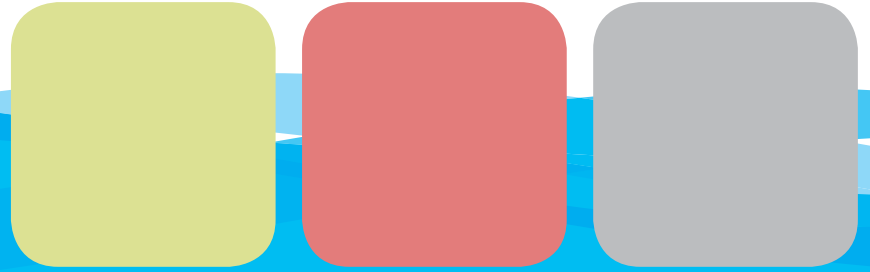


# Mental Health Services



## Consumer and Carer *Participation Framework*

*partners...towards recovery*



Tasmania

DEPARTMENT of  
HEALTH and HUMAN SERVICES

[www.dhhs.tas.gov.au](http://www.dhhs.tas.gov.au)

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# Introduction

I would like to introduce the Tasmanian Consumer and Carer Participation Framework by drawing attention to the vision of the Australian Mental Health Consumer Network - Nothing about me Without me. This vision encapsulates a lot of what we are trying to achieve within the Tasmanian Consumer and Carer Participation Framework.

In particular, Mental Health Services is now in the process of implementing a model of care that is focused on the consumer, and aims to not just *treat* people with a mental illness, but to help them *recover*.

If we are going to do this effectively, we need to involve consumers and their carers in the design, delivery and evaluation of our services. Consumers participation in the development and review of their individual service plans ensures that it is tailored to their individual needs, and is valuable in helping them achieve their goals and aspirations.

While we have come a long way in changing the way mental health services are delivered, consumer and carer feedback reflects that we still have some way to go. The important changes that need to be made will present challenges for us all, especially clinicians and service managers.

For example, we need to recognise that consumers and carers provide valuable insights and are frequently sources of expert feedback on the nature of mental illness and effectiveness of therapies and treatments. We need to recognise the contribution that those voices make not only at the individual level, but also in the development of service wide systems and organisational policy.

The Consumer and Carer Participation Framework allows for organisational development at all these levels. It will encourage the participation of consumers and carers to the level at which they feel comfortable. However, for this to be fully effective in enhancing service delivery, the attitudes and relationships between health care professionals and consumers and carers need to be aligned.

The development of the Consumer and Carer Participation Framework is a good example of how we will work together in the future. The Framework was developed collaboratively, beginning with a number of broad meetings and then by a project group made up of consumers, carers, and Mental Health Services staff. The Framework that has resulted is reflective of the experience of all participants in the system, and sets out a road map for a collaboration framework that will realise the vision for Mental Health Services in 2011 - partners ... towards recovery.



Associate Professor Des Graham  
Director  
Mental Health Services

# The Essence of the Framework

The *Consumer and Carer Participation Framework* sets the direction for participation in Tasmanian Mental Health Services from 2006-07 onwards. It seeks to unite the efforts of the many people in our community who care about mental health and wish to promote both recovery from mental illness and improved wellbeing. An implementation plan will be developed to detail the actions that will be taken to turn the Framework into a practical and effective working system.

The term 'Framework' encompasses the open-minded and flexible approach that has guided both the process of development and the structure and content of the finalised document. The *Consumer and Carer Participation Framework* reflects the cooperative goodwill that enabled the people involved in its development to build a set of action-oriented concepts relevant to our local context. This structure allows us to take logical steps towards progress, while remaining able to adapt to changes in our local circumstances and be responsive to what we learn along the way.

Underpinning this Framework is the belief that participation in mental health services by consumers brings benefits to them and to the services involved. The evidence for this is mounting, as it is for the cost-effectiveness of participation. In addition, research is beginning to show that the involvement of family members and other carers can reduce the frequency and severity of episodes of mental illness for individual consumers, as well as improve the quality of life for everyone in the family. So it makes even more sense to work towards creating a culture of inclusion and collaboration among consumers, carers and service providers to achieve their common aims.

## Why the Framework?

More than a decade ago, the Commonwealth and all state and territory governments agreed that there needed to be a national approach to reform the mental health system from being institutionally based to being consumer focused, with an emphasis on supporting the individual in their community. This agreement became known as the National Mental Health Strategy and is accompanied by a National Mental Health Plan which further guides State governments in progressing mental health reform.

As everybody knows, real change needs more than an agreement at high levels of government. It also requires planning at every level which is centred on national goals and aimed at implementing them in practise.

The newly developed *Strategic Plan for Tasmanian Mental Health Services 2006 – 2011* has been influenced by the priorities of the Department of Health and Human Services, which has responsibility for the delivery of mental health services in Tasmania. Consumer and carer participation is seen as so crucial to the development of better services that it is one of the six strategic priorities for Tasmanian Mental Health Services for the next five years.

The *Consumer and Carer Participation Framework* is a major step forward and is part of continuing efforts to involve consumer and carers to improve outcomes for individuals and the community as a whole.

Mental health problems impact on many individual lives and much of the care and support for those affected takes place outside traditional health services and in private homes. The roles of the consumer, family or other carer, and service provider in care and support are each unique, highlighting the importance and practicality

# The Essence of the Framework

of cooperative relationships that best support each individual consumer in their journey towards improved wellbeing.

Some mechanisms already exist for people to participate in the mental health system in Tasmania. Individual petitions, focus groups, forums, committees, lobby groups and representation by consumer and carer organisations are ways that consumers and carers have some say about the services they experience. It is widely acknowledged that, at this stage, only a limited number of people have access to these mechanisms and we have a way to go to improve opportunities for consumers, family members, carers and service providers to work together in a collaborative way.

The *Consumer and Carer Participation Framework* brings together a number of different processes and mechanisms into one coordinated system of participation. It provides a means for everybody to be clear about what participation might mean at different times and in different places within the mental health system. As a result, participants will receive appropriate support because there will be a better understanding of what sort of support is needed. A flow-on effect may be that even more consumers and carers will feel encouraged to participate, leading to increasingly responsive services that make the best use of available resources.

