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10.1. ATTACHMENT 1 Project Brief

10.2. ATTACHMENT 2 Membership of the Project Reference Group

Reference Group Membership

Chairperson	Joanna Birdseye, Manager, Service Monitoring and Review, Mental Health Branch
Executive Officer	Gilbert Van Hoeydonck, Senior Project Officer, Service Monitoring and Review, Mental Health Branch
Members	Freida Andrews, Senior Project Officer, Service Planning and Development, Mental Health Branch
	Robyn Duff, Area Manager, Northern Area Mental Health Service
	Andrew Howard, Senior Project Officer, DHS Grampians Regional Office
	Anne Jeffs, Consumer Consultant, North East AMHS
	David Mithen, Consumer Consultant, Bendigo Health Care Group
	Jenny Smith, Area Manager, Inner West Area Mental Health Service
	Julie Van Dort, former Consumer Consultant (parent representative) at Travancore

10.3. ATTACHMENT 3 Project Discussion Paper

10.4. ATTACHMENT 4 Methodology

Consultation Strategy

Overview

In November 1998 Service Quality Australia was contracted by the Mental Health Branch of the Victorian Department of Human Services to review consumer participation in public mental health services in Victoria. Key objectives of the project were to:

1. *Assess how effectively the policy of consumer participation has been implemented in Victoria's mental health services with a view to improving consumer input into service planning, development, delivery and evaluation.*
2. *Identify best practice in consumer participation locally, nationally and internationally.*
3. *Provide recommendations about future policy development that will ensure meaningful consumer participation in mental health services in Victoria.*

These three objectives were to be achieved through meeting a number of specifications set out in the Tender Brief. Three of these specifications impacted on methodology:

1. *Conduct an evaluation of consumer participation in Victoria's twenty-one (21) Area Mental Health Services using a range of methods that may include*
   - *a survey tool to gather information*
   - *structured interviews with individuals and focus groups*
   - *review of relevant documentation.*
2. *Ensure that the proposed methodology allows for extensive consultation with the range of stakeholders. These include AMHS managers, staff (including consumer consultants), consumers and carers, consumer/carer advocacy organisations and DHS regional staff.*
3. *Respect the right to confidentiality of all participants in the review.*

Key Issues

In conducting this evaluation a range of issues needed to be addressed. These issues related to the complex dynamics of the public mental health system and, if not addressed, would limit the effectiveness of the evaluation. The biggest impact was likely to be on the design of the consultation process. The following is a summary of these issues.

Involving the Range of Stakeholders

A diverse range of stakeholders have an interest in the implementation of consumer participation in public mental health services. In developing a consultation strategy it was important that all these stakeholders had an opportunity to contribute.

Consumers were clearly the most important people to involve in consultations. Consumer participation is fundamentally about consumers. The success or failure of consumer participation policy is necessarily determined by the perceptions of consumers. Therefore consultation strategies needed to focus largely on maximising consumer input. However, while this evaluation was specifically focused on the role of consumers in decision-making, the participation of others who may at times act as representatives for consumers also needed to be considered. Thus, it was important to ensure carers and advocates had an opportunity to participate in the consultations.

As one of the key mechanisms for consumer participation, consumer consultants were essential to involve in the evaluation. They were able to undertake a dual role in consultations. On the one hand their thoughts on consumer participation were likely to be highly informed with a strong consumer focus, on the other they were a key means of contacting a wide range of consumers who might be interested in participating in consultations.

Psychiatric Disability Support Services, peak bodies and a range of statewide and regional consumer organisations needed to be involved to ensure a broader perspective was brought to the evaluation.

Finally, the people responsible for developing and implementing consumer participation strategies needed to be consulted. Department of Human Services staff have guided and overseen development of policy, service managers have developed and implemented a range of strategies, and staff (including allied health staff, clinicians, case managers and nursing staff) have implemented those strategies on the ground.

Definitions

In order to evaluate consumer participation in public mental health services a number of terms needed to be defined. Service Quality Australia, in consultation with the Project Reference Group, developed definitions that were detailed enough to enable people to understand the project focus, but were sufficiently open to allow people to explore issues without feeling too constrained.

Who are Consumers

For the purposes of this evaluation consumers were considered to be people who had used, or were currently using, public mental health services.

Definition of Consumer Participation

Consumer participation can be defined in a number of ways. In this evaluation it was taken in its broadest sense as referring to the right of people who use services to play an active role in decision-making about those services. This ranges from decisions about the services they receive as individuals, through to decisions about how services are planned, managed, delivered and evaluated. At another level it also

includes decisions about how government policy and programs are developed and implemented.

The Goals of Consumer Participation

In order to assist people to think about consumer participation it was considered important to set out some of the potential goals of consumer participation. On this basis effective consumer participation was seen to be achieved when consumers were able to influence how mental health services were provided.

As stated in its *Guidelines for Consumer Participation in Mental Health Services* (1996), the Department of Human Services is committed to ensuring consumers play an effective role in the delivery, planning and development of mental health services so that:

- Services are consumer-focused and responsive to consumer views.
- Services achieve improved outcomes for consumers.
- Consumers' experiences and views are incorporated in service planning and development.
- Staff receive feedback on appropriate standards of practice.

These goals for consumer participation were taken as the starting point for discussions in the consultation process.

Diverse Service Types

The consultation strategy needed to take into account the different service types operating in the public mental health system. These were identified as:

- acute inpatient
- non-acute inpatient (such as Community Care Units)
- community-based

Each presented a unique relationship between service provider and consumer. While many aspects of consumer participation practice applied across service types each would have some unique requirements for effective consumer participation. Data gathered needed to enable analysis at this level.

Different Service User Groups

Area Mental Health Services in Victoria are divided according to the age of consumers:

- Child and Adolescent Mental Health Services
- Adult Mental Health Services
- Aged Persons Mental Health Services

In order to provide an effective analysis differences between these services needed to be explored. Issues affecting consumer participation were likely to vary. For children and adolescents the tension between consumer participation, carer responsibility and the child's transition to adulthood needed to be acknowledged. For Aged Persons' Mental Health Services issues arising from long-term, deteriorating mental health and the role of the consumer's carer in decision-making were important to explore.

The Nature of Clinical Services

It was important to take into account that a significant proportion of services provided by Area Mental Health Services were clinical services. The evaluation needed to be sensitive to the intensity of the service experience, as well as the clinical focus of most services. The existence of Involuntary Admissions, Hospital Orders and Community Treatment Orders, which impact on the consumer's right to participate in some aspects of decision-making, were also important to acknowledge in an exploration of consumer participation.

Consultation Strategy

A wide array of survey tools were used to ensure cost-effective but broad and comprehensive input from consumers and other stakeholders. The consultants aimed to give opportunities to stakeholders in all Area Mental Health Services an opportunity to participate in the evaluation. Direct contact was used wherever possible.

Opportunities for input included:

- Focus groups
- Interviews (face-to-face and over the phone)
- Freecall 1800 telephone service
- Written submissions
- Service provider questionnaire

Table 1 Consultation Matrix provides details of the range of strategies used, the stakeholders targeted and the range of Area Mental Health Services involved in the evaluation.

Focus groups and interviews were conducted intensively in the period 7 December to 18 December 1998. Some interviews were conducted after this period where it was considered that more information was needed to assist in analysis.

The Freecall 1800 telephone service could be contacted during business hours in the period 7 December to 18 December 1998. People who rang after that date were still interviewed up to 24 December.

Written submissions could be submitted up to 15 January 1999.

Service provider questionnaires could be submitted up to 15 January 1999.

Notification of Stakeholders

The range of opportunities to be involved in the evaluation process were advertised in a number of ways.

A Consumer Flyer was developed to advertise opportunities for input available to consumers. A copy of the Flyer is at the end of Attachment 7.

An Evaluation Framework and Discussion Paper was developed to provide all stakeholders with information about opportunities to participate in the evaluation. In addition, it detailed background information and questions to guide the consultation process. A copy of the Evaluation Framework and Discussion Paper is at Attachment 3.

Several copies of the Discussion Paper and ten copies of the Flyer were distributed with explanatory letters via all Area Mental Health Services, Psychiatric Disability Support Services and consumer consultants. Current mailing lists provided by the Department of Human Services were used.

A number of additional methods were used to ensure as many consumers as possible were notified about opportunities to have input. These included use of informal networks of consumers, Area Mental Health Service newsletters, and a consumer internet site. A presentation was made to VICCAG about the project and members were asked to circulate information about the project. Both VICSERV and VMIAC carried information about the project as an insert to their December 1998 Newsletters.

Evaluation Framework

An Evaluation Framework was developed to provide a structure to consultations. This Framework contained definitions, background information and a series of evaluation topics. There were six key topics which in turn were broken down into several specific questions. The key topics were:

1. What you understand consumer participation to mean.
2. The purposes of consumer participation in public mental health services.
3. What makes consumer participation effective.
4. Your experiences in relation to consumer participation in Victoria's public mental health services.
5. What differences you believe consumer participation strategies have made to mental health services.
6. How consumer participation can be improved.

A copy of the Evaluation Framework is at Attachment 3.

The Framework was developed in consultation with the Project Reference Group.

Coverage of Stakeholders

Consultation with Adult Consumers

To ensure adequate coverage of consumers three separate strategies were employed to gain feedback. These were: regional focus groups, the Freecall 1800 telephone service and written submissions. Consumers were informed of these opportunities through distribution of the Flyer and the Evaluation Framework and Discussion Paper.

Focus groups were held in a number of metropolitanpolitan and rural locations. However, not all areas were covered. To ensure input from consumers in areas where there were not focus groups the Flyer and the Discussion Paper both encouraged consumers to participate by using the 1800 Freecall number or providing a written submission.

Consumers were strongly encouraged to use these alternatives if they were unable or did not wish to attend a focus group.

Consumers who participated in focus groups or used the 1800 Freecall service were taken through questions set out in the Evaluation Framework, but also had opportunities to make other comments or suggestions in relation to consumer participation.

Consultation with Consumer Consultants

A number of focus groups and individual interviews were organised with consumer consultants. The aim was for a minimum fifty percent coverage of consumer consultants employed in public mental health services, with sufficient representation of metropolitanpolitan and rural services to enable meaningful analysis of results.

Focus groups and interviews with consumer consultants were structured using the questions in the Evaluation Framework as a guide.

Consultation with Staff and Managers

Staff and Managers had opportunities to participate through interviews, focus groups and written submissions. Managers had additional opportunities to participate through completion of a Questionnaire on Consumer Participation. Staff and Managers from all service types within Adult, Aged Persons and Child and Adolescent Mental Health Services were targeted.

Focus groups and interviews with staff and managers were conducted as structured interviews based on the Evaluation Framework.

Consultation with Consumers and Carers in Child and Adolescent and Aged Persons Mental Health Services

Specific focus groups and interviews were set up to ensure input from consumers and carers in Child and Adolescent and Aged Persons Mental Health Services. These also were based on the Evaluation Framework.

Consultation with Other Stakeholders

A range of focus groups and individual interviews were organised to ensure input from:

- Consumer advocacy groups
- Carer representatives
- Psychiatric Disability Support Services
- Department of Human Services - Mental Health Branch

Details about the number of people who participated and their roles in the service system are at Attachment 5.

Coverage of Service Type, Focus and Location

As stated above, direct consultation was not designed to provide blanket coverage of all Area Mental Health Services. To ensure data was available to enable analysis at the

appropriate level interviews and focus groups were organised for consumers, direct service delivery staff and managers of:

Child and Adolescent Mental Health Services
Aged Persons Mental Health Services
Adult Mental Health Services

This was done for both rural and metropolitan Area Mental Health Services. Details of the range of Area Mental Health Services targeted can be found in Table1 - Consultation Matrix.

Freecall 1800 Telephone Service

The Freecall 1800 telephone service was advertised in the Flyer and Discussion Paper. Consumers were strongly encouraged to use this service, but other stakeholders were also able to ring. It was presented as an opportunity for people who, for whatever reason, were unable or did not wish to participate in focus groups.

The service operated during business hours from December 7 to December 18 inclusive. A Telephone Typewriter (TTY) was available for deaf consumers , and the Victorian Interpreting and Translating Service was linked to the Freecall service for people requiring a language interpreter. These facilities were advertised in the Flyer, and the Victorian Deaf Society were advised of the evaluation and this service.

De-briefing from the telephone interview was offered to consumers through VMIAC, which had agreed to accept referrals. Respondents were also made aware that their contribution was confidential and that they could retract any of their statements up to the time of writing of this report.

Respondents could opt for a question/answer interview structure or for a more open ended discussion. Questions followed the Feedback Topics stated in the Flyer, with additional detailed questions from the Evaluation Framework and Discussion Paper. This paper was also referred to for definitions, for instance: the definition of consumer.

The Report of Freecall 1800 Telephone Responses is located at Attachment 7.

Written Submissions

Opportunities to provide written submissions were advertised in the Flyer and Discussion Paper. Submissions were invited from anybody with an interest in the evaluation. People who were not involved in direct consultations (interviews and focus groups) were strongly encouraged to provide written submissions. Submissions could be mailed, faxed or e-mailed.

People sending written submissions were encouraged to use the Evaluation Framework outlined in the Discussion Paper as a basis for submissions. However, they could use other formats if they preferred.

Details of written submissions received can be found at Attachment 5.

Service Provider Questionnaire

A questionnaire was distributed to all public mental health services in Victoria. The questionnaire was mailed out using a current mailing list provided by the Department of Human Services in late December 1998, with responses requested by mid January 1999.

The questionnaire was developed specifically for this evaluation. It was designed to give public mental health service providers the opportunity to evaluate consumer participation in their services in two ways.

1. To identify current practices, including the degree to which a range of consumer participation practices and policy initiatives such as consumer consultants and Consumer Participation Plans had been implemented.

2. To rate the service's performance in relation to key criteria for effective consumer participation.

Analysis of data from the questionnaire was set at the level of service type, service focus and location. Within these the following categories were examined:

1. Service type
   - Acute inpatient
   - Non-acute inpatient
   - Community-based

2. Service focus
   - Adults (Adult Mental Health Service)
   - Aged Persons (Aged Persons Mental Health Service)
   - Children and Adolescents (Child and Adolescent Mental Health Service)

3. Location
   - Metropolitanpolitan
   - Rural

The Report on Service Provider Questionnaire Responses is located at Attachment 6.

Identification of Effective Practice Examples

A process for identification of effective practice examples was developed. This included:

- a review of national and international literature on consumer participation
- initial scoping interviews to identify well-known best practice examples in Victoria
- identification of effective practice during consultations with follow-up interviews and examination of documentation
- phone interviews with people involved in nationally recognised effective practice examples

Information about perceived effective practice in Victoria was requested from Area Mental Health Services and non-government services. This was done partly through the mail-out

of material notifying stakeholders of the project, partly through contact with consumer consultants, and partly through information gathered during focus groups and interviews. Where good practice was identified in mental health services interviews were conducted to determine the factors which had led to this outcome.

Confidentiality

Confidentiality was an important requirement for many stakeholders prior to providing their candid views on the effectiveness of consumer participation strategies. Confidentiality was reinforced by:

- ensuring participation was informed and voluntary
- ensuring potential participants in focus groups and interviews were contacted in ways which maintained their privacy and confidentiality to the highest degree possible
- ensuring that the reporting of findings did not contain information that would enable the identification of individuals without their expressed permission

Strengths and Limitations of Consultation Approaches

As with any evaluation the approach taken in this project has strengths and limitations.

Focus groups and interviews

Focus groups and interviews were designed to provide rich qualitative data about consumer participation practice in public mental health services. The structured interview approach was used to ensure that consistent information was gathered in focus groups and interviews. This made it possible to analyse data derived from all services and stakeholders.

The relative merits of qualitative data, as opposed to quantitative data, has been well researched. Given the need to focus on the experiences of stakeholders and to explore what had and had not worked in implementation of policy the emphasis on qualitative data was considered most appropriate for this evaluation.

One limitation within consumer consultations was that not all consumers were familiar with the concept of consumer participation. While this was an important observation about consumer participation in public mental health services, it also meant that there were less opportunities for informed consumer analysis of some consumer participation strategies. Fortunately, a number of consumers, as well as the consumer consultants, were very familiar with current initiatives.

Other limitations relate to who participated in consumer consultations. Specific efforts to ensure consultations accessible were made via such things as the availability of a telephone typewriter (TTY) and interpreter services through the Freecall 1800 number. However, unless consumers were part of a current consumer or service network they would not be aware of consultations. This meant that groups not strongly linked to existing consumer participation networks were particularly likely to have lower participation rates, eg participation by people with dual diagnosis, people from non-English speaking backgrounds and Koories was likely to be limited.

Participation of consumers of Child and Adolescent and Aged Persons Mental Health Services was also likely to be limited due to the existence of fewer consumer participation mechanisms (such as consumer consultants) thus limiting opportunities to inform consumers and carers about the project. In addition, issues that generally provided challenges to effective consumer participation in these services, as discussed earlier in this methodology section, were also likely to limit participation in the evaluation.

Written submissions

Written submissions were complementary to focus groups and interviews. They enabled respondents to provide a more detailed and considered response to the key evaluation questions. In this way a wide range of perspectives could be provided, giving greater depth to the data. Written submissions tend to be more reflective and often well researched, contextualising responses gained from more immediate processes such as focus groups and interviews.

