

Caring together

An action plan for carer involvement in Victorian public mental health services



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Foreword

The important role of families and friends in providing support to people with a mental illness has long been recognised. The Victorian Government provides a range of services to support families and other carers of people with a mental illness, such as the Carer Support Program, respite care and mutual support and self-help services.

In September 2002, the Victorian Government launched *New directions for Victoria's mental health services*. One of the priorities identified in that document was to consolidate the existing guidelines into a new policy statement on the role and needs of carers.

It gives me great pleasure to now introduce an action plan for further improving carer participation in public mental health services. Carers of people with a mental illness have made great contributions already to the way our specialist public mental health service system responds to the needs of people with a mental illness; with this action plan, these existing strengths will be consolidated and extended.

A person with a mental illness exists, as we all do, in a broader social context of family, friends, work and the community. Taking account of this social context is essential in treating the whole person. Carer participation and involvement is, therefore, an important element of the collaborative partnerships between the person with a mental illness, staff and services. Together, we do better.



Hon Bronwyn Pike MP
Minister for Health

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1 Introduction

1.1 Background

Families and carers are widely acknowledged as having a legitimate and appropriate role in supporting a person with a mental illness. Family members may be involved in monitoring symptoms, medication compliance and requesting professional intervention for the person with a mental illness. Caring for someone with a mental illness is a complex experience that requires significant commitment and understanding.

Carers of children have a legal responsibility to care for children and are required to be active decision makers in all aspects of the child's life. Carers of aged persons may also have involvement in decision-making. Depending on the legal guardianship status of the person with a mental illness, their capacity to make decisions and the nature of consent provided, the carer will have different degrees of involvement in that person's treatment and support.

The role of carers

Caring involves many demands and challenges, including balancing the specific caring role with the carer's other family and work responsibilities and the carer's own needs. The caring role also varies across the life span, depending on the age of the carer and the person with a mental illness who is being cared for.

The role of carers includes a range of activities. These can be providing 'hands on' personal care and household assistance, motivating, supervising, encouraging, dealing with behavioural changes, providing companionship, supporting participation in the community, and obtaining and coordinating services.

Some unique features influence the carer role in mental health, such as:

- the stigma, guilt and isolation of mental illness
- intermittent periods of illness with fluctuating symptoms.

Due to the nature of mental illness, some people with a mental illness, when acutely ill, may:

- experience difficulties complying with treatment
- not have sufficient insight into their need for assistance
- disengage from social contacts.

The care provided by family members, friends and other people to a person with a mental illness often exceeds the usual expectations of a close family or personal relationship. This informal care can enable people with a mental illness to function more independently, and manage their own illness more effectively, than may otherwise be possible. The element of 'carer choice' in undertaking this role can also vary, with some carers actively choosing this role, while others feeling compelled to be a carer due to specific circumstances.

The needs of carers

Carers need a range of direct and indirect support to enable them to undertake their caring role. Direct support to carers includes the provision of:

- information about mental health services
- information concerning mental illness
- advice and support in the management of mental illness
- recognition and inclusion by public mental health services
- personal support
- crisis assistance when the person with a mental illness is particularly unwell
- respite care to provide ‘breaks’ from caregiving.

Indirect support to carers can be provided through access to and use of mental health services, including supported accommodation and sub-acute services. Through improved mental health services for consumers, carers have more choice about their level of involvement when people with mental illness are not well enough or able to be cared for at home.

Carers may also need support to raise issues with mental health services. Identifying the needs of carers and developing and monitoring carer-responsive strategies should be an ongoing activity within the mental health service system.

1.2 Policy context

The key policy guidelines relating to carer participation in Victoria as at 2003 are:

National		State	
Mental Health Statement of Rights and Responsibilities	1991	Mental Health Act	1986
First, Second and Third National Mental Health Plans	1991 –2008	In partnership: families, other carers and public mental health services	1996
National Standards for Mental Health Services	1996	Case management guide	1996
		Support for Carers Program	1996
		New directions for Victoria’s mental health services	2002

Further details on carer policies and guidelines are provided in **Appendix 1**.

1.3 Achievements to date

Since 1996, Victoria has implemented a number of carer support services and mechanisms for carer participation. These include recurrently funded services such as:

Carer Participation Services	Recurrent annual amount 2003–04
Family Sensitive Training (FaST) Program	\$70,000
Respite for carers available as planned, emergency or occasional respite	\$2.4 million
Mutual support and self-help services that provide information, support and assistance to families and carers dealing with mental illness	\$1.26 million
Direct support for carers of people with a mental illness through the Carer Support Program	\$3 million
Carer support and resource workers located in metropolitan and rural Victoria	\$461,000
Network of Carers of People with a Mental Illness	\$37,500
Koori support – Carer Support Program	\$550,000
Total	\$7,778,500

From 2004, a recurrent part-time carer academic position will be funded at the Bouverie Centre.

Other carer support strategies are in place, such as:

- **formal consultative mechanisms** with carers of people with a mental illness, such as the Ministerial Advisory Committee on Mental Health and the Network of Carers of People with a Mental Illness
- the option of employing a part-time **carer consultant** from Carer Support Program funds for adult mental health services (as this is optional, access to a carer consultant is variable across services)
- a **resource kit** for carers, *Information for families and carers of people with a mental illness*, available in 10 community languages
- a **website** that includes a directory of public mental health services, links to related sites and a specific page for carer information and links.

Additional details on these achievements are provided in **Appendix 2**.