The *Consumer and Carer Participation Framework* is a key document and has been long awaited by consumers, carers and Mental Health Services staff. It moves us closer to a time when we will talk about the high quality of our services without needing to highlight or justify a particular level of meaningful consumer and carer participation. Instead, it will be understood that, in Tasmania, that is just the way our system works.

## How the Framework was Developed

Since the development of the national reform agenda over a decade ago, much good work has been done to improve participation of consumers in their own treatment, care and support. In addition, gradual recognition of the role of carers has led to a higher profile for families and other carers within the mental health system.

The benefits of increased consumer and carer participation for individuals and services have been highlighted in national and international research and demonstrated by pioneering services across the world (see *Appendix 1: Making a Difference - Some Stories, Story 3 for an Australian example, and Appendix 4: Bibliography*).

The aim of the *Consumer and Carer Participation Framework* was not to produce a detailed document discussing and analysing all available information about participation. Rather, it was to learn from the good work done in other places, connect that with our own rich experiences here in Tasmania and produce a document focused on practical measures to improve the experience of consumers, carers and service providers within our local mental health system.

The development of the Framework began with a number of meetings of representatives from the Tasmanian Community Advisory Group (TasCAG), the Mental Health Council of Tasmania (MHCT), Tasmanian Association for Mental Health (TAMH), the Association for the Relatives and Friends of the Mentally Ill (ARAFMI) and Mental Health Services staff in 2003 and 2004 (see *Appendix 2: Partners in Developing this Framework*). In 2005, forums were held in the three health regions, with the 58 people attending comprising a good mix of consumers, carers and service providers. In addition to information gathered at these forums, written material was received from 23 people.

# The Essence of the Framework

A Project Resource Group, made up of consumers, carers and Mental Health Services staff, guided the development process, influencing everything from the processes and systems outlined in the Consumer and Carer Participation Framework to the structure and language of the final document.

This process has resulted in a Framework that is firmly embedded in the Tasmanian experience, a document that sets the scene and gives us a roadmap for how participation should occur in mental health services in Tasmania.

## The People Involved – Who This Framework is For and About

### Consumers and Carers

Consumers and carers have unique perspectives and these need to be regarded separately as distinct parts of an entire situation. Among individual consumers and carers, there are also, of course, a wide range of differing and unique needs and issues. Finally, some consumers may be caring for someone else with a mental illness, and some carers may become consumers during the course of caring for someone else.

### Consumers

A mental health consumer is a person with a mental illness making use of mental health services. While the term consumer is commonly used in Australia, there are many Tasmanians who find it less than satisfactory. In the interests of being practical and in line with national practice, this document uses it, with apologies to people who are not keen on it, and with hopes that one day a better term will be found.

Consumers want services to be responsive to their unique and individual situations, with individual plans reflecting their own goals and recovery aspirations. They want to be able to access a range of services and know that their experiences and opinions are given due weight by the people they encounter within the mental health system. They want to be carefully listened to, given honest information about their illness, their treatment and its side effects, and their service options, and they want access to people who can answer their questions and help them build their own knowledge and confidence along their journey towards recovery.

### Carers

A carer is a family member, friend or other significant person caring for someone with a mental illness. The role of the carer is not necessarily static or permanent and may vary over time according to the needs of the consumer and carer (Department of Human Services 2004).

Carers want to be treated with respect as members of the care and support network. They want service providers to consider the insights they have gained through knowing and living with the consumer. They want information and education that will help them support the consumer. They would also like there to be recognition that supporting an unwell family member can be stressful at times. Many want to see a widespread attitude shift in service providers where families are valued as an important key to improved wellbeing.

# The Essence of the Framework

## **Consumer and Carer Non-Government Organisations**

Consumer organisations play a crucial role in facilitating successful participation. They work at grass-roots level, have well-connected networks and provide support to consumers. Carer organisations fulfil a similar role for family members and carers of people with a mental illness. Both types of groups enhance the skills of individuals and provide unique support from its members having had similar experiences.

## **Service Providers**

People providing mental health services are the 'other half' of the participation equation and they work in Mental Health Services and non-government organisations. They include clinicians (psychiatrists, psychologists, social workers, nurses, occupational therapists), support workers and case managers. They are supported in their work by managers, policy developers and administrative staff.

## **Other Groups**

This Framework does not specifically refer to general practitioners and the private psychiatric sector, although the principles of participation are equally relevant to their work with consumers and carers.

# Important Principles

During the development of this Framework, consumers, family members, carers and service providers who contributed to the process, identified what they believe are the most important considerations in making participation meaningful. Principles developed for a national framework model for consumer and carer participation were also studied (National Consumer and Carer Forum 2004). *An excerpt is included in Appendix 3: NCCF Participation Principles.* The following principles draw on both of these sources and underpin the Framework:

- Keep the focus on improved health and wellbeing.
- Acknowledge that consumers and carers have distinct needs and provide unique expertise due to their lived experience of mental illness.
- Use inclusive, simple language and avoid jargon.
- Have enough structure to make participation workable and enough flexibility to keep it human and real.
- Be creative and good humoured as much as possible and work together with patience, encouragement, mutual respect, cooperation, compassion and continuing hope.
- Recognise that everyone is learning how to act and work in this new way, and that different types of support will be needed along the way.
- Monitor and evaluate progress to celebrate improvements and get back on track when needed.

# Ways to Participate in Mental Health Services

Broadly speaking, as citizens of Australia, we each have a democratic right to participate fully in our community and achieve our full potential. Each of us has the right to say or write what we think privately or publicly, about the government, or any topic or issue. We also have the responsibility to do this factually and constructively (Department of Immigration and Multicultural and Indigenous Affairs 2005).

Participating in the mental health system may be a logical extension of our nationally recognised rights and responsibilities, but not every consumer and carer does so. Some are not aware that they have a right to be involved in this way, while others don't know how to. Be some people don't feel able to participate at a particular point in time, while others find that services do not provide the opportunity to become involved.