Service Provider Questionnaire

The questionnaire used in this project provided both quantitative and qualitative data about practice in public mental health services. As such it was designed to elicit responses from a cross-section of services across Victoria. Detailed comparisons could then be made between services according to type, focus and location. In addition, it provided data that was complementary to the qualitative data gathered in focus groups, interviews and written submissions. A number of conclusions gathered from these processes could be tested against questionnaire data, thus enabling a more balanced analysis.

The obvious limitation of this type of questionnaire is that a number of the measures (but certainly not all) were subjective. There will always be biases arising from self-reporting. However, when taken with the wide range of techniques for gathering data this limitation is minimised.

Overall

This evaluation of consumer participation in public mental health services used a diverse range of approaches. Both qualitative and quantitative data was sought from the range of stakeholders. This approach minimised biases implicit in any one evaluation technique. There were likely to be challenges in accessing all stakeholders. The most likely gaps were amongst consumers.

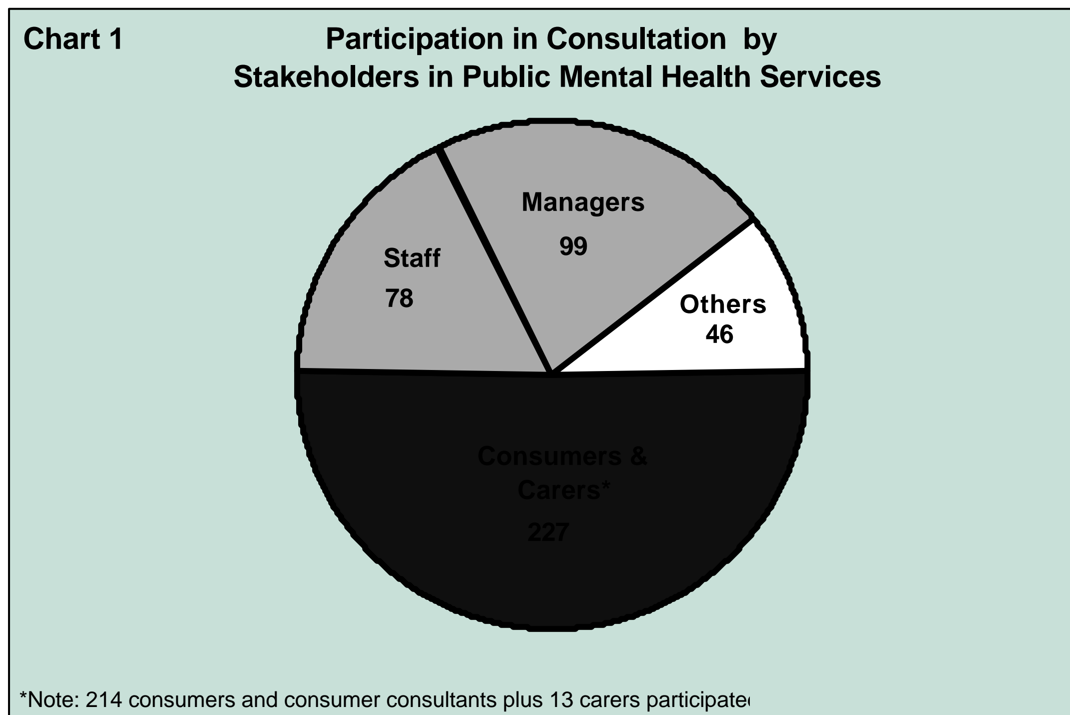
Table 1 Matrix Highlighting Consultation Strategies Used for all Area Mental Health Services and Stakeholder Groups

Area Mental Health Service	Consumer Focus Groups Adults Aged Child & Adolescent			1 800 number	Consumer Consultant Focus Groups/Interviews	Service Provider Questionnaire	Direct care staff focus groups Acute / Community based		Manager Interviews**
North Eastern/ Wangaratta & Wodonga	Yes			Yes	Yes	Yes	Yes		Yes
Goulburn	Yes			Yes	Yes	Yes	Yes		Yes
Gippsland				Yes	Yes	Yes			Yes
Loddon Campaspe /Southern Mallee	Yes	Yes		Yes	Yes	Yes		Yes	Yes
Northern Mallee				Yes	Yes	Yes			Yes
Barwon				Yes	Yes	Yes			Yes
Glenelg				Yes	Yes	Yes			Yes
Grampians				Yes	Yes	Yes			Yes
North East	Yes			Yes	Yes	Yes			Yes
Northern	Yes			Yes	Yes	Yes	Yes		Yes
Dandenong	Yes	Yes		Yes	Yes	Yes	APMHS		Yes
Inner South East	Yes			Yes	Yes	Yes			Yes
Middle South	Yes	Yes		Yes	Yes	Yes	APMHS		Yes
Peninsula		Yes		Yes	Yes	Yes			Yes
Mid West	Yes		Yes	Yes	Yes	Yes		Yes	Yes
North West	Yes		Yes	Yes	Yes	Yes		Yes	Yes
South West	Yes		Yes	Yes	Yes	Yes			Yes
Inner West	Yes		Yes	Yes	Yes	Yes			Yes
Inner Urban East	Yes			Yes	Yes	Yes			Yes
Central East	Yes		Yes	Yes	Yes	Yes		CAMHS	Yes
Outer East	Yes	Yes	Yes	Yes	Yes	Yes		CAMHS	Yes

** Some interviews were conducted by telephone

Other focus groups include: Carers, Advocacy Groups, and Non-govt. organisations

10.5. ATTACHMENT 5 Project Participation



Others (46) includes: Psychiatric Disability Support Services, DHS Regional Staff, Peak Bodies, Advocacy Groups, Advisory Groups/Committees and Officers, Non-Mental Health Professionals, Community Visitor/Coordinator, Researchers, and interstate (10) and international (1) individuals with expertise or experience in consumer participation.

Staff include: AMHS Acute Staff, AMHS Community Based Staff, APMHS Staff, CAMHS Staff

Managers include: AMHS Managers, APMHS Managers, CAMHS Managers.

Key to abbreviations: AMHS = Adult Mental Health Service, APMHS = Aged Persons Mental Health Service, CAMHS = Child & Adolescent Mental Health Service.

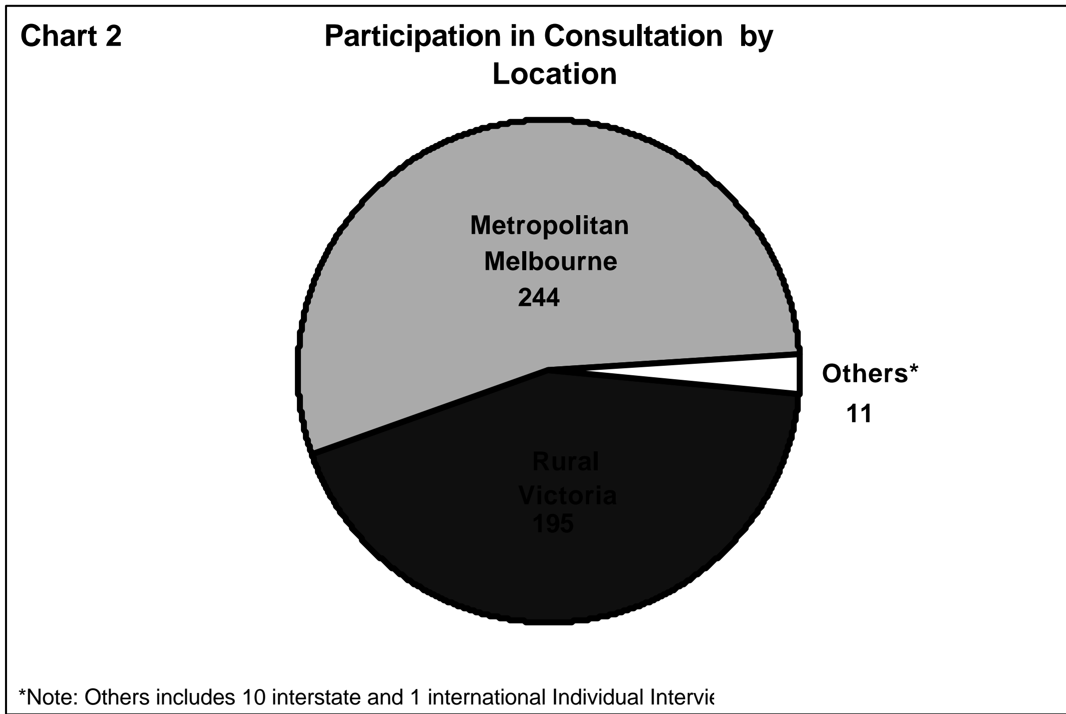


Chart 2
Participation in Consultation by Location
Metropolitan Melbourne
244
Others*
11
Rural Victoria
195
*Note: Others includes 10 interstate and 1 international Individual Intervie

Summary Of Participants In Consultations

Table 1. Rural Participants In Consultations

INFORMATION SOURCE > STAKE HOLDERS v	Focus Group Partici-pants	Individual Interview	Q'aire / Survey	1800 Phone Service	Written Sub-mission	TOTAL
Consumer Consultants	10	7	-	-	7	24
Carers (only)	-	2	-	2	1	5
AMHS Consumers	55	4	-	12	5 (incl 1gp)	76
APMHS Consumers	-	3	-	-	-	3
CAMHS Consumer/Carers	-	2	-	-	-	2
AMHS Acute Staff	3	-	-	-	-	3
AMHS Com'ty Based Staff	9	3	-	-	-	12
APMHS Staff	10	-	-	-	-	10
CAMHS Staff	-	-	-	-	-	0
AMHS Manager	-	6	15	-	-	21
APMHS Manager	-	1	13	-	1	15
CAMHS Manager	-	-	6	-	-	6
PDSS*	6	-	-	-	1	7
DHS Regional Staff	-	5	-	-	-	5
Other**	1	3	-	2	-	6
TOTAL	94 #	36	34	16	15	**195**

* **PDSS** : Psychiatric Disability Support Services, and includes Non Government Service Providers.
** **Other** includes : Advocacy Groups, Advisory Groups and Officers, Non- Mental Health Services Professionals, Community Visitor/Coordinator.
# 94 individuals were consulted via 16 focus groups held in rural Victoria.
Key to abbreviations: AMHS = Adult Mental Health Service, APMHS = Aged Persons Mental Health Service, CAMHS = Child & Adolescent Mental Health Service.

Table 2. Metropolitanpolitan Melbourne Participants In Consultation

INFORMATION SOURCE > STAKE HOLDERS v	Focus Group Partici-pants	Individual Interview	Q'aire / Survey	1800 Phone Service	Written Sub-mission	TOTAL
Consumer Consultants	25	7	-	-	2	34
Carers (only)	3	1	-	3	1	8
AMHS Consumers	34	3	-	7	5	49
APMHS Consumers	2	-	-	9	-	11
CAMHS Consumer/Carers	15	-	-	-	-	15
AMHS Acute Staff	3	1	-	-	-	4
AMHS Com'ty Based Staff	28	-	-	-	1	29
APMHS Staff	10	-	-	-	-	10
CAMHS Staff	5	4	-	-	1	10
AMHS Manager	6	3	20	-	-	29
APMHS Manager	1	1	12	-	1	15
CAMHS Manager	1	3	9	-	-	13
PDSS*	-	3	-	-	3	6
DHS Regional Staff	-	-	-	-	1	1
Other**	1	6	-	2	1	10
TOTAL	134 #	32	41	21	16	**244**

* **PDSS** : Psychiatric Disability Support Services includes Non Government Service Providers.
** **Other** includes : Peak Bodies, Advocacy Groups, Advisory Groups/Committees and Researchers.
# 134 individuals were consulted via 29 focus groups held in metropolitanpolitan Melbourne.
Key to abbreviations: AMHS = Adult Mental Health Service, APMHS = Aged Persons Mental Health Service, CAMHS = Child & Adolescent Mental Health Service.

Table 3. Total Participants In Consultations

INFORMATION SOURCE > STAKE HOLDERS v	Focus Group Partici-pants	Individual Interview	Q'aire / Survey	1800 Phone Service	Written Sub-mission	TOTAL
Consumer Consultants	35	14	-	-	9	58
Carers (only)	3	3	-	5	2	13
AMHS Consumers	89	7	-	19	10 (incl. 1gp)	125
APMHS Consumers	2	3	-	9	-	14
CAMHS Consumer/Carers	15	2	-	-	-	17
AMHS Acute Staff	6	1	-	-	-	7
AMHS Com'ty Based Staff	37	3	-	-	1	41
APMHS Staff	20	-	-	-	-	20
CAMHS Staff	5	4	-	-	1	10
AMHS Manager	6	9	35	-	-	50
APMHS Manager	1	2	25	-	2	30
CAMHS Manager	1	3	15	-	-	19
PDSS**	6	3	-	-	4	13
DHS Regional Staff	-	5	-	-	1	6
Other***	2	20**	-	4	1	27
TOTAL	228 #	79	75	37	31	**450**

* **Consumer consultants** includes more than one contact with some individuals.
****PDSS** : Psychiatric Disability Support Services includes Non Government Service Providers.
*** **Other** includes : Peak Bodies, Advocacy Groups, Advisory Groups/Committees and Officers, Non-Mental Health Services Professionals, Community Visitor/Coordinator, Consumer Groups and Researchers. **11 interviews with interstate and international (1 New Zealand consumer) individuals with expertise or experience in consumer participation are included in the totals for this table and do not appear in Table 1 or Table 2** (see List of Interviews Conducted Re: Literature Review).
# 228 individuals were consulted via a total of 45 focus groups.
Key to abbreviations: AMHS = Adult Mental Health Service, APMHS = Aged Persons Mental Health Service, CAMHS = Child & Adolescent Mental Health Service.

List of Interviews Conducted Relating to the Literature Review

- Paul Cain Australian Psychiatric Disability Coalition (APDC)
- Jan Carter Deakin University
- Desley Casey Northern Sydney Area Health Service, NSAS Mental Health Consumer Network
- David Clark VICSERV
- Disability Employment Action Centre
- Mabine Drake Health Consumer Council (Western Australia)
- Merinda Epstein Consumer Consultant
- Julian Gardiner (President) Mental Health Review Board
- Judy Hardy Network of State Consumer and Carer Advisory Committees (NOAC)
- Jenny Luntz Alfred CAMHS
- Mara Pacers Prahran Mission
- Arane Pearson (New Zealand)
- Kate Silburn Health Issues Centre
- Greg Turner Queensland Consumer Advisory Group
- Yolande Wadsworth Research Fellow, Dept. Psychology, Victoria University
- Wendy Weir (New South Wales)
- Peter Wellington Australian Transcultural Mental Health Network

Written Submissions Received:

Thirty one written submissions were received, 12 from individuals or agencies requesting not to be named. Some were from private individuals and some from people representing agencies. Submissions were received from:

- Carol Andrew
- Bairnsdale & Sale Consumer Groups (combined submission)
- Janice Chesters Team Leader Sale, Special Needs Access Program Inc. (SNAP)
- Sandra Davidson Manager, Aged Psychiatry Service, Wangaratta District Base Hospital, North East Psychiatric Services
- Sophie Delaney Solicitor/Policy Worker, Mental Health Legal Centre
- Chris Dickinson A/Executive Officer, Inner East Mental Health Services Association

- Julie Johnstone Researcher/ Student
- Steafan Kilkeary Social Worker/Teacher, Health and Community Studies, NMIT
- Anne McLoughlin Senior Social Worker, Convenor Consumer Participation Working Group, Austin & Repatriation Medical Centre, Child & Adolescent Mental Health Service
- Olwyn New
- George Osman Program Manager (Aged Psychiatry), Peter James Centre, Inner & Easter Health Care Network
- Pam Rycroft Program Manager - Clinical Services, The Bouverie Centre
- Samantha Taylor
- Peter Wellington Transcultural Psychiatry Unit

10.6. ATTACHMENT 6 Report of Service Provider Questionnaire Responses

Background

This report presents the findings from a questionnaire designed to gain input from Victoria's public mental health service providers about consumer participation in their services. The questionnaire was part of an independent evaluation of consumer participation undertaken by Service Quality Australia on behalf of the Mental Health Branch of the Department of Human Services. Key evaluation objectives of the project were:

- To assess how effectively the policy of consumer participation has been implemented in Victoria's public mental health services with a view to improving consumer input into service planning, development, delivery and evaluation.
- To identify best practice in consumer participation locally, nationally and internationally.
- To provide recommendations about future policy development that will ensure meaningful consumer participation in public mental health services in Victoria.

A range of strategies aside from the questionnaire were used to ensure input from key stakeholders in public mental health services. This consisted of focus groups, meetings and interviews throughout Victoria. A Freecall 1800 telephone service and opportunities to provide written submissions were also made available to ensure involvement of people who would otherwise be unable to participate.

Aim of This Report

The aim of this report is to present the findings of the questionnaire returns and provide an analysis of these findings in relation to the project objectives. Specifically, it provides an analysis of the service provider perspective on:

- Consumer participation as it has been implemented in services, including Consumer Participation Plans
- The service provider experience of the Consumer Consultant Program
- Performance of the service in relation to key criteria for effective consumer participation

Methodology

Distribution

A questionnaire was distributed to all public mental health services in Victoria. Specific services within Area Mental Health Services, as well as statewide services, were targeted. The questionnaire was mailed out using a current mailing list provided by the Department of Human Services in late December 1998, with responses requested by mid January 1999.