An analysis of the existing policy framework on carer participation indicates the extent of progress and issues for further consideration (**Appendix 3**). A brief review of progress to date regarding carer participation leads to three major findings:

- 1) A number of significant achievements have been made linked to the implementation of existing policy and guidelines. These achievements have had substantial and positive impacts on carers and other stakeholders.
- 2) The existing national and state policies and guidelines, while still relevant, require reinforcement and further development to strengthen carer participation.
- 3) Areas for improvement in carer participation exist, particularly in relation to:
 - recognition of the carer's role by professional mental health staff, in the management and treatment of the person whom they care for.
 - monitoring the translation of carer participation policy into practice through the use of relevant performance measures and reporting mechanisms.

Strengthening carer participation in specialist public mental health services is an important policy priority of the Victorian Government.

2 Carer Participation Action Plan 2003–2008

A Carer Participation Action Plan has been developed that:

- is based on an understanding of the role and needs of carers in relation to carer participation in mental health services
- addresses the experiences of the last decade in terms of achievements and areas for improvement
- provides specific strategies for implementation over the next five years.

2.1 Rationale

Carer participation in mental health services is vital in providing successful programs and services to improve the wellbeing of carers and maintain and improve the mental health of people with a mental illness¹. A considerable body of research strongly supports effective and responsive partnerships between consumers, carers and professionals, with the benefits enduring beyond the period of immediate contact. Involvement of carers has been found to contribute to:

- reducing the incidence of relapse
- improving adherence to treatment
- improving family functioning
- increasing periods of wellness
- improving the consumer's quality of life and social adjustment.²

For the carer, the benefits of family/carer involvement in the treatment and support of a person with a mental illness can include:

- improved carer and family wellbeing
- reduced carer stress
- reduced burden of care
- improved understanding of mental illness, treatments and services.

Research supports the importance of effective treatment for the consumer as the primary means of reducing burden on caregivers³.

2.2 Purpose

The aim of this Carer Participation Action Plan is to improve the active participation of carers of people with a mental illness in the planning, development, implementation, delivery and evaluation of mental health services in Victoria, including the clinical mental health sector and psychiatric disability rehabilitation and support services (PDRSS) sector. This participation is undertaken in partnership with mental health service providers, consumers, government and the community.

1 Mental Health Council of Australia, Consumer and carer participation policy template, 2003

2 Pitschel-Walz, G., Leucht, S., Bauml, J., Kissling, W. & Engel, R. The effect of family interventions on relapse and rehospitalisation in schizophrenia – a meta-analysis, Schizophrenia Bulletin, Vol 27, 1 2001.

3 Ohaeri, J. The burden of caregiving in families with a mental illness: A review of 2002, Current Opinion in Psychiatry, Vol. 16 (4), July 2003, pp. 457-465.

2.3 Definition

Carer participation refers to either voluntary or paid involvement in formal and informal activities associated with mental health services, as well as in all processes that affect the lives of consumers and carers, through sharing of information, opinions and decision-making power.

For the purposes of this plan, the term 'carer' is defined as someone who is actively caring for a person with a mental illness with whom they have an ongoing relationship. The carer need not necessarily live with the person with a mental illness. A carer may be a family member, friend or other person who has a significant role in the life of the person with a mental illness. The role of carer may not necessarily be a static or permanent one but may vary over time according to the needs of the consumer and carer.

'Carer participation' has been interpreted in a broad sense that covers formal and informal carer participation in mental health service delivery, staff training and support to carers. A carer can be indirectly involved in service provision through the service provided to a consumer (carer participation) or can also be a direct recipient of services themselves (carer support). Direct services to carers include support and assistance in their caring role. Paid carers, such as professional staff in services, attendant carers or residential workers, are **not** included in this definition.

2.4 Principles that underpin the Action Plan

The Victorian Government has established a set of principles that reflect the value placed on carer participation. These principles are based on nationally recognised principles developed by the Mental Health Council of Australia and the National Resource Centre for Consumer Participation in Health. They are:

- **Carers of a person with a mental illness should participate and have a direct and active role in processes involving that person that affect the carer's life (*subject to consent issues being addressed*).**
- **Carers should be respected and empowered in their relationship with mental health services through a positive partnership that recognises the diversity of carer needs and backgrounds.**
- **Information should be shared and exchanged between consumers, carers and mental health services to enable effective participation, enhanced carer wellbeing and improved choice.**
- **Participation of carers in local mental health services is an important component of continuous quality improvement.**
- **Carer participation can be enhanced by the use of carer representatives with appropriate expertise to represent the interests of carers.**
- **Both a consumer and a carer representative are usually required to represent the views of consumers and carers. A family representative may be appropriate to represent younger children and their families.**
- **Opportunities should be provided for the ongoing support and relevant training and education for carers to assist in their effectiveness as carer representatives.**

- **Carers of people with a mental illness have an important contribution to make to the planning, development and evaluation of statewide service delivery initiatives, policy directions and issues.**
- **Carers with appropriate expertise and links to carer networks should be appointed to represent the interests of carers at a statewide and systemic level.**
- **The mental health service system recognises the need for resources and support to enable effective carer participation.**

There are three levels of carer participation and involvement in the mental health service system:

- assessment, treatment and support for **individuals** with a mental illness
- **local service** planning, delivery and evaluation
- **systemic** service planning, delivery and evaluation.

The participation and involvement of carers from all age sectors of the public mental health service system should occur at these levels, with carers associated with child and adolescent, adult and aged persons mental health services being appropriately represented and engaged. Adult services include the PDRSS sector.

The nature of service provision in child and adolescent mental health services (CAMHS), with its strong focus on the family, can allow for an integrated consumer and carer strategy. Due to the active engagement of parents/carers in the therapeutic process, mental health services identify children, young people and carers as ‘consumers’. The appointment of separate consumer and carer representatives therefore may not be necessary in these services, as a family representative includes both the carer and consumer perspective. However, for older children or in situations where carers may have different needs to the child or young person, all views should be represented to the service.