Most consumers, family members and carers are concerned with their individual care and support. For them, participation is an opportunity to address a personal issue and offer constructive solutions for problems, based on their experience and expertise.

Other people want input into service improvement and policy. For them, participation involves having a say about what they see as deficiencies in current services. For example, people may like to see the hospital admissions procedure improved, or greater availability of secure long-term accommodation, better and more secure respite facilities, or the increased availability of case workers or psychiatrists.

Policy decisions are made and prioritised at different levels of government and the service system. Consumers, family members and carers need to know the extent to which they can influence these decisions, and how they can best go about doing this as individuals and as members of an organisation.

The *Consumer and Carer Participation Framework* acknowledges that there are different ways people can participate. The Framework aims to make it as easy as possible for people to participate in whichever way or ways they choose, while making sure that the associated processes can be easily understood and successfully coordinated.

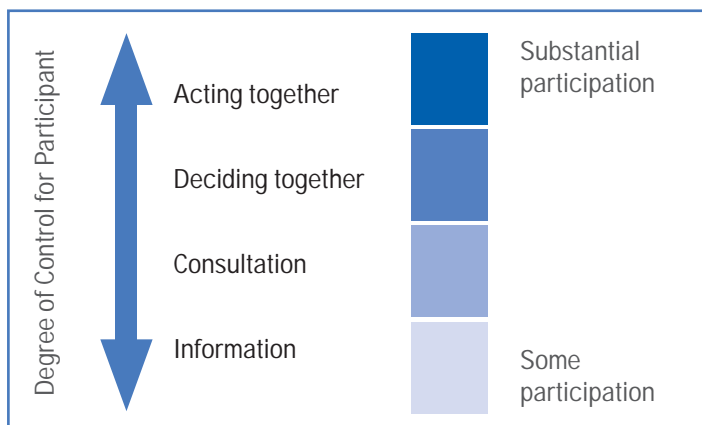
There are two important dimensions to participation in Mental Health Services. One is the extent to which people want to participate and the other is the area or areas in which they want to participate.

# Ways to Participate in Mental Health Services

## Extent of Participation

People may choose to participate to a lesser or greater degree depending on their individual preferences and circumstances, which may change over time. Figure 1 shows a commonly used model for participation which applies well to our Tasmanian setting (Wilcox 2004).

Figure 1: Extent of Participation



**Acting together:** Different interests decide together what is best and also form a partnership to carry it out.

**Deciding together:** The organisation encourages others to provide ideas and options, and join in deciding the best way forward.

**Consultation:** The organisation offers a number of options and listens to the feedback they get.

**Information:** The organisation tells people what is planned or in the process of being planned.

# Ways to Participate in Mental Health Services

## Areas of Participation

Consumers and carers may want to participate in one or a number of areas such as:

**Personal:** Participating in own care, as a consumer or carer, with service provider/s.

**Local Services:** Improving individual services.

**Policy and Service System:** Improving policies and services statewide.

**Government:** Improving policies and services statewide and nationally.

Figure 2: Areas of Participation for Consumers and Carers

Personal – Individual Service Providers
Local Services – Range of Individual Services
Policy and Service System – Tasmanian Mental Health Services
Government – Mental Health Policy and Planning (state and national)

Although the areas of participation stand alone, there will be a natural flow-on effect if resources and effort are concentrated in the 'Personal' area. As consumer and carer participation at that level grows and strengthens, the shape of services will start to reflect the experiences and expectations of participants. Over time, the influence of consumers and carers on these services will grow in legitimacy and form a vital part of the knowledge base that guides the development of new policies and services. Figure 2 shows how each area relates to the others and Figure 3 provides detailed examples.

# Ways to Participate in Mental Health Services

Figure 3: Summary of the variety of ways people may choose to participate in each area

Area	Examples	How Initiated	Support Needed
<b>1. Personal</b> <ul style="list-style-type: none"> <li>Individual care and support for consumers</li> <li>Involvement of family members and carers</li> </ul>	<ul style="list-style-type: none"> <li>Direct involvement with service provider in development of individual plans</li> <li>Participation in case conferences with service providers</li> <li>Family/carer meetings with service providers</li> </ul>	<ul style="list-style-type: none"> <li>Consumer and/or carer in discussion with their service provider</li> <li>Service provider in discussion with consumer and/or carer</li> </ul>	<ul style="list-style-type: none"> <li>Discussions to raise awareness among consumers, carers and service providers</li> <li>Training and/or mentoring for consumers and carers</li> <li>Training and/or mentoring for service providers</li> </ul>
<b>2. Local services</b> <ul style="list-style-type: none"> <li>Planning</li> <li>Developing</li> <li>Improving</li> <li>Reviewing</li> <li>Evaluating</li> <li>Providing</li> </ul>	<ul style="list-style-type: none"> <li>As a worker eg consumer consultant, carer consultant, peer support worker in Mental Health Services and non-government organisation services</li> <li>On consumer advisory groups set up within services and programs</li> <li>Through consultation processes eg when new services are being set up</li> <li>As a delegated representative at planning meetings, in reference and working groups for projects, on job selection panels as appropriate</li> <li>As a reviewer in Accreditation processes</li> <li>By lodging complaints for investigation and service improvement through Mental Health Services, Official Visitors Scheme, Health Complaints Commissioner</li> </ul>	<ul style="list-style-type: none"> <li>Employed by Mental Health Services, non-government organisation or other organisation eg University</li> <li>Nominated via agreed representative processes</li> <li>Complaint initiated by consumer, carer or official visitor in response to matter of concern</li> </ul>	<ul style="list-style-type: none"> <li>Training and/or mentoring for consumers and carers</li> <li>Training and/or mentoring for service providers</li> <li>Support with governance and other organisational processes for consumer and carer bodies and mental health services</li> </ul>
<b>3. Policy and service system</b> <ul style="list-style-type: none"> <li>Planning</li> <li>Developing</li> <li>Improving</li> <li>Reviewing</li> <li>Evaluating</li> <li>Reforming</li> </ul>	<ul style="list-style-type: none"> <li>As a worker eg consumer consultant, carer consultant, peer support worker in Mental Health Services and non-government organisation services</li> <li>Representative on Mental Health Services statewide management group, on policy working groups, in Accreditation processes, on national policy forums</li> <li>In-specific programs designed to make social environments more consumer-friendly (eg government working parties to improve access to sport or employment programs)</li> </ul>	<ul style="list-style-type: none"> <li>Employed by Mental Health Services, non-government organisation or other organisation eg University</li> <li>Nominated via agreed representative processes</li> </ul>	<ul style="list-style-type: none"> <li>Training and/or mentoring for consumers and carers</li> <li>Training and/or mentoring for service providers</li> <li>Support with governance and other organisational processes for consumer and carer bodies and mental health services</li> </ul>
<b>4. Government</b> <ul style="list-style-type: none"> <li>Ministerial advice</li> </ul>	<ul style="list-style-type: none"> <li>Representative on Ministerial Advisory Group or through peak body</li> </ul>	<ul style="list-style-type: none"> <li>Nominated via agreed representative processes</li> </ul>	<ul style="list-style-type: none"> <li>Support with governance and other organisational processes for consumer and carer bodies and mental health services</li> </ul>

