental health field.*

Responses gathered by the project for this item have been included in the summaries of service system activities for each State/Territory.

2. *How much money does your agency allocate to mental health services and how much money pa does your agency allocate to the support of carers of people with mental illness?*

Agency Total Mental Health Budget \$ \_\_\_\_\_ pa.  
Agency Total Allocation to Mental Health Carer Support \$ \_\_\_\_\_ pa.

*If you would like to make clarifying comments about this expenditure please do so.*

Responses gathered by the project for this item have been included in the summaries of service system activities for each State/Territory.

3. *Please estimate the numbers of carers who may be involved in caring activities for the client populations of people with mental illness for which your agency has direct service responsibilities and/or service funding responsibilities.*

Estimates provided for: Northern Territory 3000 families, Western Australia 15000 people, Victoria; PRISM client information records show that about 10,000 registered public mental health clients were living with someone at the time of their data base entry, but this figure would underestimate the total Victorian mental health carer population

4. *Case management frameworks are generally regarded as important tools for ensuring appropriate quality and professional accountability in Mental Health service practices. Please give a brief outline of case management frameworks which apply to your agency's mental health responsibilities and whether the roles of carers are specified in these frameworks. (The Project is particularly interested in understanding the extent to which case management standards and practices are engaging carers in client service decisions about admission/assessment/diagnosis, care and treatment planning, non-Government service delivery, case review and discharge including service actions where the client is an involuntary participant.)*

Based on evidence gathered, the project believes that comprehensive jurisdiction wide public mental health case management frameworks are mandated to operate in Victoria, Queensland and the ACT. The project has not been able to assess the consistency of

operation and the effectiveness of carer engagement in case management in these three jurisdictions. During the realignment process under the South Australian Mental Health Services a 'clinical case management model' was adopted as the primary framework for adult mental health. Further investigation of this model is needed to understand its carer engagement dimensions and its degree of implementation within local mental health services. The 'Northern Territory Approved Procedures' under the Territory's new mental health legislation provide a strong foundation for jurisdiction wide case management sensitive to carers. Territory Health Services is conducting a professional development strategy for the implementation of the legislation.

5. *The Project is seeking to understand how and the extent to which the roles, rights and responsibilities of carers of people with mental illness are or should be codified in legislation and/or policy. This includes an understanding of the basis upon which a carer of a person with mental illness, should be provided with professional case information about the person they are caring for, in order that the carer can effectively perform his/her caring role. Please provide details of the extent to which your agency has codified the roles, rights and responsibilities of carers of people with mental illness or the extent to which your agency believes this should occur. Please address the issue of carer access to client case information in your response.*

The codification in legislation of carers rights and responsibilities remains limited across Australia. References to carers in legislation, predominantly focuses on the provision of consumer information to carers based on conditions for this to occur involving consumer consent and safeguards for the maintenance of confidentiality in information transfer. The project has drawn the tentative conclusion that currently the Northern Territory and Victorian mental health legislation are probably the best structured to facilitate practical resolutions to the enduring problem identified in focus group findings of carers not being provided with consumer information essential for the carriage of their carer roles. However more detailed analysis is required of both the legislative provisions in each jurisdiction and the their potential to yield case procedures 'on the ground' which are practically supportive of carers information needs, before additional commentary or recommendations on this topic can be reliably made.

6. *The family and household groups of which carers and the people they care for are members, are never really static in their composition but undergo change and evolution. These changes impact positively or negatively on the family's/household's caring capacities. Caring capacities are often reduced or placed under pressure by children growing up and leaving the family home, partners separating and people (either carers or those cared for) growing older. What solutions does your agency have to changes in family and household structures which result in a reduction of or increased pressure being placed on the capacities of carers of people with mental illness, especially in the case of carers and/or the people they care for growing older?*

The project has found little evidence of jurisdictions addressing, on a strategic system wide client population basis, the service planning implications arising from ageing carers, and their reducing capacities to offer care. Several Departments have given some helpful examples of local program and service activities which are responding to these needs on a mainly case specific basis. This includes the work of the fledgling ACT Older Persons Mental Health Service, the Collaborative Action program in South Australia involving case management which is combing tailored support and specialist nursing care to people with mental illness and their carers, aspects of Western Australia's Independent Living Program which is addressing support in ageing caring households and Victorian agencies funded through the Mutual Support and Self Help Program. The ACT is seeking

Commonwealth funding assistance to pursue a best practice project which will include coverage of support requirements in ageing caring households.