Level of analysis

Analysis of data from the questionnaire was set at the level of service type, service focus and location. Within these the following categories were examined:

1. Service type
   - Acute inpatient
   - Non-acute inpatient
   - Community-based

2. Service focus
   - Adults (Adult Mental Health Service)
   - Aged Persons (Aged Persons Mental Health Service)
   - Children and Adolescents (Child and Adolescent Mental Health Service)

3. Location
   - Metropolitanpolitan
   - Rural

Confidentiality was guaranteed, with responses to be returned directly to Service Quality Australia. Therefore, nothing from the data analysis identifies specific services or areas.

Respondents were able to mail the questionnaire back using Freepost.

Questionnaire design

A questionnaire was developed specifically for this evaluation. A copy can be found at the end of this report. The questionnaire was designed to give public mental health service providers the opportunity to evaluate consumer participation in their services in the following ways:

1. To identify current practices.

2. To rate their perception of the degree to which a range of consumer participation practices have been implemented.

3. To rate their perception of he service's performances in relation to key criteria for effective consumer participation.

Current Practice

Service providers were asked to rate the level of consumer participation they believed the service had achieved in three key areas:

1. At the individual service level.
2. In service planning and delivery.
3. In service evaluation.

In addition, the implementation of two key consumer participation initiatives was examined:

1. Consumer Participation Plans.
2. Consumer consultants.

Providers were asked to rate their service on a range of typical consumer participation practices. Most questions required the provider to rate the degree to which consumers participated in a specific practice. In these cases providers were asked to rate the degree of participation on a five point scale, with 1 rated as “Always” and 5 as “Rarely”.

There were also a range of checks made in relation to particular practices. Providers were asked to note whether these practices were in place or not.

In other cases examples or evaluative comments were requested.

The specific practices measured are detailed in the questionnaire at the end of this report.

Service Performance

Service providers were asked to rate what they perceived to be the the performance of their service in achieving effective consumer participation practice using five key criteria.

These criteria were:

1) This service has a systematic way of incorporating the views of consumers on the operational practice of the service and its staff.

2) This service has a clear strategy by which consumers are involved in service planning and evaluation activities.

3) This service has a clear process by which consumers can lodge complaints and have them considered.

4) This service advertises in a prominent way the opportunities for consumer involvement.

5) This service has a process for selecting consumers for in-service planning and evaluation activities.

Providers were asked to rate themselves using a 5 point scale, ranging from 5 - “not doing at all” through 3 - “adequate” to 1 - “doing outstandingly well”.

Approach to Data Analysis

To facilitate analysis the 5 point ratings scales were collapsed to 3 point scales. This was done to identify general trends in the data. Therefore, ratings used in the section on Current Practice have been redefined as follows:

Ratings of 1 or 2 have been collapsed into a rating titled "Frequent".

A rating of 3 has been titled "Usual".

Ratings of 4 or 5 have been collapsed into a rating titled "Infrequent".

Ratings used in the section on Service Performance have been redefined in a similar way:

Ratings of 1 or 2 have been collapsed into a rating titled "Good".

A rating of 3 has been titled "Adequate".

Ratings of 4 or 5 have been collapsed into a rating titled "Not adequate".

Results

Response were received relating to 78 services across all Area Mental Health Services. The responses were as follows:

35 responses from Adult Mental Health Services
  20 metropolitan
  15 rural

25 responses from Aged Persons Mental Health Services
  12 metropolitan
  13 rural

15 responses from Child and Adolescent Mental Health Services
  9 metropolitan
  6 rural

3 responses from statewide services

Several questionnaires were completed by managers on behalf of several services from the one Area. These have been treated as if there were separate responses from each of Adult, Aged Persons and/or Child and Adolescent Services listed. It is important to note the effect of this on data analysis. Differences between Adult, Aged Persons and Child and Adolescent Services will have been reduced. Thus, where differences have been identified it is likely that in reality these differences would be even more pronounced.

Limitations to Analysis

The questionnaire is based on a self-reporting model. As such the responses in most cases reflect the perceptions of the service provider. Perceptions of performance are obviously not the same as more objective measures. However, a number of questions did require data that was externally valid. This enabled perceptions of performance to be checked against external measures. In addition, data gathered from other consultation processes used in the project enabled these perceptions to be further compared. This rich mixture of perceptual and objective information was designed to enable complex analysis to take place. However, in the end all ratings based on perceptions need to be viewed as such and not mistaken for statements of fact.

While responses were provided from services in all Area Mental Health Services, not all services responded. This needs to be taken into account in analysing the data. For instance, questionnaire responses indicate that about one third of Adult Mental Health Service have not developed Consumer Participation Plans. Yet direct consultations indicate that when all services are taken into account this figure is much closer to fifty percent.

The sample size is, however, sufficient to reveal general trends and enable a range of useful comparisons. It is only when differences are fairly minor, or where there have been insufficient responses in relation to a particular element of service provision, that analysis would not be meaningful. All these elements have been taken into account in the analysis presented in this report.

Findings In Relation to Adult Mental Health Services

Current Practice

The extent of consumer involvement in a range of consumer participation practices varied considerably between Adult Mental Health Services. However, clear trends emerged, with higher consumer participation rates in individual decision making, and lower consumer participation rates for organisational decision-making.

Trends relating to specific measures are detailed here:

Individual Service Level

Adult Mental Health Services generally believed active consumer involvement in Individual Service Plan (ISP) development and ongoing treatment and care decisions was "frequent".

Consumer involvement in acute care treatment decisions, medication decisions and decisions about legal status was generally rated as "usual".

Carer input into treatment and care was considered to be "frequent".

Service Planning and Delivery

Adult Mental Health Services generally viewed consumer involvement in decisions relating to service delivery as "frequent".

Twenty-seven of the thirty-five respondents identified one or more service planning committees on which consumers were current members. Of these respondents five cited one or two committees that had consumer members, while the other twenty two cited four or more such committees.

Consumer involvement in other planning committees were predominantly considered to be “usual” and “infrequent”.

About half of respondents said that participants were reimbursed for costs of committee membership. Most other respondents said that participants were neither reimbursed nor subsidised for these costs.

Seventy percent of respondents said they had a designated support person for consumer committee members.

Service Evaluation

Involvement of consumers in the planning of service evaluations was considered to be “infrequent” by most services. In contrast to this a majority of services rated the extent to which consumers were asked for their views on service quality as “frequent”.

There was a split between services on whether consumers were given feedback about their contribution. Half the services believed this practice was “frequent” in their service while a slightly smaller group rated it as “infrequent”. A similar trend occurred in regard to whether consumer views on service improvement were implemented.

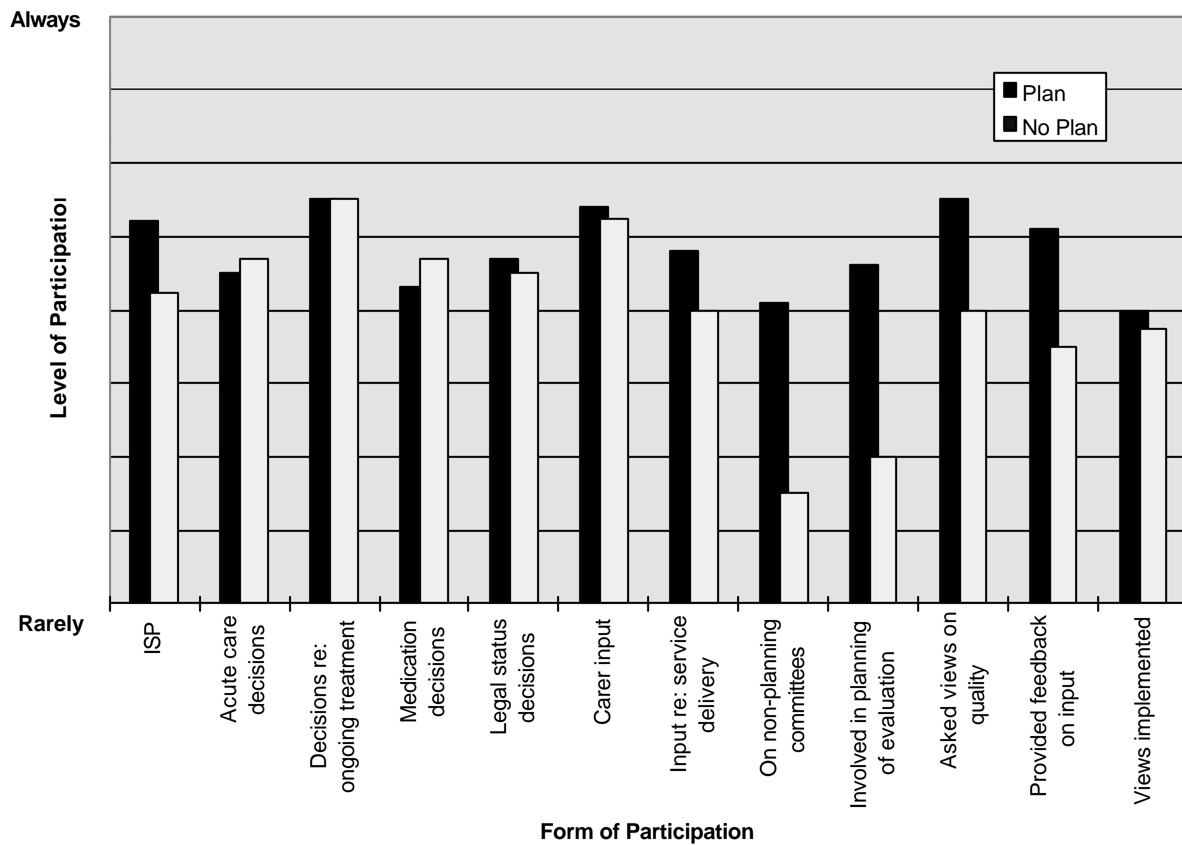
Most services did not have any consumer-managed evaluation projects in place.

Consumer Participation Plans

Of the thirty-five Adult Mental Health Service respondents twenty-two said they had Consumer Participation Plans in place. Nineteen of these had involved consumers in the development of their Plans, twenty were currently implementing Plans, and twenty were reviewing implementation through a specific group that included consumers.

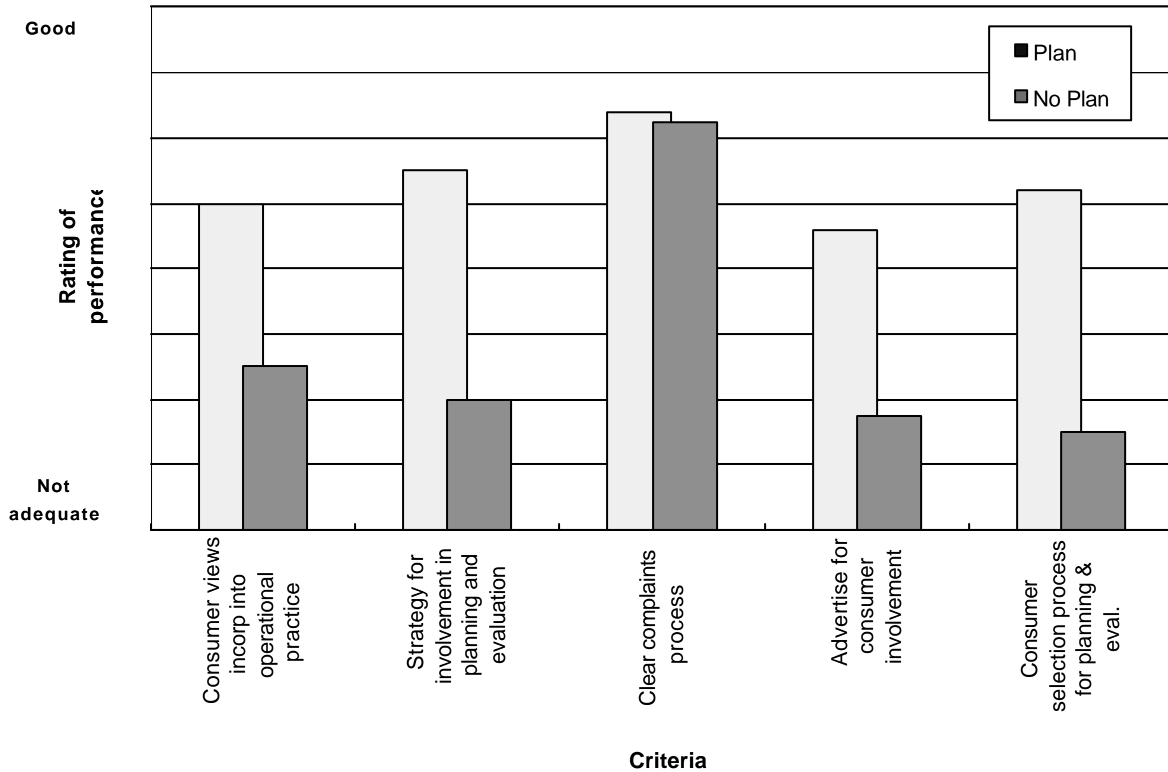
Respondents that did not have Consumer Participation Plans in place rated the degree of consumer participation at the individual service level at similar levels to those that did have Plans in place. However, respondents that did not have Plans place considered that the degree of consumer participation in service planning and delivery and in service evaluation was at lower levels than those with Plans in place. These differences are clearly illustrated in Diagram 1, below. Services with Plans had on average four planning committees with consumers members. Services without Plans had on average one or two planning committees with consumer members. Services with Plans had a greater diversity of consumer participation strategies in place than those without Plans.

Diagram 1 - Self-rating of Level of Consumer Participation in Adult Mental Health Services - Services With and Without Consumer Participation Plans



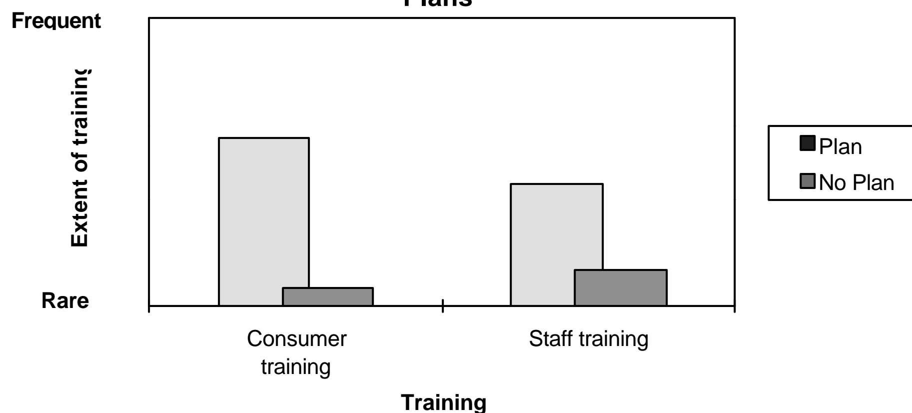
In addition, services without Consumer Participation Plans believed service performance in relation to consumer participation was significantly lower (with the exception of complaints processes) than those with Plans in place. This is illustrated in Diagram 2, below.

Diagram 2 - Self-rating of Performance in Relation to Consumer Participation Against Key Criteria - Services with and without Consumer Participation Plans



Similar trends were found for provision of consumer participation training. Services without a Consumer Participation Plan in place rated the level of training at much lower levels than those with Plans. This is illustrated in Diagram 3, below.

Diagram 3 - Self-rating of Extent of Training on Consumer Participation for Consumers and Staff of Adult Mental Health Services - Services With and Without Consumer Participation Plans



Consumer Participation Training

Perceptions of the extent to which consumers were offered training to develop skills to effectively participate were divided. Over half the respondents rated training as "infrequent", while a third rated it as "frequent".

Staff training on how to effectively support consumers to have input into service decisions was usually considered to be "infrequent".

The average ratings for each of these were the lowest of all the elements of consumer participation explored in the questionnaire. It is clear that service providers consider this to be the least frequently implemented consumer participation strategy in Adult Mental Health Services.

Consumer Consultants

Thirty-two of the thirty-five respondents said the service employed consumer consultants. In these services the number of consumer consultants ranged from one to three part-time employees, and up to five casual consumer consultants. Two-thirds of services with consumer consultants employed two or more people in the role.

The pay rate ranged from $12.00 - $21.00 per hour.

Individual consumer consultants were employed for between 8-38 hours per week, typically across a range of services. Some respondents noted that consumer consultants in their services worked across Adult, Aged Persons and Child and Adolescent Services.

Turnover was usually low.

Many respondents identified a range of strengths of the consumer consultant role. Some important themes emerged regarding the role of consumer consultants:

- they played a key advocacy/representative role for consumers
- there was increased accountability by the service to consumers
- they provided consumers with the opportunity to give regular feedback, both positive and negative, giving services a more complete picture of consumers' experiences
- they facilitated completion of the feedback loop in a coordinated and structured manner - as such they were seen as an important element in the Quality Improvement cycle
- they facilitated innovation in service delivery
- there was increased staff awareness of consumer issues, with the role destigmatising mental illness within services
- they were a communication pathway between consumers and management

- service was observed to have improved

A range of limitations on the effectiveness of consumer consultants was noted. Key limitations identified were:

- lack of time and resources to fully realise potential of position
- ambiguity in the role combined with limited training and support
- inherent challenges in the role such as the conflict between being a staff member and being aligned with consumers, staff resistance, concerns regarding confidentiality, and limited use of the role by clinical staff
- risk of illness if consumer consultants are not appropriately supported

Respondents identified a range of supports needed to ensure effectiveness of consumer consultants. The main supports identified were:

- strong management support and ownership, with direct access to the CEO or Director
- regular professional supervision
- peer support, particularly from consumer agencies and consumer consultant networks
- a clear, detailed job description
- training, including orientation training, ongoing externally facilitated training and regular update sessions on the service system
- increased resources
- training for staff on consumer participation and the role of consumer consultants
- administration support
- team support
- secure employment

Service Performance

All respondents rated the performance of the service against key criteria. Some clear trends were evident in these ratings. The first of these is that service providers, on average rated performance at a fairly modest level. This is illustrated in Diagram 4, below. The other trend was the high rating of performance in terms of having a clear complaints process in place.