Refer to Appendix 4 for more detailed descriptions and discussion points for each area.

# Making the Framework Work

Meaningful participation by consumers and carers in Tasmania's mental health system requires commitment and acceptance of change on the part of everybody involved. Many people who have been working steadily for some years to improve consumer and carer participation are confident about what needs to be done, and point out that a plan that is specifically resourced will enable much to be achieved. As well as building on local talent and expertise, we can tap into the wealth of expertise and resources available from other states. A common quality of the people consulted was their generosity with ideas and resources, and their willingness to help out to make life better for people who have a mental illness.

## 1. Coordination and Monitoring

There will need to be strong and effective coordination of both structural and functional aspects of the Framework. This means coordination of relevant processes within consumer and carer organisations, within Mental Health Services, and within Mental Health Services-funded non-government service providers. A coordinated approach will result in less duplication and confusion, and maximise efficiency and consistency.

Regular monitoring and documentation of progress of the implementation of the Framework will keep everybody's efforts on track. It will also encourage people to build on what is working well, and move quickly to address problems. Monitoring will, over time, demonstrate the contribution of participation to individual, service and system improvements.

Clarity and agreement on the basic functions required for consumer and carer participation, as described in this Framework, highlight the best way to organise and manage those functions in Mental Health Services.

## 2. Information

People need to be well informed to be able to participate. Good, simple information about a range of topics should be made available to anyone who wants to participate more actively.

Basic topics would include:

- A listing of all mental health services, including an outline of how they are organised and how to access them
- Guidelines for participation processes
- Guidelines for making complaints
- Information about privacy and confidentiality.

Information would also be tailored for different groups of people according to specific concerns and interests. This would include languages other than English, different literacy skills, communication with people with hearing impairment etc.

Avenues for providing the information include printed material, on-line websites, single-point telephone contact for enquiries, public forums and telephone and video-links.

# Making the Framework Work

Information will need to be marketed and promoted widely so as many people as possible are aware of the options available to them and can then participate where and how they want.

## 3. Feedback Processes

Mechanisms and procedures are needed for receipt, processing and resolution of suggestions, queries and complaints. Without any processes to deal with this feedback, potential participants will be easily discouraged, especially if they are not informed of the response to their concerns. Processes should be designed in such a way that consumers and carers are reassured that they need have no fear of retribution. Encouraging suggestions and responding to complaints at the earliest opportunity will result in problems being addressed while they are still relatively small. Doing this will also improve the chance of addressing problems at the local level which often brings the best outcomes for all involved.

## 4. Support for Individuals

Resources will need to be directed towards providing support for individuals so that they become more confident in participation, whether as consumers, carers or service providers. Several consumers and carers who participated in the development of the Framework were keen to emphasise that all service providers be involved, including psychiatrists. Some of the ways that this would happen include:

### Training

Some programs would be offered to all groups ie consumers, carers and service providers; others would be offered to each of the groups individually. There are already a number of packages developed in other states which could be purchased or borrowed and run locally.

Topics would include:

- Participation basics
- Assertiveness skills
- Advocacy skills
- How to participate in decision-making processes
- How to run consultative processes
- How to work with government departments
- How to work collaboratively
- How to set up consultation processes that suit all groups.

As much as possible, programs would be run collaboratively, however there would be occasions when consumer and carer organisations and mental health services (government and non-government) would run their own programs.

# Making the Framework Work

## Networking

Regular forums would provide opportunities for consumers and carers to meet with service providers to explore aspects of working collaboratively as well as specific issues to do with service improvement. Opportunities could also exist for connecting with the private sector, probably through the National Network of Private Sector Psychiatric Consumers and Carers. Stories of successful innovations could be shared and new ideas explored. The format of these forums could include facilitated group discussion followed by time for general talk, giving people the opportunity to connect in more informal ways.

## Mentoring and Supervision

As consumers develop their knowledge and skills in participation and take more of an active role in their own care and support, they will be trying out new strategies. Having someone to debrief with, reflect on how they handled a situation, and what they might do differently another time is crucial in building their confidence. The same is true for carers. Consumer and carer organisations will play an important role in this process, with individuals with more experience guiding and supporting those new to this way of working.

Service providers will also benefit from both debriefing and supervision by peers, supervisors and managers as they hone their skills and become more confident in working collaboratively with consumers and carers.

## Improving Access

There will need to be attention paid to practical ways that will help people to participate, for example, child care, transport and assistance with costs. There will also need to be policy decisions made about remuneration for people who participate.

## 5. Capacity Building for Consumer and Carer Organisations

Resources will need to be directed towards strengthening the capacity of consumer and carer organisations to support and improve participation. Some of the ways that this will happen include training and mentoring in:

- governance
- how to run organisations well
- how to develop policies
- how to have accountable and transparent operations
- how to evaluate programs
- how to make representation work well.

A coordinating organisation would have an important role in working with consumer and carer organisations to produce or procure good resources and run the required training and mentoring programs.

