

# Summary of the 2003-2004 survey of consumer & carer experience of Victorian public aged persons mental health services

## 1. Introduction

### 1.1 Survey Aims

An important aspect of continuous improvement to ensure that services are meeting the needs of consumers and carers is to ask them about their perspectives of the treatment and care they received.

The aims of the 2003/04 statewide consumer and carer surveys included:

1. To provide an understanding of consumer and carer perspectives of service quality from their experience.
2. To encourage reflection on current practice, including the identification of strengths, weaknesses and priorities for improvement.
3. To provide information that assists services in planning for continuous improvement with consumers, carers and other stakeholders.
4. To facilitate sharing of information and collaboration between services for best practice development.

### 1.2 Survey methodology

In 2001/02, the Department commissioned Taylor Nelson Sofres (TNS) to redevelop the statewide consumer & carer surveys in collaboration with consumers, carers and service providers. The new survey methodology combines mail-out mail-back semi-structured questionnaires, focus groups and individual interviews.

The items in the survey reflect the needs, priorities and expectations of services identified by consumers and carers in focus groups, interviews and questionnaires conducted by TNS. The survey items were then linked to the National Standards for Mental Health Services (NSMHS) to provide meaningful benchmarks for services. The survey was developed and tested in collaboration with consumers, carers and service providers prior to full implementation in 2003/04.

## 2. Survey Sample

### 2.1 Characteristics

The consumer sample was 65 years of age or more and had used an aged persons mental health service (APMHS) during 2003. This included consumers who had since been discharged from the service. Consumers who were admitted to an acute inpatient service at the time of the survey were excluded, although those with prior admissions were included to ensure feedback from this group of service users.

The carer sample comprised of persons who provided support or care to someone aged 65 years or more who had used APMHS. This included family members, next of kin, friends and neighbours, but not paid carers employed by the service.

## 2.2 Sampling strategy

Survey questionnaires were distributed to a random sample of consumers and carers at all 17 APMHS (9 metro & 8 rural). Target sample sizes at each service were 300 consumers and 200 carers.

Sampling protocols for recruitment of consumers and carers to focus groups and individual interviews were established with the 7 APMHS (3 metro & 4 rural) involved.

## 2.3 Response rates

Overall, there were 921 respondents that included 461 consumers and 460 carers with a response rate of 13.1%. The response rate for consumers ranged from 7.5% to 33.8% between services, with an average of 13.0%. The response rate for carers ranged from 8.8% to 26.0% between services, with an average of 16.2%.

Although the response rates are low, the achieved sample is representative of the target population for age, gender, geographic location, preferred language, involuntary status and use of services.

## 3. Key indicators

The APMHS questionnaires contained four sets of questions with one or two summary questions for each. The summary questions were used as key indicators of service quality as follows:

### Information about rights & responsibilities

- Provision of information when needed
- Helping consumers/carers understand information

### Accessibility and responsiveness

- Enabling consumers/carers to get help
- Getting help to consumers/carers when needed

### Information about treatment & support

- Ensuring consumers/carers understand treatment information
- Providing treatment information when needed

### Provision of treatment & support

- Meeting consumer/carer needs

Table 1 illustrates the net positive responses of consumers and carers across the seven key indicators of service quality.

**Table 1: Key Indicators of Service Quality**

	Net positive responses (% good, very good, excellent – combined)	
	Consumers	Carers
Provision of information about rights & responsibilities when needed	84%	77%
Understandable information about rights & responsibilities	82%	76%
Enabling access to help	86%	77%
Getting help when needed	86%	78%
Provision of treatment information when needed	82%	67%
Understandable treatment information	79%	65%
Meeting individual needs	85%	71%

For consumers, there were no significant differences in net positive responses for the seven key indicators of service quality by age, gender, length of contact with the service, most recent hospital admission, or the existence of a community treatment order (CTO). There were significant differences in net positive responses b/w **metropolitan & rural services** for providing treatment information when needed (78% and 86% respectively).