As well as being involved in the treatment and support of the person with a mental illness for whom they care, carers may also be the direct recipients of services. Services that respond to the immediate needs of carers can include family therapy, financial assistance, information, respite or referral to other services outside the specialist mental health service system, such as counselling.

2.5 Action area – individual level

Most carers of a person with a mental illness are involved with the public mental health service system through the treatment and support of a person for whom they care. Carers seek input, knowledge and understanding to better assist the person with a mental illness (the consumer) manage their daily life.

The consent of the consumer is relevant in determining the extent of participation and involvement of a carer with a person with a mental illness in the public mental health system. For clients under 15 years, it is preferable to obtain consent for information to be shared with carers, however, consent is not legally required. For people over the age of 15 with a mental illness, the following examples apply to the issue of consent and carer involvement:

With consent, carers are entitled to:

- have access to the person with a mental illness
- be consulted by service providers about measures being considered for treatment of the person with a mental illness
- arrange support services such as respite care and counselling for the person with a mental illness
- exchange information with those providing treatment concerning the person and their relationship with others.

Without the consent of the person with a mental illness, carers have the right to:

- place limits on their availability to the consumer
- provide information concerning family relationships and any matters relating to the mental state of the consumer to health service providers
- assistance with their own difficulties that may be generated by the process of caring for people with a mental disorder.

(Extracts from the Mental Health Statement of Rights and Responsibilities (1991))

The following statements relating to carer participation and involvement may require the carer to seek the consent of the person with a mental illness.

Mental health services must be aware of their obligations regarding confidentiality and privacy of the person with a mental illness. Information about the person with a mental illness can be shared with families and carers with the consumer's consent **or** within the provisions of the *Mental Health Act 1986* (section 120A).

A. Enhanced involvement of carers in the treatment of a person with a mental illness, including assessment, service delivery, discharge planning and monitoring.

When a person with a mental illness receives assessment, treatment or support from a public mental health service, it is usually beneficial if their family and friends become partners in a collaborative therapeutic relationship with professional mental health workers and the person with a mental illness. This collaborative partnership operates to assist the person's management and responses to their illness. Professional staff should actively listen to carers and acknowledge and recognise the carer's role in the management and treatment of the person with a mental illness.

Collaboration involves families and other carers, and key staff, such as case managers, psychiatrists and other clinicians, acknowledging and respecting the skills and resources that all parties bring to the situation.

Strategies to improve carer involvement in the treatment and support of a person with a mental illness:

- Invite carer to attend case management meetings and other discussions about the development and monitoring of individual service plans, discharge planning and treatment options for the consumer during the entire course of the consumer's illness, that is, assessment, admission, discharge, monitoring and review, and during wellness as appropriate to prevent relapses (with the consent of the consumer).
- Discuss family and support networks with the consumer and document, in the consumer's file, the relationship and contact details of the person who provides the most support or care.
- Develop a carer plan (as part of a consumer's individual program plan) that is regularly reviewed.
- Be responsive to the complexities of the caring role and possible areas of conflict with the consumer.
- Encourage CAMHS carers to complete the outcome measurement tools for carers.

B. Improved information about mental illness

Carers need specific knowledge to participate in a meaningful way in the person's care. This knowledge includes information about:

- the particular mental illness
- medication options
- treatment and support requirements and options, both current and future
- an ongoing prognosis for the person with a mental illness (if available).

This information provides a basis for the carer to collaborate with the consumer and mental health service staff in planning, monitoring and evaluating individual treatment and support options. It is the responsibility of the service to provide this information or identify alternative sources for carers.

Strategies to improve carer information

- Provide carer information kits on first contact with service. Kits could include:
 - description of service, visiting hours, staff involved
 - information about mental illness, treatment options and mental health services
 - statement of carer rights and responsibilities
 - outline of grievance procedures
 - list of carer advocates
 - carer support services available locally and statewide
 - respite services available
 - other relevant information.
- Address carer information needs through regular review and updating of a Carer Plan.

C. Improved access to carer support services and education programs

Carers may easily feel overwhelmed, anxious or uncertain with the mental health environment, language used by professionals, and the events occurring in their lives. Asking for support from others, or requesting that information is repeated or presented in a more understandable format, are all common needs in these situations.

If an individual carer considers that they need support in discussing the treatment and support requirements of the person with a mental illness with professionals at the service, the carer can ask for someone else to accompany them. This support person could be another family member, a friend, a carer consultant, a formal advocate or anyone else who may assist. Issues with consumer consent are also relevant to the involvement of another person in discussing the consumer's situation.

Individual carers and family members need to be made aware of policies and procedures within the mental health service to follow up specific issues, make complaints and generally understand their rights and responsibilities.

It is the responsibility of the service to undertake these tasks for carers.

Strategies to improve carer access to support and education

- Arrange a meeting with the carer consultant.
- Identify carer needs in terms of appropriate cultural and linguistic diversity responses.
- Link carers with carer support services such as CarersVic, regional carer support and resource workers, local mutual support and self-help groups and mental health service providers.

2.6 Action area – local service level

Area mental health services include clinical inpatient services, community treatment and residential services. Area mental health services are managed within the general hospital sector and operate as a key element of an integrated health care system.

Mental health disability services include day programs, home-based outreach support, respite and residential programs provided by the non-government PDRSS sector.

In most cases, the local mental health service is the closest to where the person with a mental illness lives. The term 'service' is used below to include both mental health clinical services and PDRSS.

D. Enhanced involvement of carers in local service planning, delivery and evaluation.

Carers should be involved in the planning, delivery and evaluation of local mental health services through representation on formal advisory structures as well as informal processes for addressing specific issues or tasks.