# Making the Framework Work

## 6. Representation Processes

Representation processes need to reflect the community they are set up for and be as fair as possible. The National Consumer and Carer Forum provides helpful guidance in this area, highlighting the importance of selection processes that are transparent and fair, representation processes that are as broad-reaching as possible, and representative of the unique perspectives of consumers and carers (National Consumer and Carer Forum).

Barriers exist that discourage people from participating in the mental health system – some are systemic and others personal. Systemic barriers for consumers and carers include lack of opportunities; lack of education and training; and lack of processes and mechanisms to support participation. Systemic barriers for service providers include inadequate supporting processes and mechanisms, including training.

At the personal level, constraints for consumers include:

- lack of experience and confidence in this area
- work or other competing responsibilities or interests
- reluctance to be public about their situation, especially in smaller communities
- wanting to keep mental illness a small part of their life.

Also at the personal level, a major constraint for carers is the difficulty in being able to take time away from their already busy roles as employees and carers, not just of the consumer they may be supporting, but often other family members too.

The Framework aims to keep processes as simple as possible so that people can concentrate on what they want to achieve, rather than waste valuable time trying to find out how to be heard.

Although some organisations are working hard to have good representation practices, further development is needed. A structure of representation created under the overall care-taking of a coordinating body which can bring the various organisations together would be beneficial. Regular contact and work shared between organisations enables everybody to see clearly what it is that each organisation does and how well they are doing it. This has a flow-on effect of clarity and quality for the members of each organisation. Effective coordination ensures streamlined processes and sharing of resources which results in a continuity of approach that is easily understood by everybody.

Improving representation processes is important and may encourage more meaningful involvement by consumers, carers and other interested community members. As representative organisations grow stronger, they could become hosts for community action for mental health, holding meetings to formulate proposals for policy improvements and feeding back information to members, perhaps using specifically directed sub-committees.

# Making the Framework Work

Regardless of however much representation processes are improved, it will remain true that not everyone wants to or is able to participate through organisations. Individuals should always feel welcome to contribute in their own way, even though the major avenue of participation in services and the service system may well continue to be via organisational representation.

## 7. Remuneration

Resources will need to be directed towards real recognition of the efforts of consumers and carers in contributing to service and policy improvements in the Tasmanian mental health system. This will include updating policy and guidelines for payment of fees and reimbursement for costs for one-off and ongoing efforts as part of structured participation processes, and payment of salaries in the case of consumer and carer consultants.

## 8. Evaluation

All systems need evaluation and feedback, and resources will need to be directed towards evaluating the success of this Framework. This will need to commence as soon as possible in order to design the evaluation processes and collect baseline information. Feedback to consumers and carers on how their participation is helping to improve the system would be a powerful measure of the true value of participation and everyone's efforts into putting this Framework into action.

Decisions will need to be made about:

- the extent of evaluation to be undertaken
- who will perform it
- what will be measured and monitored and how often
- how and to whom it will be reported
- who has the responsibility for the implementation of any recommendations.

Regular public meetings around the state would be a useful way to ensure transparency of the monitoring process. Progress of the Framework could be discussed and further feedback sought, with people sharing their good experiences of participation as well as talking and planning together on areas needing attention.

# The Shape of Things to Come

The *Consumer and Carer Participation Framework* signals the beginning of a united and determined new approach to improving the wellbeing of people with mental illness and their carers.

As we begin implementing the Framework, we need to recognise that changing the culture of our mental health system to give participation a dominant role is an enormous task that will require patience as well as enthusiastic support.

Mental Health Services is committed to this Framework and prepared for the long-term dedication of resources and support that will be needed to make meaningful participation a reality in Tasmania.

An Implementation Plan will be developed to address the eight areas identified previously as crucial to the success of the Framework, namely:

- 1. Coordination and Monitoring**
- 2. Information**
- 3. Feedback Processes**
- 4. Support for Individuals**
- 5. Capacity Building for Consumer and Carer Organisations**
- 6. Representation Processes**
- 7. Remuneration**
- 8. Evaluation.**

Implementing the Framework will take some years. Each area requires intensive initial activity to establish systems, processes and supporting structures. After this, varying degrees of activity will be required to sustain momentum, monitor and review progress, and make changes and improvements as necessary.

Mental Health Services will implement the Framework progressively as part of the *Strategic Plan 2006 – 2011*, which has Participation and Partnerships as one of its major goals.

# Appendix 1: Making A Difference – Some Stories

## Story 1: From a Tasmanian consumer involved with a consumer advisory group

From the first group meetings I attended a few years ago, I was inspired and could see hope for us in the future. Mainly as I had known for some time that the previous system had not very much idea how we felt and what we needed to do to express, resolve and heal. Basically the overpowering authorities gave us not much of a good future, little advice and no participation in our own destiny: basically no hope. We were usually chemically suppressed and made to stay out of sight and 'out of mind'. We were expected to just survive, and not live and achieve as others could. This was very distressing as we all know and remember.

To start with, this new process and its approach is logical, creates new hope, courage, inspiration and (finally after the pain and suffering), a community and self help organisation that I feel is blessed by God in spirit and flesh.

We have lost too many confused consumers in the past, due to the clinical attitude and misunderstanding by professional advisors, who often lack real knowledge or life experience.

There is no going backward, in future it's all onward and forward for a contented and happy life for all involved. Thanks for your hard work and confidence in us all – good luck relates to good management.

### *Postscript*

My children and most of my other family members support me and love me unconditionally, 100%. They have been there in the hard and difficult times and have had to bear the burden almost as much as I did. They deserve a lot of respectful admiration.

# Appendix 1: Making A Difference – Some Stories

## Story 2: From a Tasmanian consumer involved with a consumer advisory group

When I was approached to become a member of Tasmanian Community Advisor Group (TasCAG) as a Consumer Representative I had no idea this was to involve me in participation! I hoped I was doing the organisation the favour. Now, as I end my time on the Executive, I feel sad.