7. *Does the framework operating in your State/Territory jurisdiction which defines a mental health worker's professional duty of care obligations to a client, take account of the role, capacities and support arrangements applying to that client's carer in relation to such factors as ensuring reasonable care, and reviewing risks to the safety of the client or other parties. Please give some brief details of how duty of care is interpreted in your jurisdiction including reference to carers. If carers are not addressed in this interpretation please comment on whether they should be.*

The project has been unable to discover articulated and documented duty of care frameworks within jurisdictions which take account of carers of people with mental illness and their roles and capacities in the process of professional decision making which considers the 'reasonable' steps or criteria to be addressed in ensuring client care.

8. *Please describe opportunities applying in your jurisdiction for carers of people with mental illness to participate in mental health policy, service planning or service management decisions.*

Responses gathered by the project for this item have been included in the summaries of service system activities for each State/Territory.

9. *Please describe the extent to which the mental health service system in your State/Territory applies standardised or consistent tools and information/ education resources to assist carers provide support to people with mental illness who are participants in programs of home based administered medication.*

Standardised tools and information/education resources are not in place. There have been some differences expressed about the extent to which standardised or consistent tools and resources should be in place to assist carers to better support consumers regarding medication regimes. Several jurisdictions have emphasised that support for carers of people with mental illness in this area should arise from clinicians and other mental health staff in the process of day to day service delivery. Other responses have affirmed the value of having more service wide consistency in the development and application of tools and resources for this purpose. A point has also been made that terminology which describes consumers taking medications in home based setting and the support roles of carers in this process needs to be clear and consistent or standardised.

10. *What practical steps should be put in place 'on the ground' to ensure that those aspects of the National Standards for Mental Health Services which address the roles of carers can be translated into everyday mental health service delivery and professional practice? Has your agency been able to consider action in this regard?*

All jurisdictions require their directly provided 'Departmental' services and funded agencies to base service delivery upon the NMHS including those components of the standards addressing carer roles. Departments are progressively putting in place accreditation, training, and performance monitoring initiatives about *National Standards for Mental Health Services* implementation in preparation for funding eligibility requirements under Australian Health Care Agreements due to be fully operational by 2003. Progress in jurisdictions is limited on matters dealing the development and evaluation of service

delivery practice which embraces the roles of carers. Victoria has a consumer and carer satisfaction measure as part of its Mental Health Quality Incentive Strategy. Services are financially rewarded for a high rating on the measure. The ACT is funding a project to address readiness of non-Government services to embrace the standards. These are examples of jurisdiction initiatives which will help advance carer sensitive service delivery in line with the NMHS.

11. *Are the professional mental health services which your agency directly provides or funds, available to carers of people with mental illness, so they may receive counselling, debriefing, emergency material assistance, skills training or other support to meet social and emotional needs arising from their caring role? Please provide details.*

All jurisdictions report that carers are eligible to receive counselling and debriefing assistance from public mental health clinical staff who are providing professional services to the consumer that the carer is supporting. However responsibility for the provision of a full range of direct assistance to carers is predominantly regarded by Departments as the domain of non-Government agencies with funding allocated to non-Government agencies for these purposes.