However, while these trends are present, they do not represent the full picture. When the spread of ratings is examined a more complex picture emerges. While a majority of services rated themselves in line with the trends mentioned above there was always a

group of respondents whose ratings were the opposite. This reflected a split in how respondents rated performance. Most respondents usually rated performance as "adequate" or "good". However, a smaller group of respondents consistently rated performance on all but the criteria in relation to complaints as unsatisfactory. Some of these were services without a Consumer Participation Plan (as discussed above), but this does not fully explain this trend.

The following is a detailed description of results for each of the criteria.

1) *"This service has a systematic way of incorporating the views of consumers on the operational practice of the service and its staff."*

There was an even spread of responses between the three categories ("good", "adequate" and "not adequate") for this criterion.

2) *"This service has a clear strategy by which consumers are involved in service planning and evaluation activities."*

These was an even spread of responses between the three categories for this criterion.

3) *"This service has a clear process by which consumers can lodge complaints and have them considered."*

A clear majority of services rated their performance as "good".

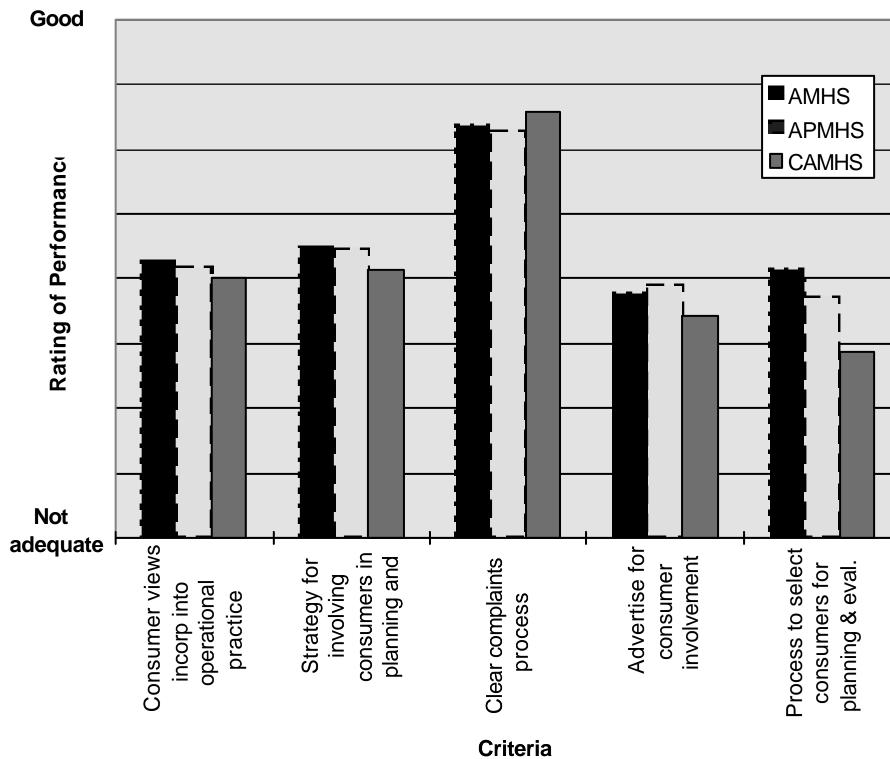
4) *"This service advertises in a prominent way the opportunities for consumer involvement."*

Most services rated their performance as "adequate".

5) *"This service has a process for selecting consumers for in-service planning and evaluation activities."*

Respondents' ratings were split for this criterion. One grouping was based on a rating of "good" performance. The other was based on a performance rating of "not adequate".

Diagram 4 - Self-rating of Service Performance Against Key Criteria for Consumer Participation - Adult, Aged Persons and Child & Adolescent Mental Health Services

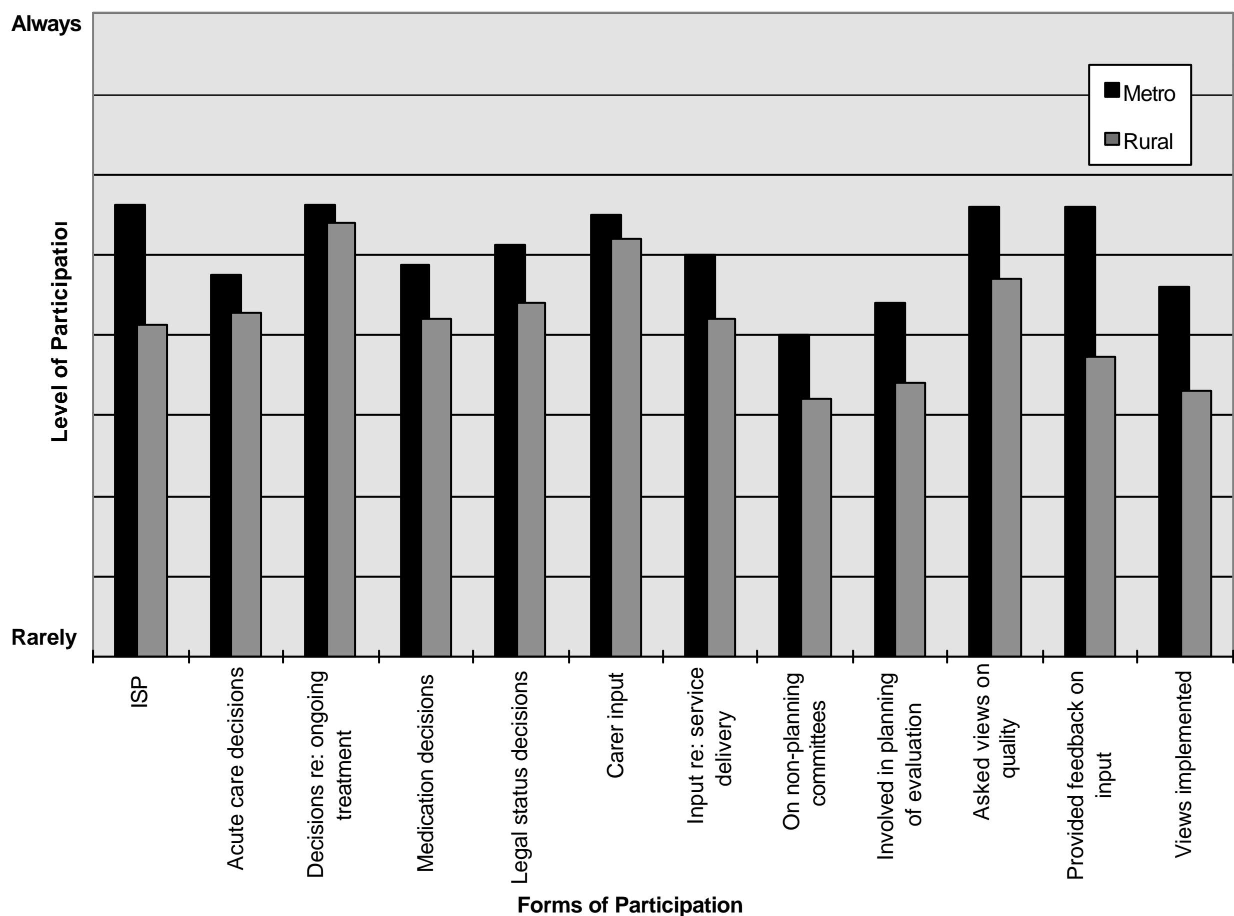


Differences Between Rural and Metropolitan Adult Mental Health Services

Current Practice

Metropolitan services generally perceived the extent of consumer involvement in their services to be at a higher level than did rural services. While there was a fair degree of overlap, with some rural services rating involvement at high levels and some metropolitan services rating involvement at low levels, this was true for all forms of participation that respondents were asked to assess in the questionnaire. These trends are illustrated in Diagram 5 below. In addition, metropolitan services were able to identify a greater number and wider range of consumer participation mechanisms in use.

Diagram 5 - Self-rating of Level of Consumer Participation in Adult Mental Health Services - Metro vs Rural Services



Consumer Participation Plan

Fifteen of twenty metropolitan services had Consumer Participation Plans. Eight of fifteen rural services had Consumer Participation Plans.

Consumer Participation Training

Rural services generally believed that the extent of training for consumers in consumer participation was at much lower levels than did metropolitan services.

Consumer Consultants

No significant differences were observable between rural and metropolitan services in relation to consumer consultants.

Service Performance

Metropolitan services generally believed service performance was "good" or "adequate" against all criteria. Rural services generally considered service performance to be "not adequate" or "adequate" for all questions except in relation to complaints where usually they rated their performance as "good".

Findings in Relation to Adult Mental Health Service Acute Inpatient, Non-acute Inpatient and Community-based Services

Ratings of the level consumer involvement in consumer participation practices measured in the questionnaire were analysed in terms of service type. The three service types examined were acute inpatient, non-acute inpatient and community-based services

Ratings by acute inpatient and community-based services reflected the trends found for Adult Mental Health Services in general. One noticeable difference was that acute inpatient service providers believed consumer involvement in decisions about legal status occurred more frequently in their services than did service providers of the other service types.

Non-acute inpatient service providers considered consumer involvement in planning and evaluation to occur more frequently than did acute inpatient and community-based service providers. They also rated their performance against the key criteria at higher levels than acute inpatient and community-based service providers.

In both acute inpatient and community-based services rural service providers rated both the extent of consumer participation and service performance in relation to participation, significantly lower than metropolitan service providers. This matches findings for rural Adult Mental Health Services in general.

There were insufficient responses from non-acute inpatient services to allow a meaningful comparison between metropolitan and rural services.

Findings in Relation to Aged Persons Mental Health Services

General Findings

Aged Persons Mental Health Services that responded to the questionnaire generally believed that the degree of consumer participation in their services was quite high. This was true for all forms of consumer participation examined in the questionnaire. However, it should be noted that nearly all Aged Persons Mental Health Service respondents indicated that they included the carer in their definition of consumer. Ratings of the level of consumer participation in these services appears to reflect a combined rating of consumer and carer participation.

Current Practice

Individual Service Level

Aged Persons Mental Health service providers generally believed that the degree to which consumers participated in the range of decision-making processes at an individual service level was “frequent”. Carer input into treatment and care was also considered to be “frequent”.

Service Planning and Delivery

Aged Persons Mental Health service providers generally considered consumer involvement in decisions relating to service delivery to be “frequent”, but consumer involvement in other planning committees was most commonly considered to be “infrequent”.

About half the respondents said that participants were reimbursed for costs of committee membership. Other respondents said that participants were neither reimbursed nor subsidised for these costs.

Service Evaluation

Involvement of consumers in the planning of service evaluations was considered to be “infrequent” by most service providers.

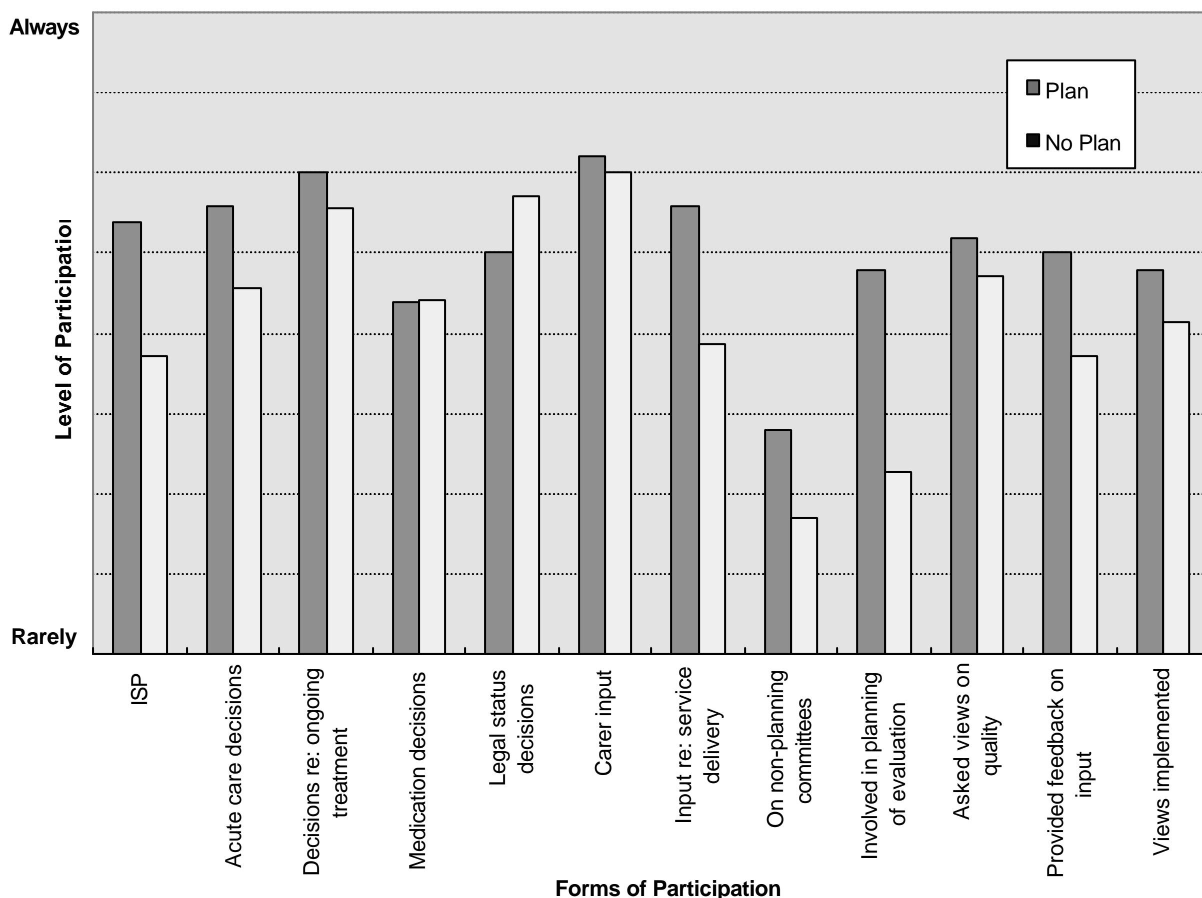
The extent to which consumers were asked their views on service quality, feedback provided to consumers about their contribution, and consumer views on service improvement implemented was most commonly considered to be “frequent”.

Consumer Participation Plan

Nine of twenty-five respondents had a Consumer Participation Plan in place. As was the case in Adult Mental Health Services, respondents who did not have a Plan in place believed that the level of consumer involvement in service planning and evaluation in their

services, as well as service performance against the key criteria, was significantly lower than did those that had a Plan in place. One notable variation from Adult Mental Health Service ratings was in terms of ISPs and acute care decisions. Aged Persons Mental Health Services that did not have Plans tended to rate the level of consumer involvement

Diagram 6 - Self-rating of Level of Consumer Participation in Aged Persons Mental Health Services - Services With and Without Consumer Participation Plans



in these at lower levels than did those with Plans. This is illustrated in Diagram 6.

Consumer Participation Training

Training offered to consumers to develop skills to effectively participate was almost universally believed to be "infrequent".

Respondents were divided on their ratings of the amount of training provided to staff on how to effectively support consumers to have input into service decisions. About half the respondents considered this training to be "infrequent". A distinct group (about a third) rated it as "frequent".

Consumer Consultants

Of the sixteen respondents who provided services only to aged persons three employed consumer consultants, or workers in equivalent roles. Of the remaining nine respondents who provided services across service types six had access to consumer consultants. It appears that these consumer consultants primarily provided support to consumers in Adult Mental Health Services, with some additional support for consumers in Aged Persons Mental Health Services. It was not clear from the data how much time cross-service consumer consultants spent in Aged Persons Mental Health Services.

The work of consumer consultants and/or their equivalents were viewed positively by services that had access to them. The strengths of the role identified by service providers included:

- providing feedback to the service
- advocacy and support for consumers
- ensuring services are sensitive to consumer needs
- increased accountability to consumers

Limitations identified included:

- lack of training for consumer consultants
- lack of experience
- lack of staff training about supporting and working with consumer consultants
- role is sometimes unclear

Supports that improved effectiveness included:

- funding for Aged Persons Mental Health Services to employ consumer consultants or similar positions directly or to boost current self-funded hours
- more staff education about the role
- peer support - statewide
- clinical supervision
- strong management support

It was usual for only one person to be acting in the consumer consultant or equivalent role.

Consumer consultants or their equivalent worked from 8 to 38 hours each per week, although the number of hours actually worked in Aged Persons Mental Health Services is unclear.

Service Performance

Aged Persons Mental Health Service providers rated performance against the key criteria in ways very similar to Adult Mental Health Services. The same trends emerged: performance was generally rated at a fairly modest level and there was a high rating of performance in terms of having a clear complaints process in place. This is illustrated in Diagram 6 above.

As with Adult Mental Health Services, when the spread of ratings is examined a more complex picture emerges, with ratings often spread quite widely.