Every AMHS has a number of committees to oversee specific areas relevant to the operation and relationship of that AMHS. Examples of these formal structures include quality services committees and emergency services liaison committees.

Likewise, PDRSS have a range of formal and informal structures that support their operations. The carer perspective should be considered in PDRSS service delivery and sector issues. Particularly for service types such as Home-based Outreach Support, where clients live with their family or other carers, the carer should be involved in developing the client's individual program plan (where participants consent to the carer's involvement).

Sometimes, working parties are formed to address general carer issues, or a group is convened to complete a task, such as the management and operations of the Carer Support Program. Carer involvement is essential in overseeing the operations of the Carer Support Program.

Carer representation on other groups should also be considered. Services should be able to identify a carer representative for specific issues or discussions as needed. Regular consultation and feedback with families and carers improves practice and keeps staff informed of emerging issues.

Services may wish to conduct family and carer surveys at entry to the service, on discharge or at other key transition points to monitor carer participation and service responsiveness.

A range of options, such as suggestion boxes and evaluation forms, can be provided so that families and carers can give feedback or comments anonymously. Designated areas for families and carers within the service while waiting or meeting with their family member or professionals (in addition to a waiting room) can assist in ensuring privacy and comfort.

Staff employed in mental health services should also participate in family sensitive training, such as that provided by The Bouverie Centre. Staff who have recently been employed, or seek to improve their understanding of the needs of carers, should attend this training.

Carer input to staff in-service training programs should be actively sought and encouraged to ensure workers understand the carer perspective. There should be carer input in relation to identification of training needs, discussion of proposed training material, and personal presentations to workers on specific issues and involvement in the evaluation and feedback of courses held. Services are responsible for implementing and monitoring these strategies.

Strategies to improve carer involvement in local service planning, delivery and evaluation

- Develop and implement a formal carer participation policy.
- Attend family sensitive training.
- Coordinate carer input to staff in-service training.
- Develop and operate formal internal complaints mechanisms.
- Provide space and equipment for carers to use.
- Appoint carer representatives to relevant committees, such as quality review committees.
- Conduct regular discussion groups to seek the views of carers.

E. Improved information about mental health services

Services should ensure that information on grievance procedures, service details, mental health and any other relevant information for families and carers are easily accessible, easily understood and updated on a regular basis. This includes responding appropriately to cultural and linguistic diversity, literacy levels and other individual needs of carers.

Strategies to improve carer information

- Develop, implement and update a carer information kit.
- Develop and deliver a range of carer information sessions that are accessible to carers in the local area.
- Provide referrals to local and statewide organisations that provide relevant mental health and carer information.

F. Enhanced access to carer support services and education programs

Local area mental health services can employ carer consultants to represent the interests of carers and advocate for their needs. Over time, it is planned to increase the number of paid carer consultants and to extend their distribution within the public mental health service system.

Carer consultants provide practical support, reassurance, information and referral to families and carers. Carer consultants also work collaboratively with service staff to provide a coordinated approach to family and carer needs. This collaborative work can include identifying service gaps and areas for improvement and implementing specific responses to improve the service. The dignity and rights of families, carers and consumers are to be upheld at all times, while respecting privacy and confidentiality.

Strategies to improve carer access to support and education

- Use a carer consultant.
- Conduct education sessions on mental illness and the impact on the consumer, families and friends.
- Provide peer support contact information.
- Coordinate carer input to the operation of the Carer Support Program.

A checklist developed by the Mental Health Council of Australia for services to measure carer participation is provided as **Appendix 4**.

2.7 Action area – systemic service level

Local mental health services are an element of the broader mental health service system. At a systemic level, carer representatives should participate in the planning, development and evaluation of statewide service delivery initiatives, policy directions and issues such as workforce development.

G. Enhanced involvement of carers in systemic service planning, delivery and evaluation.

Carers should be involved in the planning, delivery and evaluation of mental health services through representation on formal management structures as well as informal, ad hoc processes for addressing specific issues or tasks. In general, working parties or project advisory committees related to the development, monitoring and evaluation of mental health services or initiatives should have carer representation.

Carer input to staff pre-service and in-service training programs should be actively sought and encouraged to ensure workers understand the carer perspective.

Strategies to improve carer involvement at a systemic level

- Consult carers on key statewide projects and evaluations.
- Encourage carer participation in undergraduate pre-service and in-service training of mental health staff, police and other relevant professionals.
- Liaise regularly with carer representatives to enable broad representation of carer views and issues.
- Monitor and disseminate data from CAMHS carer outcome measures.

H. Improved information about mental health services

The State Government provides information on mental health services and other relevant topics for families and carers. This information is easily accessible, easily understood, updated on a regular basis, and includes information about cultural and linguistic diversity, literacy levels and other specific needs of carers.

At a statewide level, the government supports the sharing of information and research relevant to carers of people with a mental illness through conferences, publications and electronic means, such as websites.

Services can also be asked to disseminate information about good practice in the areas of carer participation and involvement.

Strategies to improve carer information at a systemic level

- Identify good practice examples from mental health services.
- Enable access to translations of relevant material.
- Disseminate good practice information on carer involvement through website and other means.
- Research relevant topics, such as the impact of family dynamics on mental illness.
- Nominate carer representatives for national mental health initiatives.

2.8 Support for carer participation

When carers make a formal contribution to planning, service delivery or policy in public mental health services at a local or systemic level, they may need assistance or support to participate. Carers can inform the service of their specific needs so that arrangements suitable to the carer and the service can be agreed.