12. *Please describe the extent to which carers of people with mental illness can access generic (ie non Mental Health specific services) which are funded through the Home and Community Care (HACC) Program, the Supported Accommodation Assistance (SAAP) Program and the Commonwealth/State Disability Program Agreement. Does your agency have protocols with these programs which assist carers of people with mental illness to access services funded from these sources?*

Departmental mental health managers generally believe that significant access barriers do not operate for carers seeking support from services funded by HACC, SAAP and the CSDA. One State department also seriously questioned the extent to which the NRCP is adequately targeting mental health carers for priority service access in the process of developing program guidelines and service agreements for local service providers. Most departmental representatives were of the view that strengthened liaison at intra or inter departmental levels between mental health branches and branches or units dealing with HACC, SAAP and the CSDA (or some of these programs) was warranted to better target mental health carers for access to these resources.

Project evidence suggests that State/Territory departmentally administered services under CSDA program arrangements are offering substantial support to mental health carers in Victoria and to a lesser extent in Queensland. Disability Services Queensland is currently developing a strategic planning framework for psychiatric disability. In other jurisdictions CSDA provision of psychiatric disability services as a proportion of total CSDA resources appears low.

The Brisbane North HACC region is currently piloting a mental health access initiative. Other references to the application of these programs for mental health carer support is found in the State/Territory service summaries.

## APPENDIX J

### Carers Focus Group Scores: State/Territory Score Comparisons and National Averages

Item	ACT	NSW	NT	QLD	SA	TAS	VIC	WA Perth	WA Gold Fields	National Average	Rank Order
The hours I give each week.	86	51.6	40.7	164	98.1	168	160.1	77	93.1	104.3	NA
Getting Essential Personal Information.	4.8	5	3.7	4.8	5.3	2.2	2.9	2.2	6.6	4.1	3
Having a Break.	1.6	0.3	0.4	2.7	3.1	0.3	7.3	1.7	0.7	2	8
Backup Help.	2	0.6	1	0.7	1.6	1.2	3.4	2.3	1	1.5	=9
Policy Decision Making.	2.7	3.4	2.2	2.6	1.7	2.7	3.8	1.8	0.1	2.3	7
Emotional and Social Support.	4.6	4.5	0.4	4.6	2.1	1.3	6	2.5	5.1	3.4	5
Action with Other Carers.	9.6	5.5	5.2	2.2	7.3	6.1	5.3	8	5.2	6	2
Consulted By Professionals.	0.3	3.3	2	4.4	2.1	2.1	2.7	0.7	5.7	2.6	6
Information, Education and Training Resources.	3.8	7.1	3	5.4	2	1.8	3.6	3	2	3.5	4
Rights and Responsibilities.	0.1	2.8	2	3.1	0.8	0.6	1.6	0.8	2.2	1.5	=9
Carer – Consumer Partnerships.	6.4	7.7	7.5	9	7.3	6.6	9.9	9.6	8.8	8	1

## APPENDIX K

### Stakeholders Focus Group Scores: State/Territory Score Comparisons and National Averages

Item	ACT	NSW	NT	QLD	SA	TAS	VIC	WA Perth	WA Gold Fields	National Average	Rank Order
Effectiveness of Co-ordination Arrangements	3.1	2.1	4	3	2.3	3.4	3.4	2.7	4.4	3.1	5
HACC Access	4.8	1.3	2.5	2.4	2.4	2	3.5	1	3	2.5	=8
Comm./State Disability Programs Access	3.1	1.6	2.2	2.6	1.7	2.6	3.6	0.9	3.4	2.4	9
SAAP Access	4	1.6	7.6	2.8	2.3	2.3	2.8	2	4.2	3.3	4
TAFE/Higher Education access	2.6	1.2	0.2	2.1	3.3	2.2	2.7	0.6	4	2.1	10
Policy Participation	2.6	2.8	5	2.1	2.3	1.6	3.4	1.4	3.6	2.7	7
Emotional and Social Support	4.2	3.6	6.2	3.3	3.4	2.6	2.5	2.9	4.6	3.7	3
Partnerships between the Mental Health Sector and Other Carer Organisations	7.3	5.1	6	6	6.4	4.75	7.1	6.3	6.3	6.1	1
Inclusiveness of Professional Practice	2.8	2	6	2.7	2.5	2.8	2.5	0.6	4.6	2.9	6
Psychiatric Facility Decisions	2.5	1.4	4.7	2.1	2.1	1.6	2.4	0.5	4	2.3	10
Carer Rights and Responsibilities	3	1.6	4.7	3	1.7	2.5	2.7	0.9	3	2.5	=8
Carer – Consumer Relationships	2.6	3.6	8.5	4.7	4.8	3.2	4.3	2.5	5.1	4.3	2