1) *"This service has a systematic way of incorporating the views of consumers on the operational practice of the service and its staff."*

Equal numbers of respondents rated performance as "good", "adequate" and "not adequate".

2) *"This service has a clear strategy by which consumers are involved in service planning and evaluation activities."*

There was a split in how services rated performance against this criterion. The greater number of services rated performance as "good". However, about a third rated performance as "not adequate".

3) *"This service has a clear process by which consumers can lodge complaints and have them considered."*

Over eighty percent of services rated their performance as "good".

4) *"This service advertises in a prominent way the opportunities for consumer involvement."*

There was a split in ratings of performance against this criterion. About forty percent of respondents rated performance as "good". However, another forty percent rated performance as "not adequate".

5) *"This service has a process for selecting consumers for in-service planning and evaluation activities."*

Service providers were split in their rating of performance against this criterion. About forty percent of respondents rated their performance as "good". However, another forty percent rated their performance as "not adequate".

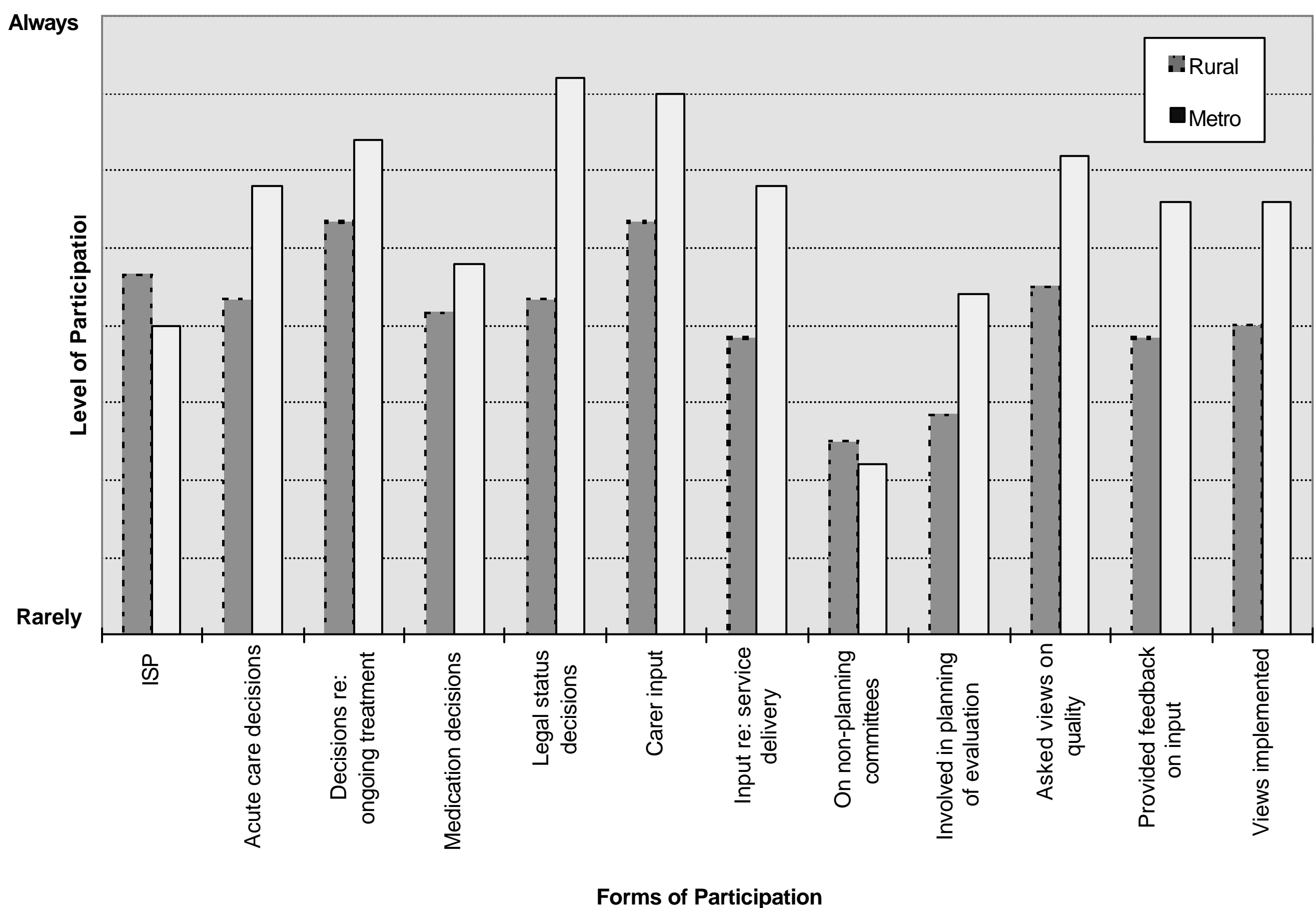
Differences Between Rural and Metropolitan Aged Persons Mental Health Services

Current Practice

Metropolitan Aged Persons Mental Health Services tended to rate the extent of consumer involvement in their services at a higher level than did rural services. This was true for all

forms of participation that respondents were asked to assess in the questionnaire: participation in decisions relating to one's individual service, participation in service planning and delivery, and participation in service evaluation. This generally follows trends identified in Adult Mental Health Services, but is even more pronounced here. Diagram 7 illustrates the self-ratings of metropolitan and rural services in relation to levels of participation. The number and diversity of consumer participation practices in rural services were also at lower levels than metropolitan services.

Diagram 7 - Self-rating of Levels of Consumer Participation for Common Forms of Participation in Aged Persons Mental Health Services - Rural and Metro Services



Consumer Participation Training

Metropolitan services rated the extent of training of staff in supporting consumers to participate at higher levels than rural services. Metropolitan services believed that staff training was "frequent" or "usual" while rural services generally rated it as "infrequent".

Training for consumers was considered to be "infrequent" in both metropolitan and rural services.

Consumer Consultants

Rural services stated that they had greater access to consumer consultants or equivalent roles than did metropolitan services. Only one of twelve metropolitan services identified itself as having a consumer consultant or equivalent, while eight of thirteen rural services identified that they had consumer consultants or equivalents. A number of these were identified by rural respondents as consumer consultants employed in Adult Mental Health Services who had extended their service to cover Aged Persons Mental Health Services. What this translated to in hours 'on the ground' was unclear.

Service Performance

Metropolitan services generally believed their service performance was better than did rural services, except in relation to complaints, where both rated performance as "good". This again reflects trends found in rural and metropolitan Adult Mental Health Services.

Findings in Relation to Aged Persons Mental Health Service Acute Inpatient, Non-acute Inpatient and Community-based Services

Acute inpatient, non-acute inpatient and community-based services followed the same trends that applied generally to Aged Persons Mental Health Services. However, non-acute inpatient service providers believed the level of participation in their services to be much higher for almost all forms of participation than did acute inpatient and community-based services. This difference was most evident in service planning and delivery and in service evaluation.

Findings in Relation to Child and Adolescent Mental Health Services

General Findings

As was the case with Aged Persons Mental Health Services, many Child and Adolescent Mental Health Services that responded to the questionnaire stated that they included the carer (typically the family) in their definition of consumer. Ratings in relation to consumer participation need, therefore, to be viewed as ratings of carer and consumer participation.

Current Practice

Individual Service Level

Child and Adolescent Mental Health Services generally believed the degree to which consumers participated in the range of decision-making processes at an individual service level to be “frequent”.

Carer input into treatment and care was considered to be “frequent”.

Service Planning and Delivery

Ratings of the extent to which Child and Adolescent Mental Health Services involved consumers in decisions relating to service delivery were spread fairly evenly from “frequent” through to “infrequent”. Services were divided on rating consumer involvement in other planning committees: a majority of respondents considered participation to be “infrequent”, but a third of services rated participation as “frequent”.

About half of respondents said that participants were reimbursed for costs of committee membership. Other respondents said that participants were not reimbursed or subsidised for these costs.

Service Evaluation

Involvement of consumers in the planning of service evaluations was considered to be “infrequent” by most services.

The extent to which consumers were asked their views on service quality was generally believed to be “frequent” or “usual”.

The extent to which feedback was provided to consumers about their contribution were spread evenly between the three ratings.

The extent to which consumer views on service improvement were implemented was considered to be “frequent” or “usual”.

Consumer Participation Plan

Seven of fourteen respondents had a Consumer Participation Plan in place. As was the case with both Adult and Aged Persons Mental Health Services, the presence of a Plan was an indicator of greater perceived levels of consumer participation, a broader range of participation strategies and higher ratings of service performance.

Consumer Participation Training

The extent to which consumers were offered training to develop skills to effectively participate was generally considered to be “infrequent”.

The extent to which services provided staff with training on how to effectively support consumers to have input into service decisions was generally believed to be "infrequent".

Consumer Consultants

Of the eight respondents who provided only Child and Adolescent Services four employed consumer consultants, or workers in equivalent roles. Of the remaining seven respondents who provided services across service types six had access to consumer consultants who were primarily employed to work in Adult Mental Health Services. It is not clear from the data how much time consumer consultants working across services spent in Child and Adolescent Mental Health Services.

Pay rates varied from $12.00 to $21.00 per hour for part-time workers, and up to $80.00 per 'session' in two services that only employed people for attendance at committees or for very short periods relating to project development.

Consumer consultants or their equivalent worked from 2 to 22 hours each per week.

Service Performance

Child and Adolescent Mental Health Services tended to rate performance at similar levels to Adult and Aged Persons Mental Health Services, as revealed in Diagram 4, above. As was noted for ratings of current practice these ratings should be viewed in the context of a blurred definition of consumers that includes carers.

1) *"This service has a systematic way of incorporating the views of consumers on the operational practice of the service and its staff."*

Most services rated their performance as "adequate".

2) *"This service has a clear strategy by which consumers are involved in service planning and evaluation activities."*

Responses to this were spread evenly between the three ratings.

3) *"This service has a clear process by which consumers can lodge complaints and have them considered."*

A clear majority of services considered their performance to be "good".

4) *"This service advertises in a prominent way the opportunities for consumer involvement."*

There was a split in ratings of performance. The greater number of services rated performance as "not adequate". However, about a third of respondents rated performance as "good".

5) *"This service has a process for selecting consumers for in-service planning and evaluation activities."*

Most services believed their performance to be "not adequate".

Differences Between Rural and Metropolitan Child and Adolescent Mental Health Services

There were insufficient responses from rural services to make a meaningful comparison.

Findings in Relation to Child and Adolescent Mental Health Service Acute Inpatient, Non-acute Inpatient and Community-based Services

There were insufficient responses to compare ratings for Child and Adolescent Mental Health Service non-acute and community-based services. Responses in relation acute inpatient services reflected the overall trends for Child and Adolescent Mental Health Services noted above.

Findings in Relation to Statewide Services

There is only a small number of statewide public mental health services in Victoria that provide clinical services to consumers. Three of these completed questionnaires. While this is not a sufficient number to enable detailed analysis some important points could be made about consumer participation.

Particular aspects of consumer participation at an individual level were in some cases not considered relevant or appropriate, but most were. Consumer involvement in service planning and delivery and service evaluation were all rated, as was service performance against key criteria. It was apparent that statewide services had the task of developing consumer participation 'in mind'.

Discussion

Consumer Participation in Adult Mental Health Services

Consumer Participation in Individual Service

The range of ratings given suggests that implementation of consumer participation at this level is quite varied across Adult Mental Health Services. With more than 25% of respondents believing participation was "infrequent" in their service there is clearly an opportunity for further improvement.

Service provider perception that there are greater levels of consumer input into planning their own treatment (ISPs, ongoing treatment and care decisions) than in acute care, medication and legal status decisions reflects the challenges faced by consumers and service providers alike when a consumer is unwell. However, the analysis shows that some services, including acute services, believe they have been able to gain higher levels of consumer input in these forms of participation.

Consumer Participation in Service Planning and Delivery

Most services believed consumers were actively involved in decisions about service delivery. They could also typically identify three or more planning committees in which consumers participated. However, consumer involvement in other committees was minimal. The data suggests that while many services are making serious efforts to ensure consumer involvement in service planning and delivery the extent of that involvement is often limited. Consumers have generally not been integrated into the range of decision-making structures potentially available in Adult Mental Health Services.

The fact that most services do not reimburse consumers for participation costs and that a third of services do not provide designated support people for consumers participating on committees both indicate that providers could do further work to increase participation at this level.

Consumer Participation in Service Evaluation

Service providers believed that consumers were generally given opportunities to say what they thought of services. However, they were not usually involved in choosing how services would be evaluated. Only a handful of services cited examples where consumers managed evaluation projects. It appears that consumers are more likely to be consulted in mental health services than be given the opportunity to actively shape those services.

Consumer Participation Plans

Since being launched the Consumer Participation Plan initiative has not been taken up by as many services as would be hoped. Given that these Plans are an opportunity to address consumer participation in a systematic way that enables culture change, a higher level of uptake would be desirable. The positive impact of Plans on levels of participation, the range of participation practices used and perceived performance of services highlights this. They appear to make a difference to consumer participation by providing a comprehensive framework for developing effective consumer participation. It is clear that service providers with Plans in place feel more positively about consumer participation than those without Plans.

Consumer Participation Training

A minority of services appear to have actively developed and provided training to consumers to enable them to participate more effectively. However, most services have not done this. Few services have provided practical training to staff on facilitating consumer participation. Given that staff and consumers are the key people involved in the practice of consumer participation this presents a significant barrier to effective participation. A number of services highlighted the importance of training in changing culture, and in particular staff attitudes, yet training has not been provided. Clearly more needs to be done to ensure that appropriate training of consumers and staff takes place.

Consumer Consultants

With all but three Adult Mental Health services employing consumer consultants on an ongoing basis, the consumer consultant initiative appears to be the key consumer participation initiative adopted by services. Feedback in the questionnaires indicates that the consumer consultant model was well regarded by service providers and had led to improved consumer participation and improved service delivery. Many services identified consumer consultants as their key consumer participation mechanism. Most services wished to further develop the consumer consultant role.

Most services employed at least two consumer consultants, but a third employed only one person in this role. When the initiative was first developed the preferred model was for at least two people to be employed to provide peer support. Given that peer support was still identified by respondents as a key element in ensuring effectiveness of the role this issue needs to be re-examined.

Pay rates and hours employed varied enormously. In some cases the amount spent was significantly more than the original grants provided by the Department of Human Service. In others it was significantly less. Some services were clearly providing additional funding to support the consumer consultant role. Others appear to be spending little of the grant money on consumer consultants. There is no data from the questionnaire about how that money was being spent.

Service Performance

Ratings of performance against key criteria indicate that there is a lot of variation in the satisfaction of service providers about consumer participation levels. A number of services were relatively comfortable with their performance, but many were not. Very few services rated performance at the highest level. This suggests that most service providers believed there was room for improvement.

Some service providers had a wide range of consumer participation practices in place, yet many of these rated service performance at quite low levels. This may reflect an understanding of the difficult reality of implementing effective consumer participation. Others had few or no consumer participation practices in place, yet a number of these rated service performance at quite high levels. This may reflect low expectations about what constitutes effective consumer participation, or a lack of awareness of the potential range of participation practices available.

Most respondents believed they had clear complaints processes in place. While this may be true in a formal sense, the experience of consumers often contradicted this. Feedback from the direct consultations and the 1800 Freecall telephone line often revealed that consumers were not aware of complaints mechanisms, feared negative repercussions from raising complaints, or had negative experiences from making complaints. This highlights the difference between having something right on paper, but not in practice. The consumer experience suggests that there is a big difference between having a clear process and a workable one. There is a difficulty here if service providers are currently feeling comfortable with their performance in terms of complaints processes. It would be useful for them to be aware of the deep consumer dissatisfaction regarding complaints processes. See Attachment 6 Report of 1800 Telephone Line.

Rural Services Rated the Level of Consumer Participation and Service Performance at Lower Levels than Metropolitan Services

Almost all rural services rated the extent of consumer participation in their services at lower levels than metropolitan services and had a smaller range of consumer participation activities. Rural services generally rated service performance at lower levels and fewer had developed Consumer Participation Plans than metropolitan services. These disparities may reflect a number of issues raised by service providers and consumers in direct consultations. These include:

- difficulties associated with distance - consumers need to travel much greater distances to participate in face-to-face decision making at an organisational level
- greater challenges communicating with geographically isolated and/or disparate consumers
- fewer opportunities to network between Areas - fewer opportunities to discuss practices, more difficult to observe good or new practices on the ground
- physical distance from Melbourne as representing distance from policy decision-making
- additional consumer participation-related expenses due to greater distance (and therefore time) which is not acknowledged in funding

Several rural services rated the extent of consumer participation in their services very highly. In some cases this could be due to low expectations of what consumer participation can achieve. However, some of these services were able to identify a wide range of specific consumer participation practices they currently had in place. This suggests that with the right supports consumer participation in rural services can be effective, and potentially reflect best practice, in the current funding framework.

Participation Levels were Believed to be Higher in Non-Acute Inpatient Services

Non-acute inpatient services (ie. Community Care Units) rated participation in service planning and delivery, and service evaluation, at higher levels than acute inpatient and community based services. This is most likely explained by the nature of services provided in non-acute inpatient services. These services have a less clinical focus. Contact with consumers often touches on many areas of consumers' lives. Consumers usually have prolonged contact with the service while being relatively well. Thus, a number of the factors that make participation more difficult to implement in other public mental health services are not present to the same extent in non-acute inpatient services. In addition, the ongoing nature of many non-acute services, and their central role in the lives of consumers, places greater responsibilities on services to ensure that consumers have effective input.