Participating in the consumers' groups has given me the opportunity to be involved with other consumers and carers who have the main goal of improving mental health services to my community. To do this, I have had to stay motivated and interested in the welfare of others. I have had goals, which in turn helped me to 'keep well' and motivated. There are times when on the road to recovery I feel alone as a mental health consumer.

To give, rather than always receive and to serve rather than be served, has always given me a boost to my morale. I have always had a need to help others. To be able to participate has enabled me to see I have a positive future and I am able to continue to function and take my part in the life of my community. This, in spite of being a 'Mental Health Consumer'!

I have learnt to ignore adverse response to my condition. I try to alert others that I may be too sensitive and raise my voice unexpectedly, however sometimes it is hard to remain confident in social situations. The more I participate, the more I learn about myself and my condition.

A final comment, perhaps my participation in TasCAG may have benefited by more formal training if that were available.

## Story 3: Between a consumer and a general practitioner

A General Practitioner (GP) was reviewing the care of Tim, a 38 year old man. The GP used a clinical perspective to identify his problems as being bipolar disorder and high blood pressure. He was also overweight, his alcohol intake was high and he had not been taking his various medications regularly. The GP asked Tim what he saw as 'his problems' and his answer was simply and sadly, "I don't want to lose contact with my son." He had recently separated from his partner and the custody of his 10-year-old boy was being considered. The GP worked with Tim to develop an Individual Program Plan that was based on an overall goal of Tim maintaining a relationship with his son. All his medical problems were managed with that goal constantly in sight and Tim took a real interest in his own treatment and care.

# Appendix 1: Making A Difference – Some Stories

## Story 4: From a non-government organisation employing consumer consultants

Prahran Mission, a large non-government organisation in Victoria provided this story from some 15 years experience in working closely with consumers.

Prahran Mission was the first community-based organisation in Victoria to employ a Consumer Consultant, using private money from a small bequest. The position fits into a culture where 'recovery' from severe and long-term mental illness is accepted and acted upon. It took three years for the position to become integrated with all programs and the organisation itself, to be part of the value system and culture of recovery.

The first and very crucial step was to have a clear Job Description, which was accepted by the Board of Governance, staff, consumers and the successful candidate. The position was advertised internally and outside via newspapers, consumer newsletters and networks, and via email to other similar organisations.

The role included attending forums such as *Have Your Say Meetings*, which were program meetings where staff and consumers decided on future plans for particular programs, running a consumer forum meeting, being available for consumers to bring their concerns about programs and mechanisms (not personal), monthly attendance at Senior Managers' meetings to give feedback about consumer ideas and concerns, and to help with addressing of problems. Also, attendance at Board of Governance meetings a couple of times a year proved valuable as this is where resources are allocated for larger and long-term plans and problems. The Consumer Consultant was also invited by clinical services and community forums to attend a myriad of external meetings to advise on consumer participation and give input into how to go about improving outcomes. Other community organisations such as Richmond Fellowship Victoria also began to consider a like role and called on Prahran Mission's experiences to help with their plans.

Prahran Mission's management knew that the first Job Description would need constant assessment and revision. The eternal problem related to the huge nature of the job role. It was important that the Consumer Consultant felt able to say 'no', so the Job Description became very specific about responsibilities. Also, it became clear that there was a need for constant support and supervision by a Senior Manager as well as peer support.

Most important for the position's success, which in turn meant improved access and participation for all consumers, was the way formal structures and mechanisms helped all areas of the organisation address the Consumer Consultant's findings. An example was how recommendations in a Report on 'Reducing Stigma', which the Consumer Consultant had researched with other consumers, were implemented. The Board of Governance put the recommendations into the Three Year Strategic Plan and allocated resources. All programs accepted the recommendations and the issue is part of ongoing discussions, planning and processes.

Acceptance of this position by other staff was not immediate. Some staff initially felt threatened and expressed concern that their work and programs could be undermined. Gradually a culture of working together developed.

# Appendix 1: Making A Difference – Some Stories

## Consumer Participation at all levels of the Organisation

At Prahran Mission consumer participation is encouraged at all levels of the organisation, from membership on the Board of Governance, to having a say about organisational issues and giving input into individual program planning. This has been the case for at least three decades. Consumers give input into the Three Year Strategic Plan.

Attention has been given to access points, mechanisms and formal structures. In addition, ideas and issues are addressed at the appropriate level so that consumers feel validated.

It is important that consumers are encouraged and supported to participate, and that their participation is real. That is, that change occurs. Encouragement and support come from staff and other consumers, as well as families and carers. Training is an important issue and the Mission has just begun to address this issue. At the Board of Governance level, peer support by another Board member who is prepared to talk about issues, and go through minutes and papers with the Consumer Representative, has been in operation for many years. More is required.

## Employment of Consumers

Prahran Mission has a long history of employing consumers. There are so many success stories. Their employment has enriched the organisation in many ways – they certainly keep the organisation honest. They challenge Departmental and organisational thinking eg questioning what is 'evidence-based practice' when nobody has asked them and heard about their experiences. They see certain accepted practices as harmful and anachronistic to their ability to recover.

One of our consumers came to Prahran through the *JobSupply Employment Program*. She is brilliant, committed to the values of the Mission, speaks with authority to Management and the Board and is now in a leadership role where she helps to deliver training as a consumer. She is a role model for other consumers, who often pop up to see her in the library, chat about issues and go away with literature relevant to their situation.

## Volunteering

Many consumers work as volunteers, often on their pathway to skills, learning and paid employment. Most are supported to volunteer in other organisations.

## Consumer-Operated Services

There are many different consumer-operated services around the world, some in Australia. This is an area for further consideration. Consumers are demanding more of it with very good reasons: relevance, cost effectiveness, identification of gaps in services and better outcomes. Consumers and their families see that much more is possible.

## Values

The story of consumer participation at Prahran Mission is not complete without mention of the values and culture that support participation by both consumers and staff. The psychosocial rehabilitation programs at the Mission express values such as hope, acceptance, welcome and inclusiveness. These values underpin the experience

# Appendix 1: Making A Difference – Some Stories

of recovery and also participation by consumers. Moving from being a consumer to being a staff member can involve a transitional period where you feel like neither one nor the other. However, the community that has evolved at the Mission is an inclusive one that also provides the space to grow into new roles.