2.9 Summary of strategies for carer involvement

Service level	Activity	Strategies for carer involvement	Mechanism for measuring progress
Individual	Enhanced involvement of carers in the treatment of a person with a mental illness, including assessment, service delivery, discharge planning and monitoring	<ul style="list-style-type: none"> • Invite carer attendance at case management meetings and other discussions. • Ensure discussion occurs with the consumer about family and support networks and document in consumer file a record of relationship and contact details of the person who provides the most support/care. • Develop a carer plan (as part of a consumer's individual program plan) that is regularly reviewed. • Be responsive to the complexities of the caring role and possible areas of conflict with the consumer. • Encourage CAMHS carers to complete outcome measurement tools for carers. 	Carer feedback
	Improved information about mental illness	<ul style="list-style-type: none"> • Provide carer information kits on first contact with service. • Address carer information needs through regular review and updating of a carer plan. 	
	Improved access to carer support services and education programs	<ul style="list-style-type: none"> • Arrange a meeting with the carer consultant. • Identify carer needs in terms of appropriate cultural and linguistic diversity responses. • Link carers with carer support services such as CarersVic, regional carer support and resource workers, local mutual support and self-help groups and mental health service providers. 	
Local/AMHS	Enhanced involvement of carers in local service planning, delivery and evaluation.	<ul style="list-style-type: none"> • Develop and implement a formal carer participation policy. • Attend family sensitive training. • Coordinate carer input to staff in-service training. • Develop and operate formal internal complaints mechanisms. • Provide space and equipment for carers to use. • Appoint carer representatives to relevant committees such as quality review committees. • Conduct regular discussion groups to seek the views of carers. 	<p>Carer Participation Plan</p> <p>National Survey of Mental Health Services</p> <p>National Standards for Mental Health Services</p> <p>Monitoring and analysis of Carer Experience Survey</p> <p>Clinical reviews</p>

Service level	Activity	Strategies for carer involvement	Mechanism for measuring progress
	Improved information about mental health services.	<ul style="list-style-type: none"> • Develop, implement and update a carer information kit. • Develop and deliver a range of carer information sessions that are accessible to carers in the local area. • Provide referrals to local and statewide organisations that provide relevant mental health and carer information. 	<p>Carer Participation Plan</p> <p>National Survey of Mental Health Services</p> <p>National Standards for Mental Health Services</p> <p>Monitoring and analysis of Carer Experience Survey</p> <p>Clinical reviews</p>
	Enhanced access to carer support services and education programs.	<ul style="list-style-type: none"> • Use a carer consultant. • Conduct education sessions on mental illness and the impact on the consumer, families and friends. • Provide peer support contact information. • Coordinate carer input to the operation of the Carer Support Program. 	
Systemic	Enhanced involvement of carers in systemic service planning, delivery and evaluation.	<ul style="list-style-type: none"> • Consult carers on key statewide project development and evaluations. • Encourage carer participation in undergraduate/pre-service and in-service training of mental health staff, police and other relevant professions. • Liaise regularly with carer representatives to ensure broad representation of carer views and issues. • Monitor and disseminate data from CAMHS carer outcome measures. 	
	Improved information about mental health services	<ul style="list-style-type: none"> • Identify good practice examples from mental health services. • Enable access to translations of relevant material. • Disseminate good practice information on carer involvement through website and other means. • Research relevant topics, such as the impact of family dynamics on mental illness. • Nominate carer representatives for national mental health initiatives. 	<p>Overview of Carer Experience Survey results</p> <p>Links with networks</p> <p>Carer representation on project initiatives</p> <p>Carer's web page updated</p> <p>Examples of best practice and research outcomes disseminated</p>

3 Implementation and monitoring strategy

The Carer Action Plan will be implemented on a staged basis from 2003 to 2008. A range of strategies will be used to measure the extent of implementation of this Action Plan for each level of carer participation. Some of these strategies can be implemented immediately, while others are future priorities.

3.1 Individual level

Carer feedback

Carers can provide feedback on their experience of public mental health services through locally developed surveys, direct comment to the service and through other strategies that provide opportunities to measure service responsiveness and effectiveness in meeting carer needs.

3.2 Local service level

At the local mental health service level, a number of strategies to assess progress will be employed.

Carer participation plans

The key mechanism for assessing progress in improving carer participation will be the development and implementation of three-year local service level carer participation plans.

National Survey of Mental Health Services

Another strategy will be the annual National Survey of Mental Health Services. All clinical and some PDRSS services are required to complete this annual survey. For those PDRSS not currently included in this survey, it is proposed to circulate the carer participation criteria from the national survey as a stand-alone survey to ensure total coverage of all public mental health services.

A performance measure will be developed for inclusion in all agency service agreements for 2004–05 to measure the extent of carer participation against the criteria specified in the National Survey of Mental Health Services.

These criteria are:

- Carer consultants are employed on a paid basis to represent the interests of carers and advocate for their needs.
- The organisation holds regular discussion groups to seek the views of carers about the mental health services.
- The organisation has developed a formal (documented) policy on carer participation.
- The organisation periodically conducts carer satisfaction surveys.
- The organisation has a formal internal complaints mechanism in which complaints made by carers are regularly reviewed by a committee that includes carers.

National Mental Health Standards

An additional strategy to assess the extent of carer participation in local services is the record of progress in implementing the National Mental Health Standards. Standard 3 of the National Mental Health Standards specifies seven criteria for measuring the extent of consumer and carer participation. Assessment of the progress will also be recorded in the National Survey of Mental Health Services and will be analysed at state level.

Carer Experience Survey

Analysis of the statewide Carer Experience Survey in clinical services and the PDRSS sector has been undertaken, with detailed feedback to individual services and more general analysis provided of the overall results.