## BIBLIOGRAPHY

*A Long Way to Go: National Survey of Services for Carers of People with Mental Illness*, SANE Australia, 1998.

*A Plan for Now and the Future: Mental Health Services Tasmania Strategic Plan for 1999 – 2002*, Tasmanian Department of Health and Human Services, 1999.

*Annual Client and Service Data Collection 1997*, West Australian Disability Services Commission, May 1998.

Bakshi L, O'Neil K and Rooney R, *Reducing Stigma About Mental Illness in Transcultural Setting: A Guide*, Australian Transcultural Mental Health Network, Melbourne, 1999.

Beach, Scott R (PhD) and Schulz, Richard (PhD), *Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study*, Journal of the American Medical Association, Vol. 282, No. 23, December 1999.

*Bringing them Home : Report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from their Families*, Commissioner: Ronald Wilson: Human Rights and Equal Opportunity Commission, Sydney, 1997.

*Carer Education: Making a Difference for Those at Home*, ACT, Department of Human Services, 1999.

*Carer Information Initiative Update No. 1*, Carers Association of Australia, January 2000.

*Carers Association of Australia Annual Report 1998/99*, Carers Association of Australia, 1999.

*Carers Count*, West Australia Disability Services Commission, July 1997.

*Carers Offering Peers Early Support: (COPES) Project Description*, Maroondah Hospital Area Mental Health Service and Eastern Access Community Health, Melbourne, May 2000.

*Carers Speak Out on Community Services: Consultation with Carers in the Southern Metropolitan and Grampians Regions (June – July 1999)*, Carers Association Victoria, 1999.

*Caring Costs: A Survey of Tax Issues and Health and Disability Related Costs for Carer Families*, Carers Association of Australia, August 1998.

*Caring Enough to be Poor: A Survey of Carers' Income and Income Needs*, Carers Association of Australia, February 1997.

*Caring for Carers*, West Australia Disability Services Commission Carers' Strategy, July 1997.

*Case Management in Mental Health: Professional Development Program for Mental Health Services*, Queensland Health and The University of Queensland, circa 1998.

- Consumer and Carer Participation in Planning, Implementation and Evaluation of Mental Health Services*, Mental Health Division, Health Department of Western Australia, March 1999.
- Department of Health and Aged Care, *Mental Health Information Development: National Information Priorities and Strategies under the Second National Mental Health Plan 1998 – 2003 (First Edition June 1999)*. Commonwealth of Australia, 1999.
- Disability Services Commission 1998-99 Annual Report*, West Australian Disability Services Commission, August 1999.
- Dunt D, Long H, Mihalopoulos C, Naccarella L and Pirkis J, *The Role of General Practitioners and other Primary Care Agencies in Transcultural Mental Health Care*, Australian Transcultural Mental Health Network, Melbourne, 1999.
- Dunt D, Long H, Mihalopoulos C, Naccarella L, Pirkis J and Summers M, *Evaluating Mental Health Services for Non-English Speaking Background Communities*, Centre for Health Program Evaluation and the Australian Transcultural Mental Health Network, Melbourne, 1999.
- Education and Training Partnerships in Mental Health, National Mental Health Strategy*, Commonwealth Department of Health and Aged Care, February 1999.
- Guidelines for Consumer and Carer Participation in Mental Health Services*, Tasmanian Department of Health and Human Services, 1999.
- Handbook for the Operating of the Tasmanian Community Advisory Group on Mental Health*, Tasmanian Community Advisory Group on Mental Health, Tasmanian
- Information Sharing in Mental Health Crisis Situations - Final Report of the Mental Health Crisis Invention Ad Hoc Advisory Group, crisis intervention practice, police and mental health services*, Mental Health and Special Programs Branch, Commonwealth Department of Health and Aged Care, February 2000.
- Jackson A, Klimidis S, Lewis J, McKenzie D, Minas H, Pennella J and Ziguras S, *Draft Evaluation of the Bilingual Case Management Program*, Victorian Transcultural Psychiatry Unit, Melbourne, May 2000.
- Literature Review Relevant to the NSW Carers' Framework*, Ageing and Disability Department and the NSW Health Department based on work prepared by Barbara Murphy, August 1999. (unpublished).
- Meeting the Needs of Families and Carers of People with a Mental Illness*, CarerLinks North, Department of Human Services, Northern Region, January 2000.
- Mental Health and Related Services Act 1998: Northern Territory Approved Procedures*, Government of the Northern Territory, October 1999.
- Mental Health Council of Australia: 1999 – 2001 Strategic Plan*, Mental Health Council of Australia, ACT, 1999.
- Mental Health Project: Briefing Paper*, Department of Veterans' Affairs, January 2000.
- Milojevic, Ivana, *Home and Community Care Services: Generic or Discriminatory?*, HACC Action Research Project Final Report, March 1999.