*Thanks to Joan Clarke and Dianne Friend for this story and other helpful advice in the development of this Framework.*

*Joan Clarke, OAM, PhD, is former CEO of Prahran Mission and Member of the Victorian Ministerial Advisory Committee on Mental Health, and currently Consultant and Trainer at the Centre of Psychosocial Rehabilitation, Prahran Mission.*

*Dianne Friend MBus (IT), Grad Dip Media, AALIA is Assistant Director of the Centre of Psychosocial Rehabilitation at Prahran Mission. She has personal experience of the recovery journey from perspectives of being a researcher, consumer and staff member.*

## Story 5: From a consumer involved in participation in the private sector

I am a consumer and consumer representative in the private mental health sector. I am a member of The Hobart Clinic's Consumer and Carer Advisory Committee and the Tasmanian representative for the National Network of Private Psychiatric Sector Consumers and Carers. Many issues and problems are common to both the public and private sectors. Adequate and appropriate standards of service provision, continuous quality improvement, and a comprehensive definition of consumer and carer participation are needed for both sectors. Moreover, from the viewpoint of a consumer representative who is very interested in both sectors, there is an urgent need for meaningful integration between the two sectors.

The Hobart Clinic's Consumer and Carer Advisory Committee has operated enthusiastically and productively since its inception in 2002. For example, it has conducted forums for staff, consumers, carers, and NGOs. Perhaps the most revealing was a carer forum organised in November, 2004. As in the public sector, carers play an indispensable role in the provision of mental health services; yet in practice this role is frequently ignored, rejected or undervalued. In some cases this appears to be a response to the requirement that the consumer's privacy be protected. Whether this is a pretext or a reality is debatable. The carer's rights are not observed nearly so assiduously. Our forum made it abundantly clear that carers want genuine recognition at all service levels; they want greater access to service providers, especially doctors; they want substantially more educational opportunities for gaining the information and skills necessary for self-care and utilising community resources, especially support groups and crisis services; and full-time carers want a higher level of remuneration than they currently receive. Because of our forum, The Hobart Clinic is making a determined effort to improve carer participation at the hospital level. Furthermore, partly because of my representation, the National Network has made carer participation a priority in its strategic plan for the next three years.

# Appendix 1: Making A Difference – Some Stories

The National Network of Private Psychiatric Sector Consumers and Carers seeks to represent the national interests of those involved in the private sector. Apart from matters directly related to private health insurance, the National Network has become an integral part of key policy and decision-making processes affecting many Australians in both the private and public sectors. Recently, it produced a submission to the *Senate Select Committee on Mental Health*, raising such issues as the availability of services across the continuum; acceptance of genuine consumer and carer participation; integration between the private and public sectors; consumer and carer-driven education of service provider personnel; adequate training of consumer and carer representatives; reform of national standards for mental health services; and the special needs of such groups as children, adolescents and the aged, indigenous Australians, and those living in rural and remote areas.

Thanks to The Hobart Clinic and the National Network, I recently attended the 15th Annual Mental Health Services Conference in Adelaide. I was able to share ideas and gain valuable advice concerning consumer and carer participation in the private and public sectors and in the non-government organisations. This was especially rewarding in the light of the emphasis placed on deinstitutionalisation, holistic care, and the recovery-focused model.

As a consumer representative, I have also been directly involved in the public sector consultations. I sincerely believe that there must be greater integration between the two sectors, especially concerning consumer and carer participation. Partnerships, involving government assistance and private provider cooperation, and the ability of consumers to traverse easily between settings are required if optimal outcomes are to be achieved. Moreover, there can be meaningful integration in terms of involvement in programs aimed at training consumer and carer representatives for more than token participation in both sectors.

*Thanks to Trevor G Bester for this story.*

# Appendix 2: Partners In Developing This Framework

As mentioned earlier in this document, much work has already been done in Tasmania on improving participation, and several consumer and carer organisations have made significant contributions to this developing work. They include:

- Tasmanian Community Advisory Group (TasCAG)
- Mental Health Council of Tasmania (MHCT)
- Tasmanian Association for Mental Health (TAMH)
- Association for the Relatives and Friends of the Mentally Ill (ARAFMI), in the north and the south of the state
- Tasmanian Mental Health Consumer Network

Along with many other organisations, they will have important roles in future developments.

# Appendix 3: National Consumer and Carer Participation Forum Principles

The following best practice principles (National Consumer and Carer Forum 2004) have been identified as necessary steps for implementing consumer and carer participation, and are presented as a standard benchmark for mental health organisations to aim for when promoting and practising consumer and carer participation.

## 1. Core Principles

- Consumers and carers provide unique expertise due to their 'lived' experience of mental illness
- Consumer and carer participation will be promoted at all levels of mental health care
- Consumers and carers have distinct and separate needs
- Mental health organisations will seek formal and informal links with peak bodies for jurisdictional representation
- Mental health organisations are encouraged to adopt or adapt this participation policy to local needs
- Mental health organisations will need to adapt to the particular communication and participation needs of representatives

## 2. Principles for defining the role of consumer and carer representatives

- The role of consumer and carer representatives is to be clearly defined for all staff members
- Consumer and carer representatives have responsibilities to fulfil
- Mental health organisations will be prepared for ill health affecting consumers and carers
- Mental health organisations will have conflict resolution processes in place

## 3. Principles for selection of consumer and carer representatives

- Mental health organisations will select appropriately supported consumer and carer representatives
- Mental health organisations will select appropriately skilled consumer and carer representatives
- Mental health organisations will have transparent processes for the selection of consumer and carer representatives
- Mental health organisations will provide information to assist with the recruitment of consumer and carer representatives

# Appendix 3: National Consumer and Carer Participation Forum Principles

## 4. Principles for employment of consumer and carer representatives

- Consumers and carers will be remunerated for representative duties
- Consumer and carer representatives will receive relevant and necessary ongoing support, education, training and resourcing
- Mental health organisations will utilise consumers and carers as educators
- Mental health organisations will ensure adequate information flows and feedback mechanisms
- Review and evaluation of consumer and carer participation will occur annually