Clinical service reviews

At the service level, the Chief Psychiatrist also undertakes a program of clinical reviews of the standards of treatment and care delivered by area mental health services. While these reviews focus on the treatment and care delivered to individual patients, reviews look for evidence of the extent to which services involve family and carers in the treatment and care process.

Carer participation in local mental health services will, therefore, be assessed through these mechanisms:

- development and implementation of carer participation plans
- the National Survey of Mental Health Services
- the statewide Carer Experience Survey
- progress towards implementation of National Mental Health Standards
- clinical reviews.

The major additional requirement will be the inclusion of a performance measure in agency service agreements for 2004–05 to use data from the national survey for state monitoring purposes, and the conduct of an audit of current carer-sensitive practice.

3.3 Systemic service level

Links to key networks

At a statewide systemic level, carer participation and involvement is occurring through liaison with the Network for Carers of People with a Mental Illness, Ministerial Advisory Committee on Mental Health, mental health carer support workers and the Carer Consultant's Network.

Carer representation

Carer representatives are currently included in key project initiatives such as the Mental Health Workforce Review. Carer representation will continue on external advisory committees and groups that are initiated by the Mental Health Branch.

Information dissemination

The Carer's page on the Mental Health Branch website is updated on a regular basis, with future developments planned to support improved information on carer-related issues.

Research

In terms of research, *beyondblue* and the Carer's Network are undertaking a **needs analysis of carers of people with high prevalence disorders**. The project aims to achieve better recognition for carers and families of people with high prevalence disorders and raise community awareness of these issues. A focus group methodology has been used to develop a report and publication detailing the needs and experiences of carers of people with depression or anxiety.

Further opportunities for research into the needs of carers and the impact of carer participation on client and service outcomes will be a priority.

Sharing of best practice

Mental health services will be requested in 2004 to provide examples of best practice in carer participation and involvement. A summary of responses will be made available to encourage the sharing of effective practices in this area.

Proposed timelines:

Activity	Date	Frequency
National Survey of Mental Health Services	December 2003	Annual
Request for good practice from mental health services	2004	Biennial
Inclusion of carer participation performance measure in agency service agreements	2004-05	Annual

3.4 Future priorities

Future priorities to increase carer participation and involvement over the next five years include:

- increased access by mental health staff to family sensitive training
- identification of options for carer input into staff in-service training programs
- improved access to carer consultants in adult and aged clinical mental health services
- provision of additional respite for carers
- establishment of a family support consultant in CAMHS (combining the role of consumer and carer consultant)
- extension of the mental health carer support worker role
- ongoing development of the carers' page on the Mental Health Branch website
- research on the impact of family dynamics and other relevant areas.

Regular monitoring of progress in carer participation will occur through analysis of the results from the National Survey of Mental Health Services. This data will be shared with mental health services for comparative purposes. Data over the five-year period will be reported to demonstrate the increased level of carer participation. Additional means of measuring the extent of carer participation will also be considered, such as feedback from carer consultants and service-level data and information.

4. Evaluation

It is proposed to formally evaluate the implementation of the new Carer Action Plan during the five-year period to develop next steps and identify further areas for future development.

Appendix 1

Existing carer participation guidelines and policy

An examination of existing carer participation guidelines identifies a number of relevant publications produced by Commonwealth and state governments up to 2003.

At Commonwealth level, a National Mental Health Policy Framework has been articulated through the *First, Second and Third National Mental Health Plans and the Mental Health Statement of Rights and Responsibilities (1991)*.

A *Third National Mental Health Plan (2003–2008)* has recently been developed. This plan states that the enhanced role of carers must be recognised and supported. The needs of families and carers should be acknowledged, and services put in place to support their efforts and ensure that their own wellbeing is maintained.

Three key directions are outlined to achieve improved **support** for families and carers:

- develop guidelines for carer planning, which emphasise regular review of the needs of carers
- improve the range of supports available for carers, which may include respite services and services for children of parents with a mental illness
- improve the extent to which information is shared with carers so they are able to participate in care planning.

The importance of consumer and carer **participation** is also reaffirmed, with consumer and carer participation seen as the hallmark of a quality mental health system. To achieve increased levels of carer participation, key directions include:

- review and improve current structures for carer participation in policy and service planning, development and evaluation at national, state and local levels
- review and improve structures for ensuring consumer and carer participation in individual care and recovery plans
- identify improved service quality and consumer outcomes afforded by enhancing consumer and carer participation at all levels
- provide support and training for consumers, carers and their families to strengthen their capacity to participate at all levels, particularly in quality assurance processes.

In Victoria, the document *In partnership: families, other carers and public mental health services* was released in 1996. This described the importance of collaborative working relationships between professionals and carers and identified specific strategies for fostering this collaboration.

The *Mental Health Act 1986* was amended in 1996 to acknowledge carers in the section on confidentiality. The *Case management guide 1996* incorporated the role and needs of carers. At a more general level, a statewide Support for Carers Initiative (1996) made a whole-of-government policy commitment to support and strengthen the relationship between carers and those for whom they care.

In September 2002, the Victorian Government launched *New directions for Victoria's mental health services*, which outlines priorities for the development of mental health services provided to consumers and their carers over the next five years. One of the five key principles for future development of Victorian mental health services relates to consumer and carer participation in the development and review of mental health services, and the involvement of consumers and carers as active partners in individual treatment and care planning.

New directions strongly supports the role of carers of people with a mental illness in ensuring an effective, responsive mental health service system.

Carer participation is considered an integral element of public mental health service planning, delivery and evaluation at local, regional and statewide levels. Formal systems for carer involvement are to be developed and strengthened over the next five years, while informal mechanisms will be encouraged and facilitated by local services.