Nankervis, Julie and Rebeiro, *Carers Speak Out: A Consultation on Community Services with Carers in the Southern Metropolitan and Grampians Region*, Carers Association Victoria, March 2000.

*National Standards for Mental Health Services, National Mental Health Strategy*, Commonwealth of Australia, January 1997.

*NSW Government Carers Statement*, Ageing and Disability Department, NSW Government, October 1999.

*Our Commitment to Australia's Seniors: Statement on the 1999 – 2000 Budget by the Honourable Bronwyn Bishop MP Minister for Aged Care 11 May 1999*, Commonwealth of Australia, 1999.

*Progressing the Needs of Carers within the Mental Health System*, 1999 October Forum, Carers Association of South Australia, 1999.

*Psychiatric Disability Support Services: A Guide to Services in the Western Region*, Western Region Community Education Team – Psychiatric Disability, Melbourne, circa 1999.

Raphael, B. and Swan, P., *Ways Forward: National Aboriginal and Torres Strait Islander Mental Health Policy – National Consultancy Report*, Commonwealth of Australia, Canberra, 1995.

*Review of Information Resources and Training Packages Available to Carers of People with a Mental Illness*, SANE Australia Draft Report to the Commonwealth Department of Health and Aged Care, December 1998.

Senator Jocelyn Newman, *Budget 1999 – 2000: Media Release*, Department of Family and Community Services, Commonwealth of Australia, 1999.

*Skills for Carers – ACT*, Australian National Association for Mental Health, 1997 National Conference, Canberra Institute of Technology, 1997.

Sozomenou A, Mitchell P, Fitzgerald M H, Malak A and Silove D, *Mental Health Consumer Participation in a Culturally Diverse Society*, Second Edition, Australian Transcultural Mental Health Network, Sydney, 2000.

*The Blueprint Guide to Carer Education and Training*, SANE Australia, 1999.  
Thompson, Jenny, *Mental Health Carers Project*, ACT, Carers Association of the ACT, December 1999.

*Toward a National Approach to Information Sharing in Mental Health Crisis Situations*, Expert Advisory Committee Report, *National Mental Health Strategy*, Commonwealth of Australia, February 2000.

*Towards a Strategic Plan for Psychiatric Disability Services and Support: A Discussion Paper*, Disability Services Queensland, Queensland Government, May 2000.

*Victoria's Mental Health Services Consumer Information Guide: How Case Management Can Help You*, Department of Health and Community Services, Psychiatric Services Division, Victorian Government, 1995.

Wiseman, Heather, *Managing Mentally Ill Parents*, Australian Doctor, 5 November 1999.