# Appendix 4: Areas of Participation – Detailed Descriptions

## 1. Personal

### Types of Participation

Consumers	Carers and Family Members
Individual care and support	Involvement in consumer's care and support

### Where Participation Occurs

May be consumer's or carer's home or service facility

### Examples

Consumers	Carers and Family Members
<ul style="list-style-type: none"> <li>• Direct involvement with service provider in development of individual plans</li> <li>• Participation in case conferences with service providers</li> </ul>	<ul style="list-style-type: none"> <li>• Family/carer meetings with service providers</li> <li>• Participation in case conferences with service providers</li> </ul>

### How Participation is Initiated

Consumers	Carers and Family Members
<ul style="list-style-type: none"> <li>• In discussion with service provider</li> </ul>	<ul style="list-style-type: none"> <li>• In discussion with service provider</li> </ul>

### Suggested Discussion Points

- Who will attend the meeting?
- Who will arrange it?
- How will privacy and confidentiality be managed?
- What care and support is being recommended?
- What facilities are available and how can they be accessed?
- What other assistance is available (respite, supported accommodation, Centrelink)?
- What other advice and tips can be offered?
- What follow up will there be?

### Support Needed to Enhance Participation

- Information and discussions to raise awareness among consumers, carers and service providers about individual participation
- Training and/or mentoring for consumers and carers
- Training and/or mentoring for service providers

# Appendix 4: Areas of Participation – Detailed Descriptions

## 2. Local Services

### Types of Participation

Planning, developing, reviewing, evaluating and providing services

### Where Participation Occurs

Meetings, visiting facilities

### Examples

- As a worker eg consumer consultant, carer consultant, peer support worker in Mental Health Services and non-government organisation services
- On consumer advisory groups set up within services and programs
- Through consultation processes eg when new services are being set up
- As a delegated representative at planning meetings, in reference and working groups for projects, on job selection panels as appropriate
- As a reviewer in Accreditation processes
- By lodging complaints for investigation and service improvement through Mental Health Services, Official Visitors Scheme, Health Complaints Commissioner

### How Participation Might Be Initiated

- Employed by Mental Health Services
- Employed by Quality Management Systems
- Employed by non-government organisation or other organisation eg University
- Nominated via agreed representative processes
- Complaint initiated by consumer, carer or Official Visitor in response to matter of concern

### Suggested Discussion Points

- Is there a position description (if a worker/consultant)?
- Is there a role description or terms of reference (if delegated representative in meetings, reference and working groups for projects, Accreditation reviewer)?
- Are there guidelines (if on selection panels)?
- Have we explored the extent of participation eg consultation, joint decision-making, acting together? Are consumers and carers equal participants in the process?
- Does the person have sufficient information about any constraints that are not negotiable and might impact on the decision-making process?

# Appendix 4: Areas of Participation – Detailed Descriptions

- Is the person expected to consult further with other consumers or carers?
- Is the person expected to provide feedback to the organisation they are representing?
- Is there a particular process to follow when lodging a complaint? What feedback can the person expect to receive?

## Support Needed to Enhance Participation

- Information and discussions to raise awareness among consumers, carers and service providers about this level of participation
- Training and/or mentoring for consumers and carers
- Training and/or mentoring for service providers
- Capacity building for organisations
- Support with governance and other organisational processes for consumer and carer organisations and mental health services

## 3. Policy and Service System

### Types of Participation

Planning, developing, reforming, reviewing and evaluating policy

### Where Participation Occurs

Meetings

### Examples

- As a worker eg consumer consultant, carer consultant, peer support worker in Mental Health Services and non-government organisation services
- Representative on Mental Health Services statewide management group, on policy working groups, in Accreditation processes, on national policy forums
- In specific programs designed to make social environments more consumer-friendly (eg government working parties to improve access to sport or employment programs)

### How Participation Might Be Initiated

- Employed by Mental Health Services
- Employed by Quality Management Systems
- Employed by non-government organisation or other organisation eg University
- Nominated via agreed representative processes

# Appendix 4: Areas of Participation – Detailed Descriptions

## Suggested Discussion Points

- Is there a position description (if a worker/consultant)?
- Is there a role description or terms of reference (if delegated representative in meetings, reference and working groups for projects, Accreditation reviewer)?
- Have we explored the extent of participation eg consultation, joint decision-making, acting together?
- Does the person have sufficient information about any constraints that are not negotiable and might impact on the decision-making process?
- Is the person expected to consult further with other consumers or carers?
- Is the person expected to provide feedback to the organisation they are representing?

## Support Needed to Enhance Participation

- Information and discussions to raise awareness among consumers, carers and service providers about this level of participation
- Training and/or mentoring for consumers and carers
- Training and/or mentoring for service providers
- Support with governance and other organisational processes for consumer and carer organisations and mental health services

## 4. Government

### Types of Participation

Ministerial advice

### Where Participation Occurs

Meetings

### Examples

- Representative on Ministerial Advisory Group or through peak body

### How Participation is Initiated

- Nominated via agreed representative processes

### Suggested Discussion Points

- Is there a role description or terms of reference (if delegated representative in meetings, reference and working groups for projects, Accreditation reviewer)?

# Appendix 4: Areas of Participation – Detailed Descriptions

- Have we explored the extent of participation eg consultation, joint decision-making, acting together?
- Does the person have sufficient information about any constraints that are not negotiable and might impact on the decision-making process?
- Is the person expected to consult further with other consumers or carers?
- Is the person expected to provide feedback to the organisation they are representing?

## **Support Needed to Enhance Participation**

- Training and/or mentoring for consumers and carers
- Training and/or mentoring for service providers of peak body
- Support with governance and other organisational processes for peak body and other consumer and carer organisations

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# Notes:

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The background of the page is a vibrant blue with several overlapping, wavy, horizontal bands of varying shades of blue, creating a sense of movement and depth. The bands are semi-transparent, allowing the colors underneath to show through. The overall effect is clean, modern, and calming.

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