Support to carers to enable them to undertake their caring role is also considered a critical element of the mental health service system. A range of assistance, including practical assistance, respite services, mental health carer support workers, carer consultants and mutual support and self-help services are all components of carer support that will be strengthened over time.

In summary, the key policy guidelines relating to carer participation in Victoria as at 2003 are:

National		State	
Mental Health Statement of Rights and Responsibilities	1991	Mental Health Act	1986
First, Second and Third National Mental Health Plans	1991 –2008	In partnership: families, other carers and public mental health services	1996
National Standards for Mental Health Services	1996	Case management guide	1996
		Support for Carers Program	1996
		New directions for Victoria's mental health services	2002

Appendix 2

Achievements in carer participation

Victoria has implemented a number of significant carer support services and mechanisms for carer participation in public mental health services.

2.1 Consultative mechanisms

Victoria has in place formal consultative mechanisms with carers of people with a mental illness. These mechanisms provide advice, feedback and information on needs and priorities for carers and their relationship to the development of policy.

Ministerial Advisory Committee on Mental Health

The Ministerial Advisory Group (MAC) on Mental Health includes consumer and carer representation as well as relevant mental health stakeholders and external interests, such as general practitioners, the non-government sector and related service areas, such as drug treatment, housing, welfare and youth services. Key priorities of the MAC include:

- consumer and carer participation
- addressing the need for integrated responses to consumers with a dual diagnosis
- enhancing service structures and partnerships to improve consumer access and service management.

As well as consumers and carers being represented on the MAC, a subcommittee of consumers and carers will provide specific advice and input on consumer and carer related issues. This subcommittee replaces the Victorian Community Advisory Group on Mental Health (VICCAG) as a primary mechanism for consumer and carer consultation.

The Network for Carers of People with a Mental Illness

The Network for Carers of People with a Mental Illness is the Victorian carer peak body of organisations and groups that support carers of people with a mental illness. It is a partnership between:

- carers or former carers linked with carer groups
- representatives of statewide organisations that have a significant carer focus
- workers from programs that support carers.

The network works at a statewide level to:

- assist governments to recognise the role, contribution and needs of carers
- advocate for services that meet carer needs
- support carer involvement in the planning, delivery and evaluation of services for people with a mental illness and their carers
- facilitate communication between carers and government
- establish partnerships between carers and service providers
- encourage research on best practice in carer support.

2.2 Carer satisfaction surveys

Consumer and carer satisfaction surveys of clinical mental health services have been undertaken since 1996–97. The consumer and carer satisfaction survey was redeveloped during 2001–02 to better reflect current thinking. The specific items were developed following widespread consultation to reflect the needs, priorities and expectations of consumers and carers, and then linked back to the *National standards for mental health services* to provide a meaningful benchmark for consumers, carers and service providers. The new survey was distributed in 2003, with results provided to services during 2004.

2.3 Outcome measurement

Outcome measurement (OM) for people with a mental illness is a national initiative currently being implemented in Victoria. OM is the process of measuring health outcomes of consumers of mental health services by undertaking a series of ratings and comparing the results over time. The purpose of measuring clinical outcomes is to see whether consumers of public mental health services in Victoria get better as a result of the services they receive.

Like self-rating information provided by the consumer, feedback from carers can provide mental health professionals with valuable information that can enhance clinical decision-making and inform the OM process.

The OM suite for CAMHS contains a component that can be completed by a parent or caregiver. The suites for adults and aged persons do not as yet include a carer questionnaire. In the short term, carers will need to rely on existing processes such as dialogue with clinicians to express their views.

2.4 Carer academic

As part of implementing a mental health workforce strategy, recurrent funds have been allocated from 2004 for the part-time employment of a carer academic position. This position will:

- lead carer involvement in the education and training of mental health staff
- promote collaborative models for the involvement of carers within specialist mental health services
- mentor and support carer representatives within mental health services
- develop and maintain active linkages and networks with carer representative groups and organisations at state and national levels
- advocate for and represent the views of carers across a range of activities, including the provision of expert advice to education, training and research organisations.

The position will be located at the Bouverie Centre as an affiliate of La Trobe University.

2.5 Staff training

The Family Sensitive Training (FaST) Program was developed by the Bouverie Centre as an approach and set of resources aimed at increasing the sensitivity of mental health services to families and carers. Carers have been closely involved in the development, delivery and evaluation of the FaST Program.

FaST helps mental health workers gain an appreciation of the impact of mental health problems on the whole family, and to use this appreciation to change the way services are provided. FaST has had considerable success in improving staff responsiveness to carers since its inception in 1998. More than 450 mental health staff have participated in family sensitive training.

The Bouverie Centre is delivering an ongoing program of statewide training for mental health services with occasional specific initiatives occurring, such as a demonstration project in a service to make an inpatient unit more family-friendly.

2.6 Direct support

The provision of direct support to carers in area mental health services has been addressed through a number of strategies funded by the Department of Human Services.

Since August 2002, adult mental health services have had the option of using Carer Support Program funds for a part-time carer consultant. The role of the carer consultant is to provide information to carers, assist carers where necessary and liaise with mental health staff on behalf of carers. Respite for carers is available as planned, emergency or occasional respite that provides an opportunity for people with a mental illness and their carers to have some time out.

Through psychiatric disability rehabilitation and support services, mutual support and self-help services provide information, support and assistance to families and carers dealing with mental illness. Carer support groups are also available and provide opportunities to meet others in similar circumstances.

2.7 Financial support

The **Carer Support Program** commenced in 1996–97. The program provides \$3.0 million annually for individualised support for carers of people with a mental illness to respond to, or prevent, a crisis. These funds may also be used as mentioned above for carer consultants. Funds are administered through clinical mental health services to provide financial assistance, respite and travel, or meet other needs that enhance the caring relationship. The program was formerly known as the **Carer Crisis Support Program**.