Consumer Participation in Aged Persons Mental Health Services

Who is the Consumer?

Perhaps the most significant finding in relation to Aged Persons Mental Health Services, and an incidental one in terms of the questionnaire, is that most services include the carer in their definition of consumer. While a number of respondents believed that consumers should be involved at the individual service level, carers were seen as the key people to involve in decision-making at higher levels. This may reflect the reality that the nature of many age-related mental illnesses (ie. ongoing, often degenerative dementia accompanied by behavioural problems) left the carer to make all but the most basic decisions. Given that in many cases the carer was a life partner of the consumer and often provided their ongoing care this involvement is clearly important.

One question, untested in the questionnaire, is whether the consumer may be overlooked because it is believed they are unable to participate as a generalised assumption about mental illness and aging. In Adult Mental Health Services it is expected that every effort be made to ensure the consumer is the key person in decision making, in spite of possible difficulties such as being unwell or having a psychiatric disability. It is unclear from the questionnaire whether Aged Persons Mental Health Services have started with the same assumption, genuinely tested it and found it unworkable, or whether it needs to be revisited to ensure all reasonable efforts are made to involve the consumer.

Current Consumer Participation Practice

While the definition of consumer used in Aged Persons Mental Health Services is ambiguous some important information about consumer/carer participation practice was revealed in response to the questionnaire.

As with Adult Mental Health Services there was much variation between services in all forms of participation examined by the questionnaire. However, clear trends were apparent. Services generally believed that consumers and carers were more involved in treatment decisions than in organisational decisions, and that they generally provided consumers and carers with more opportunities to be consulted than to actively shape services. Lower levels of participation in formal mechanisms is also reflected in the low levels of consumer participation training provided to both consumers and staff.

Consumer Participation Plans

Most services did not have Consumer Participation Plans in place. As was the case in Adult Mental Health Services those services without Plans had fewer, and a narrower range of, consumer participation strategies, and believed that involvement in service planning and delivery and in service evaluation was at lower levels than did those with Plans. Services without Plans also rated service performance at lower levels than those with Plans. Consumer Participation Plans appear to make a difference in Aged Persons Mental Health Services and as such are an important initiative, in spite of their low uptake.

Consumer Consultants

While no Aged Persons Mental Health Service had received specific funding for consumer consultants, several had created similar positions, or had access to consumer consultants from Adult Mental Health Services. It was not clear from responses whether access to consumer consultants was much more than a theoretical access, given that the original funding was specifically targeted at Adult Mental Health Services. The consumer consultant role was viewed positively by service providers. The contributions of the consumer consultant-type role to Aged Persons Mental Health Services were viewed in a way quite similar to those for Adult Mental Health Services.

Services generally employed only one person in the role. This presents a challenge in terms of ensuring adequate peer support.

Service Performance

Ratings of service performance against key indicators revealed a pattern basically the same as for Adult Mental Health Services. This included:

- significant variations in service provider satisfaction about current consumer/carer participation practice as outlined in the key criteria
- an overall indication that service providers believed there was room for improvement

It is interesting to note that there is no major difference in ratings of performance between Aged Persons and Adult Mental Health Services even though ratings reflected the inclusion of carers in the definition of consumer. This raises some important questions:

- are services constrained from involving carers by the official definition of consumer and consumer participation?
- are the issues around consumer participation fundamentally the same as for carer participation (ie. that participation by any stakeholder group, particularly at an organisational or systemic level, is difficult for mental health services, irrespective of who they are dealing with)?

Rural Services Rated the Level of Consumer/Carer Participation and Service Performance at Lower Levels than Metropolitan Services

The same trends found in Adult Mental Health Services also occurred in Aged Persons Mental Health Services. It is therefore reasonable to draw similar conclusions about the additional challenges in developing effective consumer participation in rural services, including issues of cost, distance, time involved in travel, and communicating with a geographically disparate consumer population.

Consumer/Carer Participation Was Rated Higher in Non-Acute Inpatient Services

Again, the trends found in Adult Mental Health Services were also found in Aged Persons Mental Health Services, with non-acute inpatient services believing they had much higher levels of participation in service planning, delivery and evaluation. The underlying dynamics of non-acute inpatient services in both Adult and Aged Persons Mental Health Services appear to be the same: a less clinical focus, an ongoing relationship with consumers, and a focus on whole-of-life issues. These facilitate a collaborative relationship, with consumers/carers necessarily having input into decisions.

Consumer Participation in Child and Adolescent Mental Health Services

Who is the Consumer?

As was found with Aged Persons Mental Health Services most Child and Adolescent Mental Health Services included the carer in their definition of consumer. This no doubt reflects the legal responsibility of parents in decision-making for their child or young adolescent, as well as the focus of many services on supporting the family. Inclusion of carers in the definition of consumer is significant because consumer participation practices therefore need to address an often complex and changing service relationship: needing sometimes to involve the carer/family, sometimes the consumer, and sometimes both. Changes in legal status as the consumer grows older also need to be considered. Responses to the questionnaire will have been influenced by this complexity.

Current Consumer Participation Practice

Child and Adolescent Mental Health Services, like Adult and Aged Persons Mental Health Services did not give consistent ratings to levels of participation. There was much variation between services in terms of their ratings of participation levels in all forms of consumer/carer participation examined by the questionnaire.

However, familiar patterns emerged from the data analysis: services generally believed consumers and carers were more involved in treatment decisions than in organisational decisions, and generally believed they provided consumers and carers with more opportunities to be consulted than to actively shape services.

As for Adult and Aged Persons Mental Health Services, consumer participation training was uncommon and, in some services, non-existent.

Consumer Participation Plans

Half the Child and Adolescent Mental Health Services that responded to the questionnaire did not have Consumer Participation Plans in place. As was the case in Adult Mental Health Services, those services without Plans had fewer, and a narrower range of, consumer participation strategies, and rated involvement in service planning and delivery and in service evaluation at lower levels than those with Plans. Services without Plans also rated service performance at lower levels than those with Plans. From these results

it is clear that Consumer Participation Plans have been an important initiative that has improved consumer participation practice. They highlight the value of a planned approach to participation that addresses all levels of participation and the supports needed to sustain and develop that participation.

Consumer Consultants

Most respondents said they had access to consumer consultants, or workers in equivalent roles. It was not clear from responses whether access to consumer consultants was only access 'in theory', given that funding for consumer consultants has been specifically targeted at Adult Mental Health Services. Respondents emphasised the support role consumer consultants played for young people. Given that the needs of carers and consumers are not identical, the consumer consultant or equivalent role is important as a means for giving a 'space' in which young people can be heard in their own right.

Service Performance

Service performance against key indicators revealed a pattern basically the same as for Adult Mental Health Services and Aged Persons Mental Health Services. This included:

- significant variations in service provider satisfaction about current consumer/carer participation practice as outlined in the key criteria
- an overall indication that service providers believed there was room for improvement

As with Aged Care Mental Health Services, inclusion of carers in the definition of consumer did not have an impact on perceived service performance on key consumer participation criteria. Clarifying the term 'consumer' may remove some of the constraints currently blocking more effective involvement of carers and consumers.

Consumer Participation in Statewide Public Mental Health Services

It is clear from responses of statewide public mental health services that they also had an interest in effective consumer participation. Consumer participation in decisions about individual service, service planning and delivery and service evaluation were all considered to be valid means of participation in these services. Statewide service providers appeared to consider consumer participation to be an important element in how they provided services to consumers. Finding ways to enhance participation in these services was as important as it was in Area Mental Health Services.

Conclusion

There was much variation in the extent to which public mental health service consumers were involved in the consumer participation practices examined in the questionnaire. This variation was evident in the perceptions of service providers and in the actual range and number of practices in place. For each practice the response from one service to the next could be fundamentally different. External factors could explain some of these variations, but not all. Differences appear to be also due to the attitude of providers towards consumer participation, or their knowledge and skills regarding implementation of consumer participation strategies. The fact that some services have an integrated and comprehensive set of consumer participation strategies in place highlights that good practice is achievable in the current service context. The issue is whether the service provider is prepared to, or knows how to, undertake the journey to reach that point.

Overall, consumer participation levels were perceived to be highest in planning of individual services and lowest in organisational planning and development. Also, service providers believe they have had more success in consulting with consumers than providing a pro-active role for them to shape services.

There was a clear gap between metropolitan and rural services, with the number and range off consumer participation strategies, as well as ratings of participation and performance generally at lower levels in rural services. This gap highlights a need to address issues specific to rural services.

Aged Persons Mental Health Services and Child and Adolescent Mental Health Services are in a challenging position, with carers often needing to take on a much bigger role in decision-making. Perhaps because of this the definition of consumer has become blurred in these services. There is an unanswered question around the validity of this blurring, and whether the needs of the person with a mental illness should be considered as separate from those of carers. This may need to be the case if consumer participation (particularly in individual service decisions) is seen as a means of empowerment and an aid to recovery - as has been clearly articulated in other consultations in this project.

Consumer and carer participation in service planning and delivery and in service evaluation are not as well developed in most Aged Persons Mental Health Services and Child and Adolescent Mental Health Services as they are in Adult Mental Health Services. This is also reflected in lower levels of uptake of Consumer Participation Plans. Decision-making in organisational processes needs to be further developed if these services are to reach levels of consumer participation achieved by many Adult Mental Health Services.

Statewide services shared similar beliefs and concerns to Area Mental Health Services regarding consumer participation. It is clear that they are grappling with many of the same issues that any service confronts when trying to implement effective consumer participation strategies. In order to ensure consumer participation policy is enacted consistently in all public mental health services there is a need to ensure statewide services are included in policy initiatives and have the same sorts of supports and checks as Area Mental Health Services.

While there has been a limited uptake of Consumer Participation Plans, those services that had developed Plans were doing better than those that had not. Services with Plans had a greater number of participation strategies in place; had a wider diversity of activities; rated participation in service planning, delivery and evaluation at higher levels; and provided more relevant training to consumers and staff. These results suggest that

Consumer Participation Plans can lead to improved consumer participation by providing services with a systematic approach for developing participation mechanisms at all levels of participation and in all relevant areas. They also enable the creation of the supports needed to sustain and develop that participation. A key challenge is to find a way to encourage more services to develop and implement Consumer Participation Plans or similar processes.

Very little training has been provided for consumers or staff on consumer participation, yet training was seen by respondents (at least in terms of supporting the consumer consultant role) as a key strategy in developing consumer participation. This is an area that requires further work, particularly given that there is a specific section in the National Mental Health Standards that addresses consumer participation training for staff and consumers.

The consumer consultants program has been implemented by Adult Mental Health Services across Victoria. Consumer consultants were seen as an important means of ensuring services are appropriately meeting the needs of consumers. They helped complete the quality feedback loop. Many services identified consumer consultants as their key consumer participation mechanism. This raises questions about whether this role is sometimes seen as the service's consumer participation, rather than one of a range of strategies needed for effective participation. Most services believed the consumer consultants role had not yet reached its full potential and wished for it to be further developed.

Services that had grappled with implementing comprehensive consumer participation strategies often rated their performance at a low level. This indicates an understanding of the challenges faced in developing effective participation and the fact that it is a journey on a continuum. Other services with minimal consumer participation practices in place rated their performance at quite high levels. This appears to reflect low expectations about what constitutes effective consumer participation or what it can achieve, or a lack of experience in implementing the potential range of participation practices.

Many services acknowledged that they had some way to go before they would have effective consumer participation practices in place. There was a gap in knowledge for many service providers about how to improve consumer participation, but a desire to make those improvements.

Questionnaire to Public Mental Health Service Providers

10.7. ATTACHMENT 7 Report of 1800 Freecall Telephone Responses

REPORT AIMS

This report aims to summarise responses from the Freecall 1800 telephone service and discuss them in relation to the project aims.

METHODOLOGY

Prior to the consultation period, Service Quality Australia distributed a flyer about the Evaluation. This was distributed to service delivery outlets, consumer consultants, Victorian Mental Illness Awareness Council, and in focus group meetings. Consumers receiving the flyer were encouraged to relay this information to their respective networks. This included informal networks of consumers as well as a computer web site.

The purpose of the flyer was to inform interested parties about the evaluation and the free call 1800 telephone service operating during the consultation period.

People ringing the Freecall telephone service were asked for feedback about:

- What consumer participation means to you?
- The purposes of consumer participation in the public mental health service?
- What makes consumer participation effective?
- Your experiences in relation to consumer participation in Victoria's Public Mental Health Services.
- What differences you believe consumer participation strategies have made to mental health services?
- How consumer participation can be improved for you and others?

The Flyer is at the end of this report.

The Freecall telephone service operated during business hours from December 7th to December 18th inclusive. A Telephone Typewriter (TTY) was available for deaf consumers , and the Victorian Interpreting and Translating Service was linked to the Freecall service for people requiring a language interpreter. These facilities were advertised in the flyer, and the Victorian Deaf Society were advised of the evaluation and this service.

When people rang the Freecall number, they were reminded of Service Quality Australia's guarantee of confidentiality, and asked for some details to assist SQA in summarising their responses ie; their role (eg consumer, carer, service provider etc), location, and service types they had experience with. Their name and the name of the service they used/worked for was information which they could choose to be recorded or not.

De-briefing from the telephone interview was offered to consumers, and some referrals were made to VMIAC. (VMIAC had agreed with Service Quality Australia to accept

referrals). Respondents were also made aware that they could retract any of their statements up to the time of writing of this report.

Some respondents opted for a question/answer interview structure, whilst others opted for more open ended discussion. Questions followed the "Feedback Topics" stated in the flyer, with additional detailed questions from the "Evaluation Framework and Discussion Paper". This paper was also referred to for definitions eg; who are consumers?

Comments were recorded during the telephone conversation on the "1800 Telephone Response Record" (Appendix 2). This included the time and date of each call.

CONSIDERATIONS

Some respondents were concerned that information about the evaluation, and distribution of the flyer, was not made more widely available. This was noted particularly by consumers not currently linked to formal mental health service structures. Some of these consumers reported that they felt they had only received the information incidentally or through "luck".

Respondents also commented on the timing of the consultation period being so close to Christmas; this was a period when they experienced additional stress and/or were not linked with networks in their usual way. Comment was made by a few that the timing of the consultation was ironic because it seemed contrary to consumer participation principles.

SUMMARY

Overwhelmingly respondents thought consumer participation was "a good thing", however, many respondents were not immediately familiar with this term.

Responses tended to fall into three broad interacting interpretations of consumer participation being:

- A product of values or attitudes determining organisational culture and practice ie *"the way you are treated" (Respondent #28).*
- A process for change, often 'political' in nature because it challenges power imbalances and the conventional service delivery system.
- A means of empowerment and self-help for individuals.

A number of people raised concerns with the label "consumer participation"; particularly "consumer", and the attendant assumption of implied choice. Divergent views primarily concerned the perceived corruption of consumer participation.

Although respondents nominated a range of purposes of consumer participation, a central theme was that the end result should be services better met consumers' needs. The quality and effectiveness of consumer participation is a product of both how and why it is done; *how* consumer participation is done (the means) should be consistent with *why* it is done (the ends or purpose).

When asked to describe their experience with particular consumer participation strategies, most respondents talked about their experience of services rather than experience of consumer participation.

Apart from Case Management, many responses referred only to Consumer Consultants. Other consumer participation strategies and initiatives such as Consumer Participation Plans did not receive comment.

Most respondents who knew of Consumer Consultants were very supportive of this strategy, but some people were critical of what they saw as a "flawed model".

With the exception of Consumer Consultants, particular strategies were not directly cited as reasons for improvement in services. Consumer Consultants and VMIAC were credited with having worked to change community attitudes and reduce the stigma associated with mental illness.

Most respondents said they were generally treated with greater dignity by services and had more of a say than in the past, however most were unable to say why this improvement had occurred.

Respondents nearly all gave specific suggestions to improve consumer participation. These were relevant to overall service delivery and quality rather than only specific to consumer participation.

Suggestions for improvements can be viewed in context of the key factors identified in the effectiveness of consumer participation (5.3).

1. The attitudes of staff to consumers, and service history or culture:

> Many references were made by respondents to the attitudes of staff and doctors to consumers, both individually and collectively, being a barrier to participation. Respondents suggested staff and doctors in public mental health services should receive additional training or education to address 'attitudes' and 'organisational culture' as well as information about consumer participation.

2 a) Information and support consumers have regarding their rights and services, and
b) the health of the consumer at the time they are expected to participate:

> In order to participate in decisions, respondents suggested they needed specific and clear information on their rights, entry processes and the services themselves. The timing, manner and frequency of this information was considered critical by some, as was support to participate.
>
> Some respondents struggled with consumers' right to participate and make decisions versus their need for protection. Suggestions to address this included access to advocacy, and utilising periods when consumers were not so ill.

3. The availability and access to structures for participation:

> Respondents were very clear about consumer participation not being "a" task, but a process requiring a range of inputs on different levels. Improving consumer

participation would require strengthening and improving the range of ways/structures for consumers to have input into decisions.

4.The existence and implementation of supporting policies and procedures in services and across the service system:

Consumer participation is not a "stand-alone task". Effective consumer participation should be incorporated in the service system philosophy and service delivery model.

Respondents identified policies and procedures as needing to be inclusive of consumer participation principles and practices. This included legislation and complaints procedures.