For carers, there were significant differences in net positive responses as follows:

- **Metropolitan & rural services** for providing treatment information when needed (63% and 73% respectively) and meeting needs (66% and 77% respectively)
- Carers **under 65 years** compared to those 65 years and over for meeting individual needs (67% and 77% respectively) and providing understandable information about rights and responsibilities (72% and 83% respectively)
- Carers who were newer to the service (**up to 1 year**) rated more positively across nearly all indicators
- Carers with a preferred language other than English (**LOTE**) rated less positively than English speaking carers for understandable information about rights and responsibilities (65% and 78% respectively) and information about rights and responsibilities when needed (66% and 79% respectively)

#### 4. Service quality from the perspective of consumers

The following information outlines highest and lowest net positive responses from consumers for each of the structured questions. The information needs to be considered in the context of other sources of information regarding service performance, particularly because of the low response rates to the survey.

##### 4.1 Information about rights & responsibilities

- Net positive ratings ranged from 76% to 88%
- Highest net positive response ratings were for:
  - Letting you know about your right to privacy (88%)
  - That you should feel safe where you are seen by the service (88%)
  - Letting you know what the service can do for you (86%).
- Lowest net positive response ratings were for:
  - Letting you know how to comment or complain about the service (76%)
  - How to participate in overall service planning, improvement & review (77%)

##### 4.2 Accessibility & responsiveness

- Net positive ratings ranged from 79% to 91%
- Highest net positive response ratings were for:
  - Letting you know how & when they can be contacted (91%)
  - Making you feel safe where you were seen by the service (90%)
- Lowest net positive response ratings were for:
  - Providing written information in your preferred language (80%)  
*Note: Consumers with a preferred language other than English rated significantly lower (60%) compared to consumers with English as their preferred language (80%); of the total consumer respondents, 20% rated this item as average or poor*
  - Being easy to travel to (79%)

##### 4.3 Information about treatment and support

- Net positive ratings ranged from 67% to 83%
- Highest net positive response ratings were for:
  - Providing information about illness or problems (83%)
  - Providing information about the range of treatments available (83%)
  - Providing information about the medication you are taking (83%)
  - Providing information about other services that may help (81%)
- Lowest net positive response ratings were for:
  - Providing information about the Mental Health Act, including the Mental Health Review Board and CTOs (67%)

#### 4.4 Provision of treatment and support

- Scores ranged from 71% to 84%
- Highest net positive response ratings were for:
  - Helping you to improve or maintain links with your GP (84%)
  - Respecting your opinion about treatment (83%)
  - Helping you to cope with daily activities (83%)
- Lowest net positive response ratings were for help to access:
  - Education & training courses/facilities (71%)
  - Financial services (74%)
  - Accommodation (78%)
  - Leisure and recreation groups or services (78%)
  - Support groups and services (79%)

### 5. Service strengths, weaknesses and areas for improvement from the perspective of consumers

The following information represents consumer responses to open-ended questions asking them to identify service strengths, weaknesses and areas for improvement from their experience.

#### 5.1 Service strengths

- 76% made comments
- Staff (41%) – described as compassionate, supportive, caring, reassuring, helpful, friendly and non-judgemental

#### 5.2 Service weaknesses

- 54% made comments
- 28% indicated that there was nothing that they did not like

#### 5.3 Areas for improvement

- 55% made comments
- Nothing needs to change (21%)
- Increase staff levels (5%)
- More communication about the condition, progress & treatment and inclusion of carers (3%)
- Greater focus on outcomes & coping strategies (3%)
- More home visits (2%)
- Keeping in touch/follow-up after discharge (2%)
- Improve availability (2%)

### 6. Consumer use and ratings of service types

- **Community-based assessment & treatment services:** Of the 63% of respondents who used these services, 88% rated positively
- **Acute inpatient services:** Of the 25% of respondents who used these services, 84% rated positively
- **Residential services:** Of the 29% of respondents who used these services, 84% rated positively

### 7. Consumer characteristics

- **Location:** 54% metro compared to 46% rural
- **Gender:** 58% female compared to 39% male
- **Preferred language:** English was the preferred language spoken for 85% (20% metro compared to 3% rural spoke a LOTE)
- **Age:** 92% were aged 65 years or over
- **Length of contact:** 47% had been in contact with the service for less than a year; 33% for more than 1 year but less than 5 years; 20% for more than 5 years
- **Last face-to-face contact:** at home for 58%