2.8 Community development and advocacy

From 1996, six mental health carer support workers have been located in metropolitan and rural Victoria. These workers have a community development and advocacy role on behalf of carers of people with a mental illness. Through promotion, education and information sharing, the local needs of carers have been addressed through this systemic support. The workers also provide direct support to carers by facilitating support groups, establishing linkages with relevant services and maintaining effective relationships in the mental health sector.

2.9 Information

Many services have developed carer information kits that explain their service and provide useful contacts for carers. The Department of Human Services recently published a resource kit for carers titled *Information for families and carers of people with a mental illness*. The kit has also been translated into ten community languages.

Mental Health Branch has a website that includes a directory of public mental health services, links to related sites and a specific page for carer information and links.

Appendix 3

Analysis of existing policy framework

A general policy that encourages and supports carer participation in public mental health services has been in place in Victoria from 1996, and was reinforced by the publication of *New directions* in 2002.

In partnership (1996) identified requirements for collaborative work practices between mental health staff and carers. While significant progress has been made towards achieving these requirements in many services, the extent of implementation of these requirements, and subsequent changes to practice, remains variable, according to reports by families, carers and mental health services.

In addition to these reports, external bodies such as the Auditor-General and the Commonwealth have undertaken a more formal analysis of the translation of Victorian carer participation policy into practice. The Mental Health Branch of the Department of Human Services has also monitored implementation of the carer participation policy through a number of mechanisms, such as surveys and reports.

A variety of external and internal sources have therefore commented on the extent of carer participation and involvement within Victoria's public mental health service system. These assessments of Victorian carer participation in mental health service planning and delivery have identified:

- achievements to date
- areas for improvement.

The following table provides a summary of the extent of carer participation as assessed by external agencies and internal government sources in Victoria up to 2002:

Source	Findings	Conclusions
SANE 1998	Victoria is significantly ahead of other states.	In principle commitment to carers is relatively strong. Strong carers movement
Carers of People with a Mental Illness Project 2000	Carers sustain fabric and operational effectiveness of mental health service systems.	Carer policy and planning participation needs to be more inclusive, methodical and effective.
National Mental Health Report	In comparison to national survey average for 99/00, Victoria exceeded all measures of carer participation.	Carers' expectations of service responsiveness and quality are sometimes at variance with their direct experience. Mechanisms for carer participation are less well developed than for consumers.
Auditor-General's Report 2002	Carers believe crisis services for consumers, and support for carers and families, need improvement. Carers require better information, education, consultation, training and support.	Evidence demonstrates discordance between central policy directions and the experiences of carers and families.
Mental Health Branch Carer Satisfaction Surveys	Carers are most satisfied with staff of public mental health services. Carers are least satisfied with the overall hospital experience (discharge planning and time with carers). Limited access to timely, appropriate information.	Carers involved with adult mental health services <ul style="list-style-type: none"> • are the least satisfied in all domains compared to other age sectors • have experienced decreasing satisfaction from 1997-98 to 1999-2000.

Appendix 4

Carer participation policy checklist for services

Does the consumer and carer participation policy:

- ✓ State a clear purpose?
- ✓ Have a set of principles that reflect the value the organisation places on consumer and carer participation?
 - Articulate the organisation's position in relation to consumer and carer participation in:
 - ✓ Strategic planning for the organisation
 - ✓ Service planning
 - ✓ Service delivery
 - ✓ Service implementation
 - ✓ Service evaluation
 - ✓ Health decision-making
 - ✓ Resource allocation and development
 - ✓ Other
- ✓ State responsibilities of all parties in implementing the policy?
- ✓ State what measures will be taken to monitor the policy's implementation?
- ✓ State whether/when the policy should be revised and evaluated?
- ✓ State how the policy will be evaluated (including consideration of what measures or indicators may be used in the evaluation)?
- ✓ Ensure the service promotes consumer and carer participation in all processes that affect the lives of consumers and carers?
 - Include consumers and carers in every process that affects their lives, for instance:
 - ✓ Recruitment
 - ✓ Workforce
 - ✓ Resource allocation
 - ✓ Evaluation
 - ✓ Planning
 - ✓ Service delivery
 - ✓ Research
 - ✓ Evaluation
 - ✓ Other
- ✓ Allow for the employment of consumers and carers with special expertise to participate in all processes and activities that affect their lives?
- ✓ Promote the employment of consumers and carers by external agencies (e.g. accrediting agencies) to participate in all processes and activities that affect their lives?
- ✓ Ensure Terms of Reference and Duty Statements are developed for consumer and carer representation and participation on all committees?

- ✓ Ensure consumer and carer representatives on committees abide to reporting mechanisms, either written or verbal, upon completion of their representation?
- ✓ Adopt the principles and practices outlined in the National Consumer and Carer Participation Policy Template and adopt them to suit local need?
- ✓ If a State/Territory peak body, ensure consumers and carers are involved in the management and operation of the organisation?
- ✓ Ensure processes are established for the payment for consumer and carer participation and reimbursement of their expenses resulting from their active participation?
- ✓ Ensure adequate feedback mechanisms exist to facilitate information flow between the organisation and consumers and carers?
- ✓ Ensure consumers and carers with special expertise participate in staff education/orientation activities within the organisation?
- ✓ Ensure the organisation provides ongoing support, education and training for consumers and carers on their rights and responsibilities and in their participation?
- ✓ Ensure requests for employment or representation of consumers and carers is sought from key consumer and carer groups who are able to provide support and a network of consultation?
- ✓ Ensure a database is maintained of consumers and carers available for participation?

Source: Mental Health Council of Australia