5. An understanding that consumer participation is a developing and evolving notion:

Responses indicate consumer participation is developing and evolving. It was important to both recognise and support this growth.

In the context of consumer participation being an evolving process, the criticisms made of the Consumer Consultant Strategy need to be assessed, and resolved where necessary.

SUMMARY OF RESPONDENTS

A total of 37 people responded to the Freecall service. Of these, 28 people had direct consumer experience of public mental health services. The other 9 people were carers or worked with people who have used public mental health services, but were not employed by those services. A table of respondents is provided below:

TABLE OF RESPONDENTS

	Adult Mental Health Service Consumers	Aged Persons Mental Health Consumers	Consumers and Carers	Carers	Other*	TOTAL
Male	11	1	-	2	2	16
Female	7	7	2	3	2	21
Metropolitan	7	8	1	3	2	21
Rural	11	-	1	2	2	16
TOTAL	18	8	2	5	4	**37**

*Includes Community Health Practitioners (eg. Doctor, Director of Nursing, Community Psycho-Social Rehabilitation Worker)

Some respondents rang more than once. Their comments were recorded as a single response (ie; a single record was made of all their comments). Telephone conversations ranged in length from about 10 minutes to over one and a half hours long, but were typically about 20 - 30 minutes in length.

Some respondents nominated more than one "role", for example consumer and carer. Many respondents were unsure of the title of the service type they used. They nominated a range of Public Mental Health Services to which their comments related, both acute inpatient services and community mental health services. Many consumers drew on their experiences in public, private and community managed services.

For the purposes of this report, services are distinguished by Adult and Aged Persons Services, and particular service types are noted in the discussion of responses where appropriate.

No Telephone Typewriter calls were received, and no one required the Telephone Interpreting Service.

SUMMARY OF RESPONSES

WHAT THE TERM CONSUMER PARTICIPATION MEANS

Respondents were asked "*What do you believe the term 'consumer participation' means?"* Overwhelmingly respondents thought consumer participation was "a good thing". However, some respondents were not immediately familiar with the term 'consumer participation', or were unable to respond further without prompting. The definition in the SQA Evaluation Framework and Discussion Paper was read to respondents as a discussion prompt.

Respondents were varied in their interpretation of consumer participation both from the perspective or angle they viewed it from (systemic to personal), and the complexity of those views.

Responses indicate a belief that assumptions and values underpinning service systems affect how and why people are treated in particular ways, and are therefore central to the conceptualisation and process of consumer participation. Others viewed consumer participation more personally in terms of actual consumer outcomes such as being listened to, being treated with dignity and having choice at the service delivery level. These perspectives were not exclusive of each other.

Responses tended to fall into three broad, often interacting, interpretations of consumer participation being:

- A **product** of attitudes and values determining organisational culture and practice ie *"the way you are treated" (Respondent #28).*
- A **process** for change, often 'political' in nature because it challenges power imbalances and the conventional service delivery system.
- A **means** of empowerment and self-help.

A number of people raised concerns with the label "consumer participation": Particularly the word "consumer", and the attendant assumption of implied choice.

"I hate "consumer" - in hospital you're a patient and there's nothing wrong with that. There's no choice, you're not buying something."

(Respondent # 33)

This view appeared most prevalent amongst those using Aged Persons Services. However the label was also problematic for people who viewed consumer participation in a human rights framework:

"There are power imbalances; some of these things are quite subtle. The focus should be on the role rather than the label".

(Respondent #7)

10.7.1. Consumer Participation as a Product of Attitudes

This view suggested that consumer participation was about roles rather than labels or tasks, and was rooted in attitudes which inform how or "the way" consumers were treated. Some respondents described how this would be translated at the service delivery level as follows:

"Being treated like a normal human being by staff who are caring."

(Respondent #27)

"Being listened to above everything else, having the right to voice opinions, being treated with dignity, and having the services delivered that are actually promised."

(Respondent #10)

"Having a say about what you want done with you, rather than to you."

(Respondent #3)

"Being heard in the system; complaints, suggestions, people telling services what they want and expect".

(Respondent #11)

10.7.2. Consumer Participation as a Political Process for Change

Other views, not inconsistent with those above, were concerned more with rights and addressing power imbalances. They focussed on consumer participation as a process for change, with more tangible goals:

"Rights - new or changed legislation so that people can't have things done to them that they don't consent to."

(Respondent #5)

"Devolving the hierarchy and building community"

(Respondent #7)

"Policies in hospitals - consumers on hospital boards."

(Respondent #4)

10.7.3. Consumer Participation as a Means of Empowerment and Self-Help

Some respondents viewed consumer participation as directly benefiting their well being. That is, the mechanisms and conditions supporting consumer participation were of themselves beneficial:

"Being listened to gave me hope." *(Respondent #2)*

"As an input into recovery and the knowledge learnt from that it is important".

(Respondent #14)

"It increases self-worth and therefore decreases illness". *(Respondent #35)*

"It's about self-help groups; consumers reaching other consumers."

(Respondent #4)

10.7.4. Divergent Views

Apart from one person who said *"I feel frightened and uncomfortable with these new fangled methods … I don't worry about rights" (Respondent #6),* divergent views primarily concerned the perceived corruption of consumer participation.

These views were mostly focussed on a belief that consumer participation was either a sham because there was no will to change how services were delivered, or that consumer participation had been sabotaged:

"Consumers are being screwed on all angles…….it has become a money making and empire building exercise, the hierarchy, holier than thou, and them versus us attitudes."

(Respondent # 8)

> *"It's a rubbish thing: It is either token and disempowering - including financially - or really absurd."*
>
> *(Respondent # 14)*

> *"The set-up* (Consumer Consultants) *is fundamentally flawed; there is a conflict of interest between the employer and the consumer representative. I wonder if this is deliberate to make a show of giving consumers a voice."*
>
> *(Respondent # 15)*

A couple of respondents who held the above views were quite disillusioned with consumer participation:

> *"We're given the conventional proverbial mushroom treatment. I'm so sick of the bullshit and rhetoric. I just want results, and that's the best treatment".*
>
> *(Respondent # 20)*

THE PURPOSES OF CONSUMER PARTICIPATION IN THE PUBLIC MENTAL HEALTH SERVICES

Respondents were asked what the purpose of consumer participation was, or what it should be trying to achieve. Although respondents nominated a range of purposes of consumer participation, a central theme was that the end result should be consumers' needs were better met through better services;

> *"Its vital; the more consumers participate, the better services get".*
>
> *(Respondent #36).*

Respondents characterised consumers' needs as:

- Being treated with dignity and respect
- Getting the treatment and care required to get well
- Maintaining a lifestyle in the community which allowed them to fulfil other roles eg parent, worker etc
- Confidence that they could access treatment when they needed it

It was proposed that through good consumer participation:

- Service delivery staff, including managers, would more accurately understand *"what its really like to have a psychiatric illness"* and this would inform *"more humane service delivery…..directed by or focussed on real need".*
  (Respondent #10)
- Consumers would have a valued role in the service delivery system and get *"credit for work they do."*
  (Respondent #17).

- Consumers would become the focus of services through a *"complete partnership."*

(Respondent # 3).

10.7.5. Outcomes for Individual Consumers

Respondents were most clear about what they thought consumer participation could achieve for them, both in their expectations of consumer participation and the effect that participation would have on them.

Consumers' expectations included:

- Being treated with dignity and respect, evidenced in their interactions with staff.
- Being able to make complaints and have them resolved without reprisals.
- Being able to access services or support as needed ie; be involved (participate) in the decision to enter services, and have those services available to them.
- Having involvement in decision-making in services, individually and collectively.
    - Being able to discuss and contribute to decisions about treatment, including medication and support, so that it would better meet the individual's needs and lifestyle:

      "I'm a mother. Some high doses of medication prohibit me from performing some daily responsibilities, for example not being able to drive while I'm on high doses means I can't pick the kids up from school. There should be ways around this like taxi vouchers".

      (Respondent #11)

    - Having processes and mechanisms for consumers to contribute ideas and be consulted on policies and other decisions effecting service delivery.
    - Having the opportunity to have an active role in staff training and community education; changing attitudes.

Respondents felt the effect consumer participation would have on consumers included:

- Self esteem and empowerment would be increased, and this would contribute to maintaining mental health.
- Individual consumers would feel people were genuinely concerned for them (ie; they were not a nuisance or a burden)
- Consumers would hold valued roles in services eg; on hospital boards

- Services would better meet consumers' needs.

10.7.6. Outcomes for Service Delivery & Service Quality

33 of the 37 respondents were parents or carers, and the remaining 4 people were not employed in public mental health services. Therefore responses about the purpose of consumer participation for service delivery were from the perspective of people trying to access and use the system rather than deliver services.

Most people responding to this topic said the purpose of consumer participation in service delivery was to improve the quality and responsiveness of services by focussing on consumer needs.

> *"It's positive for service quality - people keep their dignity and individuality".*
> *(Respondent # 31)*

> *"More effective treatment; consumer participation means options and choices, and the consumer is likely to be more willing and cooperative."*
> *(Respondent #25)*

> *"Being directed by or focussed on real need - finding out what consumers can do".*
> *(Respondent #10)*

> *"To avoid the system becoming too staff engineered and too repetitive without the injection of new ideas by patients".*
> *(Respondent # 33)*

EFFECTIVE CONSUMER PARTICIPATION

Respondents were asked what makes consumer participation work well. Responses were very consistent with the purposes of consumer participation. That is to enhance the effectiveness of consumer participation, *how* consumer participation is done (the means) should be consistent with and reflect *why* it is done (the ends or purpose).

A number of key factors in the effectiveness of consumer participation have been identified in responses. These factors were considered crucial in either supporting or potentially undermining consumer participation and included:

1. The attitudes of staff to consumers, and service history or culture.
2. a) Information and support consumers have regarding their rights and participation in services, and

   b) the health of the consumer at the time they are expected to participate.
3. The availability and access to structures for participation.
4. The existence and implementation of supporting policies and procedures in services and across the service system.
5. An understanding that consumer participation is a developing and evolving

notion.

10.7.7. What has Worked Well

When related to the factors (5.3 above) effecting consumer participation, what respondents said worked well included:

1. The attitudes of staff to consumers, and service history or culture:

- Treating consumers with dignity and respect
- Asking for more information, and giving choices and options
- Listening to consumers
- Treating consumers *"like an ordinary person that needs help - not like a mental patient."* *(Respondent # 27)*
- Treating consumers in a fair and just manner

2. a) Information and support consumers have regarding their rights and services, and b) the health of the consumer at the time they are expected to participate:

- Ensuring consumers are given information about their rights and services.
- Providing information at a time and in a manner that is meaningful to consumers, and ensuring that consumers have further opportunities to receive this information.
- Ensuring consumers have on-going opportunities to participate or be involved ie; an 'open invitation' to participation.
- Providing support to consumers to participate, including advocacy support

"We need information about how to fix up our group" (Respondent #1)

- Giving consumers the option not to participate.

"When you're sick there's a great reluctance to be involved in any way with psychiatric services." *(Respondent #18)*

- Utilising periods when consumers can and want to participate.

"You need to utilise the times when your mental health is at its highest." *(Respondent #33)*

3. The availability and access to structures for participation:

- Having a coherent range of participation structures in place and available.

"Consumer participation can be on a lot of levels -its a whole range of things."
(Respondent # 35)

- Many respondents - but not all - said the Consumer Consultant model works well (See 5.4 for discussion of this model/strategy).

4. The existence and implementation of supporting policies and procedures in services, and across the service system:

- Clear and consistent policies, developed with consumer input; particularly complaints or grievance procedures.
- Practices that follow policies.
- Policies that are available and understood by consumers and others interacting with services.
- Transparent processes that allow for appeals.

5. An understanding that consumer participation is a developing and evolving notion:

"We're getting there in small steps, I believe we are getting better at consumer participation". (Respondent #36)

- Trying new things.
- Sharing information and learning from other services and consumers.

10.7.8. Barriers to Effective Consumer Participation

Numerous barriers to consumer participation were described by respondents. Very often these were the converse of what they said 'worked well'. Key barriers identified by respondents were:

a) Attitudes of staff :

Some respondents viewed the attitudes of staff and some psychiatrists as a barrier to participation.

"They couldn't care - you mean nothing to them". (Respondent # 6)

" There was a resentment by the nurse that a consumer should dare question the consultant doctor's opinion. The attitude is that 'we know what's good for you'. My private consultant was sympathetic but he wasn't even contacted by the regional public system."
(Respondent #8)

A few other respondents also referred to the 'medical model' and the history of psychiatric services being a barrier to consumer participation.

"Clinical services seem at odds with consumer participation".

(Respondent # 35)

"The traditional relationship doesn't deal with the empowerment issue - historically consumers are trained not to buck the system."

(Respondent #3)

b) Information and Complaints Mechanisms:

Many respondents were concerned by the lack of information about their rights as consumers, specifically complaints or grievance procedures available to them. Complaints mechanisms need to be both available and seen to be effective. Many respondents thought complaints were a legitimate way to participate in services but reported being frustrated and exhausted trying to have complaints heard or resolved.

"*I was never given any information or anything about my rights".*

(Respondent # 20

"Who do you complain to; I'm constantly getting palmed off, you exhaust yourself trying to complain."

(Respondent # 13)

c) Access to services:

A large number of complaints were voiced regarding the difficulty people experienced getting or retaining services they thought they needed. Respondents were frustrated that at this level they were not able to "participate" in services. Consumers, carers, and community health practitioners all said they experienced great difficulty being 'permitted' to participate in the decision to access acute services.

On this particular issue, respondents identified barriers as:

- Difficulties in rural areas in coordinating access to service eg: between the general hospital, police, ambulance service, and acute mental health facility (often a long distance away).

"We're 1 hour from an acute service, but it took 11 hours to get one of my patients there- once it took 23 hours! There's no clear plan, there should be a process that just kicks in".

(Respondent # 19)

- Not having information about how to access services:

"There is no pathway to access services, only a moat guarded by psychiatric nurses. As a GP in a country town I need to speak to the consultant, but I can only ever speak to the triage nurse."

(Respondent #13)

d) Distance from services:

Other rural respondents commented they were isolated or remote from the point of service delivery and were therefore less able to participate. Many of these respondents

suggested greater availability of telephone support services and outreach services would assist them to participate. One suggestion was to give consumer consultants a car so they could get to more remote rural areas.

EXPERIENCES IN RELATION TO CONSUMER PARTICIPATION

When asked to describe their experience with particular consumer participation strategies, most respondents talked about their experience of services, rather than experience of consumer participation.

This blurring of lines between experience of service and experience of consumer participation was particularly pronounced amongst those respondents using Aged Persons Services and those who had little or no contact with consumer organisations such as Victorian Mental Illness Awareness Council (VMIAC) or Consumer Consultants.

Apart from Case Management, many responses related only to Consumer Consultants. Other consumer participation strategies and initiatives did not receive comment.

Responses to particular consumer participation strategies included:

10.7.9. Case Management

Most respondents using who used Aged Persons Service were very positive about their relationship with their service. Almost all were consumers, or carers of consumers, using one metropolitanpolitan Aged Persons Service. They were almost unanimous in their praise of this service and its staff.

Comments about Case Management conducted by this particular service included:

- *"They were polite and encouraging"* *(Respondent # 16)*
- *"The doctor didn't want me to go home, but I wanted to go and they let me. They come and see if I'm O.K."* *(Respondent # 26)*
- *"I'm involved in decisions regarding my treatment - always spoken to about it - they treat you as someone special."* *(Respondent #27)*
- *"The Case Manager gives of herself unceasingly. It brings out the best in you." (Respondent # 37)*

Consumers of other (Adult) services were less enthusiastic about case management as a consumer participation strategy. Many said the effectiveness of case management in achieving consumer participation came down to personalities or individual staff rather than anything inherent in the strategy. Respondents had both positive and negative comments about their experience of case management.

Most negative responses identified not knowing how long their case manager would be working with them as a problem (ie; creating expectations that weren't met) as well as not necessarily doing anything that either enhanced their participation or the quality of the service they received. Many also perceived that resources were a barrier to this strategy ie; their case worker "was too busy" or was over-committed.

Positive responses appeared to focus on the person ie; that the individual was a "nice person", or that it was good to have someone taking an individual interest in them. Others thought that a holistic approach was the aim of case management, but said in their experience this did not happen. However some people were not happy to have someone so involved in their life ie;

"You don't need to tell your case worker everything".

(Respondent #9)

10.7.10.Consumer Participation Plans

No-one raised Consumer Participation Plans as a strategy they'd had experience of. When specifically asked about Consumer Participation Plans, all but one respondent said they didn't know what these were; typically;

"I've never heard of it - if they have one its not implemented".

(Respondent #36)

One respondent thought they were:

"All the pages of forms I filled out when I first started with my case manager. It seemed miraculous, but I never saw any of these plans, it was never reviewed and I don't believe any of it was used in an on-going method."

(Respondent #8)

10.7.11.Consumer Consultants

Consumer Consultants were closely linked by many respondents to VMIAC, many speaking about them interchangeably.

Most respondents who knew of Consumer Consultants (and/or VMIAC) were very supportive of this strategy, but some people were critical of what they saw as a "flawed model".

Respondents said Consumer Consultants had a positive impact because:

"They bridge the gap between consumers and health services"

(Respondent # 23)

"Consumer Consultants can offer personal insights … they are the primary reason consumers are involved".

(Respondent #3)

'Consumer Consultants have a lot to offer; from breaking down stigmas, educating others, bridging gaps between different disabilities, services, and the community, and offering non-clinical support - people don't see us as a threat, were just another consumer."