- **Time of last contact:** 56% in the previous month; 13% in the last 2 months; 10% in the last 3 months; 8% in the last 6 months; 12% more than 6 months ago
- **Last inpatient admission:** 49% indicated an inpatient admission and of that 50% had been admitted during 2003, 22% during 2002 and 28% prior to 2002
- **CTO:** 17% were currently on a CTO; 63% were not on a CTO; 20% were unsure
- **Completion of the questionnaire:** 55% needed assistance to complete the questionnaire, which is higher compared to consumer respondents in the child and adolescent and adult mental health service surveys

## 8. Service quality from the perspective of carers

The following information outlines highest and lowest net positive responses from carers for each of the structured questions. The information needs to be considered in the context of other sources of information regarding service performance, particularly because of the low response rates to the survey.

### 8.1 Information about rights & responsibilities

- Net positive ratings ranged from 66% to 85%
- Highest net positive response ratings were for:
  - Your right & that of the person you care for to speak with someone in your preferred language (85%)
  - Your right & that of the person you care for to feel safe where you are seen by the service (84%)
  - What the service can do for you & the person you care for (83%)
  - Your right & that of the person you care for to privacy (81%)
- Lowest net positive response ratings were for letting you know:
  - How to comment or complain about the service (66%)
  - How to participate in overall service planning, improvement & review (66%)

### 8.2 Accessibility & responsiveness

- Net positive ratings ranged from 69% to 86%
- Highest net positive response ratings were for:
  - Letting you know how & when they can be contacted (85%)
  - Making you feel safe where you were seen by the service (86%)
- Lowest net positive response ratings were for:
  - Providing opportunities for you to be involved in service planning, improvement & review (69%)
  - Providing written information in your preferred language (73%)
  - Being available when needed (73%)

### 8.3 Information about treatment and support

- Net positive ratings ranged from 54% to 72%
- Highest net positive response ratings were for:
  - Providing information about illness or problems (72%)
  - Providing information about the range of available treatment for mental illness or problems (68%)
  - Providing information about the assessment process (68%)
  - Providing information about other services and supports that may help the person you care for (66%)
- Lowest net positive response ratings were for:
  - Providing information about the Mental Health Act, including CTOs and Mental Health Review Board (54%)
  - Providing information about available services and supports for carers (62%)
  - Providing information about the discharge process (62%)

## 8.4 Provision of treatment and support

- Net positive ratings ranged from 58% to 77%
- Highest net positive response ratings were for:
  - Respecting your opinion of what might help the person you care for (77%)
  - Providing opportunities to discuss the person's illness (76%)
  - Providing opportunities to discuss the person's medication (75%)
  - Discussing effects/outcomes of treatment (74%)
- Lowest net positive response ratings were for:
  - Help to prepare for when the person no longer uses the service (58%)
  - Help to access available services and supports for carers (63%)
  - Help to recognise and manage early signs of deterioration in the person you care for (63%)

## 9. Service strengths, weaknesses and areas for improvement from the perspective of carers

The following information represents carer responses to open-ended questions asking them to identify service strengths, weaknesses and areas for improvement from their experience.

### 9.1 Service strengths

- 85% made comments
- Staff (44%) – described as compassionate, understanding, supportive, caring, reassuring, helpful, friendly and non-judgemental

### 9.2 Service weaknesses

- 64% made comments
- 19% indicated that there was nothing about the service they did not like

### 9.3 Areas for improvement

- 68% made comments
- Nothing needs to change (14%)
- More communication and inclusion of carer in decisions about treatment and progress (11%)
- More staff (8%)
- More information & assistance to access available help & support (4%)
- More information about the illness or condition and better access to this information (3%)
- Faster access, shorter waiting lists and earlier intervention (3%)
- More support & respite for carers (3%)
- More understanding, caring, compassionate & supportive staff (3%)

## 10. Carer use and ratings of services types

- **Community-based assessment & treatment services:** Of the 67% of respondents who used these services, 82% rated positively
- **Acute inpatient services:** Of the 33% of respondents who used these services, 82% rated positively
- **Residential services:** Of the 45% of respondents who used these services, 76% rated positively