(Respondent #35)

Respondents were also supportive of self-help groups, citing groups initiated by VMIAC and Consumer Consultants. These groups were thought to provide a structure for

services to consult with consumers, whilst empowering consumers (and carers where they were also involved).

Criticisms of the Consumer Consultant Strategy were nearly all focussed on the 'model' and its implementation rather than the consultants' practices. This led some respondents to believe that this strategy was *"fundamentally flawed, deliberately, to make a show of giving consumers a voice".*

(Respondent # 15)

Respondents' criticisms included:

- An inherent and un-managed conflict of interest between the Consumer Consultant (also a patient or former/future patient) and employer (their service provider).

- The model lends itself to be used as token participation;

  "Only lip service is paid to them by the system, they are placated by the hierarchy and patronised."

  (Respondent #8)

- There were no remedial or grievance procedures for Consultants to use to make services accountable for the way they use Consultants or the way this strategy/model is applied.

- There were no "*job specifications"* for Consumer Consultants including defining *"who were genuine consumers" (Respondent # 7).* The organisational structure supporting this strategy, and also that of VMIAC, reflected this lack of clarity according to some respondents. However, some respondents saw this as a good thing because Consultants were *"pioneering something new".*

- The cost to Consultants of doing a job was not adequately acknowledged financially or through other compensation or support. Costs included the Consultant's mental health - some thought that being a consumer consultant can be so stressful and traumatic, it could make you ill - and direct costs of travel, telephone etc.

- Consumers and Consumer Consultants are not paid commensurate with their value to service quality:

  "Knowledge is a commodity, and should be paid for".

  (Respondent # 15)

- The implementation of the Consumer Consultant strategy has not adequately dealt with power issues inherent in consumer participation:

  "Consumers aren't given ownership of it because of fears of giving consumers something so important as people's well-being. Its really disempowering when ideas of consumers are stolen, then owned by the service system." *(Respondent # 3)*

- Confusion about the relationship between consumer participation and advocacy, and expectations of the Consultants, VMIAC and the strategy in the broader systemic context.

THE IMPACT OF CONSUMER PARTICIPATION STRATEGIES

10.7.12.Positive Outcomes of Consumer Participation Strategies:

Respondents were asked how consumer participation strategies had made a difference, or what impact they had on service delivery.

Respondents overwhelmingly said public mental health services were better now than in the past. Respondents said they were generally treated with greater dignity and had more of a say than in the past.

> *" A difference, yes! In the late 60's no opinions were ever sought - you were locked up for expressing an opinion. Everyone was scared stiff. Now we're able to voice our opinions and give our ideas as well as the staff."*
>
> *(Respondent #33)*

> *"The hospital is much better than when I was there 9 years ago. They have a positive outlook, the physical environment is good, and I appreciate the modern approach - it really inspired me."*
>
> *(Respondent #2)*

However most were unable to say why this improvement had occurred. With the exception of Consumer Consultants, particular strategies were not cited as reasons for improvement in services. Consumer Consultants and VMIAC were credited with having worked to change community attitudes and reduce the stigma associated with mental illness.

Many respondents said that while services had improved, access to services and quantity of service was still a big problem. These people thought this was a resource issue that impacted on consumer participation.

An outcome of this resource issue was additional stress being placed on the consumer's support systems (eg family, local GP etc). Some respondents thought that their experience in recognising 'warning signs' should be listened to by services, thus avoiding a 'crisis' that may strip them of rights:

> *"There's no treatment when you can see these buggers going off the rails. There's a reluctance to admit people because of a shortage of beds. If it was any other medical illness you'd do something to nip it in the bud. It comes down to patients rights versus. certification; my son refused medication (his right) which led to certification (no rights).*
>
> *(Respondent # 18)*

A small minority of respondents thought the overall quality of services had decreased over time:

> *"The quality of services have gone down-hill since the closure of mental hospitals. They should get back to mental hygiene services - services aren't doing enough, too many are slipping through the net."*
>
> *(Respondent #6)*

> *"There's a mythology around empowerment. 24 years ago we were given a better deal, opportunities have now dried up. For older consumers things are worse, they were better 'in the bad old days'."*
>
> *(Respondent #15)*

10.7.13.Negative Outcomes of Consumer Participation Strategies:

Given that very few respondents using the Freecall service were able to identify experience with more than one consumer participation strategy, few negative outcomes of strategies were identified. These have been noted as criticisms (see 5.4.3) of the Consumer Consultant model and its implementation.

Given that this strategy was generally the only one respondents were familiar with, one negative outcome identified was that consumer participation relied solely on this strategy, and the goodwill of services or individuals employed in services.

IMPROVING CONSUMER PARTICIPATION

Nearly all respondents gave specific suggestions to improve consumer participation, however many of these were relevant to service delivery and quality rather than specific to consumer participation.

These can be viewed in context of the key factors in the effectiveness of consumer participation previously identified (5.3).

1. The attitudes of staff to consumers, and service history or culture:

Many references were made by respondents to the attitudes of staff and doctors to consumers, both individually and collectively, being a barrier to participation. Consumers and carers said they need to know they and their input is valued and welcomed without reprisal.

> *"I'll participate when services are prepared to listen to what consumers are saying. Listening needs to be demonstrated at all those levels."*
>
> *(Respondent # 8)*

Many respondents suggested staff and doctors of Victoria's Public Mental Health Services should receive additional training or education to address 'attitudes' and 'organisational culture' as well as consumer participation.

> *"Education and training. There's still old school, old thought, old social structures, especially the legal system and in medicine where they just dish out consequences ."*
>
> *(Respondent # 3)*

> *"Doctors attitudes need to be improved. They treat me like a second rate citizen at the crisis centre, and make wrong assumptions."*
>
> *(Respondent # 9)*

"Staff Training; more information about consumer participation."
(Respondent # 31)

Some respondents were more ruthless in their suggestions to address staff attitudes and disempowerment of consumers :

"Get rid of the dead wood. Patients know which ones are bona-fide carers as opposed to those who are indifferent. Training at least in interpersonal skills and communication for staff. There needs to be men's only groups as well as women's groups. There's racism - I've been told to get a 'normal' name."
(Respondent # 20)

"Power can only come from class action." *(Respondent # 8)*

Other respondents, mostly consumers of Aged Persons Services, suggested service quality improvements which might be indicators of, or enhance consumer participation. They noted that some of these, but not necessarily all, may require additional resources:

"Good food shows caring and treating people with dignity."
(Respondent # 30)

"We should aim for a service model that is happy, bright, compassionate, and friendly." *(Respondent # 27)*

"Time; everyone's too busy to give time to people."
(Respondent # 21)

2. a) Information and support consumers have regarding their rights and services

In order to participate in decisions effecting consumers' treatment, respondents suggested there should be specific and clear information on both entry processes and the services themselves. Support to participate at this stage was also considered critical by some:

"Information about how to access services, who to ring etc."
(Respondent # 13)

"Information flow; if you're not in services you miss out on a lot of things - I'm a bit out of touch. Talking about and raising issues can be scary. At first there's fear; fear of your illness and fear of the stigma of psychiatric services. There needs to be stronger links to the community…"
(Respondent #11)

Some respondents said services were not 'marketed' or delivered from the perspective of the individual consumer in that they were concerned with tasks rather than support for each individual in the context of their own lives and social structure/network. This was an issue that would only be addressed by talking to consumers; understanding their individual needs.

"More information. Look at it like marketing, for example to schools. People are unclear how services work 'what will happen if I ring' there's a fear and stigma. There's no support once you're 'signed off' their books. There's no in-between, its scary; you need somewhere to ring like "kids-line" or "parents -line". (Respondent # 35)

"Increase awareness - brochures about services and consumer consultants. Put in faxes and look at country issues like the distance to services. Listen to submissions. Rewards aren't there for the good staff to keep them."
(Respondent # 23)

There were also suggestions for improved information and education for consumers about their rights and services:

"Video; personal development, rights - lots of people can learn from TV."
(Respondent # 12)

b) the health of the consumer at the time they are expected to participate:

A number of respondents identified a potential barrier to participation as the health of the consumer. Some respondents were concerned there would be times when consumers could not, or did not want to make decisions, but didn't want to be precluded from ever participating on that basis. Respondents identified a dilemma of 'who should decide' whether consumers' decisions are sought or considered when consumers are 'really ill'. This was identified by some as a "balancing act" of rights versus protection.

A few respondents suggested a role for advocacy (including self, peer, and independent) in addressing the issues of consumers' health impacting on decision making. Other suggestions to address his issue were ensuring consumers were given a choice about participating, including how and when to participate, as well as utilising the times when consumers can and want to participate in planning and decisions.

3. The availability and access to structures for participation:

Respondents were very clear that consumer participation was not "a" task, but a process requiring a range of inputs on different levels. Improving consumer participation would require strengthening and improving the range of ways/structures for consumers to have input into decisions.

This range of structures would more likely support individual needs of consumers (see 2. above). Attention would also need to be given to geographic considerations:

"Its difficult in country areas; travel time, stigma and lack of understanding. (Regional city) has a hold on everything, (rural town) is trying to get a group going. In outlying country areas its even more difficult."
(Respondent # 4)

Specific suggestions for consumer participation structures included:

"Friendship support gives you the courage to do something - I was enraged and encouraged to do something about it. I formed a group because I was so incensed by our treatment. You also need advocacy support for example from VMIAC. "
(Respondent # 10)

"There needs to be more funding for organisations where consumers can collectively speak in one voice. You need to address barriers of distance and be more geographically sensitive for example transport and community transport"
(Respondent # 36)

*"I want direct dialogue with the decision maker - (*The Minister for Human Services*) Rob Knowles. I don't want to waste my time with submissions, but I am interested in conferences".*
(Respondent # 7)

4. The existence and implementation of supporting policies and procedures in services and across the service system:

Consumer participation is not a "stand-alone task". Responses indicate that all service policies and procedures need to be inclusive of consumer participation principles and practices. This included legislation as a foundation:

"*Rights - legislation needs to be introduced or changed so that people can't have things done to them they don't consent to."*
(Respondent # 5)

Polices specifically identified by respondents included Access or Entry and Exit Policies, as well as Complaints Procedures and the 'right of entry' for advocates and/or independent "watch-dogs".

"Public advocates or lay people visiting the hostels is very important. It gives a clear message to management that outsiders will be looking in. Its important they are legally allowed in."
(Respondent # 16)

***5.* An understanding that consumer participation is a developing and evolving notion:**

Consumer participation is developing and evolving. It was important to both recognise and support this growth:

"We are getting better at consumer participation….it can be on a lot of levels eg buddies system, a support group in each town. Community education by consultants to the doctors and police has made them terrific now, really sensitive."
(Respondent # 35)

"We are getting there in small steps" *(Respondent # 36)*

Some were less patient with this process of evolution:

" We need more action than reports, more communication."
(Respondent #17)

Other respondents encouraged the development and improvement of consumer participation through knowledge:

"Transfer knowledge; you need to have an impact on consumers' awareness of rights, empowerment etc through networks, advocacy, self and peer advocacy."
(Respondent # 34)

"Learn how social structures have broken down. This has got lost somewhere. We need interpretation of statistics - to broaden the base of input, adapt the model; look interstate at what other people are doing."
(Respondent # 3)

In the context of consumer participation being an evolving process, the criticisms made of the Consumer Consultant Strategy need to be assessed, and addressed where necessary.

Particular issues which need to be clarified are:

- The context of the Consumer Consultant strategy in the Public Mental Health consumer participation policy, and its implementation in the service delivery system.
- The reconciliation of the purposes of this strategy with the job specifications of Consultants, and the development or review of job specifications.
- Management of the apparent conflict of interests and power imbalances.
- Support available to consultants as well as fair financial compensation.

LIST OF APPENDICIES

i) Flyer:
"Evaluation of Consumer Participation in Victoria's Area Mental Health Services; Information for Consumers"

ii) Freecall 1800 Telephone Response Record

Evaluation of Consumer Participation in Victoria's Area Mental Health Services

Information for Consumers

About The Evaluation

The Department of Human Services, Mental Health Branch has appointed independent consultants, Service Quality Australia, to evaluate consumer participation in Victoria's public mental health services.

The goal is to assess how effectively the policy of consumer participation has been implemented in Victoria's public mental health services. This is a positive, forward-looking perspective aimed at building on the work that has already been done. Effective consumer participation is achieved when consumers are able to have a major influence on how mental health services are provided. This ranges from consumers being able to influence how their individual needs are met, through to consumer input into service planning, development and evaluation.

Recommendations will be developed about future directions for effective consumer participation in public mental health services in Victoria.

A crucial step in achieving this is consultation with consumers. A range of opportunities for consumer input are available. These are detailed on the back of this flier.

Who Are Consumers?
Consumers are people who have used or are currently using public mental health services.

Feedback Topics

WE PARTICULARLY WANT FEEDBACK FROM CONSUMERS ABOUT:

- ❒ What consumer participation means to you
- ❒ The purposes of consumer participation in public mental health services
- ❒ What makes consumer participation effective
- ❒ Your experiences in relation to consumer participation in Victoria's public mental health services
- ❒ What differences you believe consumer participation strategies have made to mental health services
- ❒ How consumer participation can be improved for you and others

Please note that confidentiality is considered extremely important. Any information provided by consumers will only be used in ways that guarantee that their identity will be protected.

Opportunities for Consumer Input

FREECALL 1800 007 899

Consumers are strongly encouraged to use the FREECALL 1800 telephone service set up for the evaluation. If you wish to let the consultants know your views about consumer participation in public mental health services telephone Catherine Fraser on FREECALL 1800 007 899.

The FREECALL line will operate during business hours (9am - 5pm) from Monday 7 December until Friday 18 December, excluding weekends. A Telephone Typewriter is available for Deaf consumers. If you require a telephone the Victorian Interpreter Telephone Service will also be available.

Consumer Focus Groups

Focus groups will be held during the period **Monday 7 December until Friday 18 December**. This will be an opportunity for consumers to give detailed feedback about consumer participation in particular Area Mental Health Services.

If you are interested in attending a focus group in your area contact one of the people below before 7 December to find out where and when focus groups will be held, and to register. A contribution to the cost of childcare and transport is available if organised in advance.

Area Mental Health Service			Contact Person
• Inner West • Mid West • North East	• North West • Northern • South West	• Geelong • Warrnambool	**Mary Burgess** ph 9489 4641 fax 9482 5807
• Gippsland			**Michael Bink** ph 9824 0319 fax 9482 5807
• Central East • Dandenong • Inner South	• Inner Urban East • Middle South • Outer East	• Peninsula • Monash	**Dymphna Laurie** ph 9690 1950 fax 9699 8555
• Bendigo • Grampians	• Mildura • Shepparton	• Wangaratta • Wodonga	**Chris Fyffe & Jeff McCubbery** ph 5439 5305 fax 5439 3534

Written Submissions

Anybody wishing to make a written submission can get a copy of the Discussion Paper. This provides a framework for submissions, plus information on how submissions can be sent in. To get a copy of the Discussion Paper contact Mary Burgess by any of the means listed below.

THE DEADLINE FOR WRITTEN SUBMISSIONS IS FRIDAY 15 JANUARY.

Evaluation of Consumer Participation in Victoria's Mental Health Services

1800 Telephone Response Record

Time………………am /pm **Date**……..…./ 12/ 98 **Response #**……….……

NB: Confidentiality is considered extremely important. Any information provided by consumers will only be used in ways that guarantee that their identity will be protected. ***** Denotes optional information***

Role……………………………**Name****…..……………………………………..……

Location: Metropolitan. /
Rural…………………………………………………………..

Service Type/s……………………………………………………………………..
…………………………………………………………………………………………..
(Public / Community Based/ Other………………………………….)

Service/s Used**…………………….……………………………………………….
..……………………………………………………………………………………………

❐ What consumer participation means to you

1. What Consumer Participation means
1.1. What do you believe the term 'consumer participation' means?

❐ The purposes of consumer participation in public mental health services

2. Purpose
2.1 What should consumer participation in public mental health services be trying to achieve?
- *for individual consumers*

- *for service delivery*
- *for service quality*

❒ **What makes consumer participation effective**

3. Effective Consumer Participation
3.1 What makes consumer participation effective?
3.2 What has worked well?
3.3 What are the barriers to effective consumer participation?

❒ **Your experiences in relation to consumer participation in Victoria's public mental health services**

4. Consumer Participation Strategies
4.1 Describe your experience with particular consumer participation strategies such as:
- *case management*
- *consumer participation plans*
- *consumer consultants*
- *other initiatives*

❒ **What differences you believe consumer participation strategies have made to mental health services**

5. The Impact Of Consumer Participation Strategies
5.1 How have consumer participation strategies made a difference?
5.2 What are some of the positive outcomes of which you are aware?
5.3 Are there any negative outcomes?
5.4 What differences do you think there have been for:
- *consumers*
- *carers*
- *service providers*
- *the service system as a whole*

5.5 What difference has consumer participation made to service delivery?
5.6 What difference has consumer participation made to the quality of service?

❒ **How consumer participation can be improved**

6. Improving Consumer Participation

6.1 In what ways can consumer participation strategies be improved?
6.2 What models might be effective?
6.3 What other issues need to be addressed?
Consider training, resource materials, support structures etc.
6.4 How can barriers you have identified to effective consumer participation be overcome?

10.8. ATTACHMENT 8 References

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