## 11. Carer characteristics

- **Location:** 58% metro compared to 42% rural
- **Gender:** 61% were female compared to 38% who were male
- **Preferred language:** English was the preferred language spoken for 87% (18% metro compared to 3% rural spoke a LOTE)
- **Age:** 44% aged 65 years or more; 42% aged 45-64 years; 11% aged 35-44 years
- **Age of person cared for:** 93% aged 65 years or more; 4% less than 65 years
- **Relationship:** 43% of carers were the spouse or partner and 42% were the child of the person they cared for

- **Length of contact:** 45% had been in contact with the service for less than a year; 36% for more than 1 year but less than 5 years; 20% for more than 5 years
- **Last contact with the service:** Face-to-face for 67% and telephone for 30%
- **Time of last contact:** 55% in the previous month; 12% in the last 2 months; 10% in the last 3 months; 10% in the last 6 months
- **Completion of the questionnaire:** 11% required assistance to complete the questionnaire

## 12. Qualitative findings

The use of focus groups and interviews provided a rich source of descriptive information, which adds depth to our understanding of information gathered through the questionnaires. The information in this section is summarised according to key themes that emerged.

### 12.1 Accessibility of services

- Several barriers to initial access:
  - Poor awareness of mental health services in the community
  - Stigma attached to mental illness & both the consumer' & families' reluctance to admit they need help
  - Poor understanding of mental illness, particularly the difference between 'bad behaviour' and 'illness behaviour'
  - Fear of the unknown
- Community-based services:
  - Generally accessible & responsive in crisis and ongoing case management, particularly positive about home visits & availability of 24hr telephone support
- Inpatient services:
  - Feel more confident about the availability of services when crisis management plans are used
  - Others felt delays in admission were problematic

### 12.2 Attitudes & responsiveness of staff

- Positive comments from most consumers & carers
- Use of temporary/agency staff on acute inpatient units limited rapport with consumers & carers

### 12.3 Communication

- Case managers were seen as having a pivotal role in establishing effective communication with key stakeholders
- Most consumers reported that their GP was part of the treating team & kept informed of progress
- Generally positive about handovers/communication b/w staff within the service

### 12.4 Provision of information

- That services be more proactive in providing written information about rights and responsibilities to consumers and carers.
- Consumers with involuntary legal status were particularly interested in their treatment rights, including the use of ECT and medication
- Consumers and carers preferred information to be provided on a 'needs to know' basis in plain language and tailored to the individual's ability to process & retain information at the time
- Carers preferred verbal briefings that are supplemented by simple written explanations of key aspects of the service
- Information to carers needs to be regular and ongoing, regardless of the duration of their contact with the service
- Carers requested greater assistance and support with explaining:
  - To the consumer why the service is involved and/or why they need to be admitted
  - The illness & treatment to other family members
- There was a high level of interest in information about other available services and supports that may be able to help, however consumers & carers would also like greater encouragement and assistance to access them

## 12.5 Involvement in treatment

- Consumers:
  - Although more likely to rely on and accept professional judgements, it was important that staff were willing to listen to their concerns
  - Would like more say in decisions about the use of invasive treatments such as ECT
  - Viewed maintaining (or rebuilding) social relations and links with the community as an essential part of treatment
  - Considered the availability of a range of interesting and suitable activities on the acute inpatient unit as important for recovery
  - Suggested that the environment in extended care units could be more 'homely' by, for example, allowing use of personal items & furnishings.
  - Would like greater assistance to access other services, for example, helping them to make enquiries, fill in application forms and arrange transport
- Carers:
  - Viewed themselves as an important source of information about treatment needs, progress and response
  - Expected to be involved in all major decisions about treatment including changes to medication and discharge
  - Valued any help or support they received, particularly practical support in caring for someone with a mental illness in the community, links to support programs, as well as a friendly & caring attitude from staff.
  - Some felt that they were not involved in decisions unless they asked
  - Some felt that their own needs were not considered important
  - Viewed family meetings as a potentially useful vehicle for communicating with and involving carers & other family members. In practice, however, carers found family meetings somewhat one-sided and confusing. They suggested greater clarity around the purpose of family meetings and the roles of family and staff.
  - Felt that services could provide better support and follow-up after discharge from the service including information about re-entry

## 13. Action

The survey findings provide a source of reflection and potential for improvements in practice. It is important that service give sufficient priority to the perspectives of consumers and carers about their experience.

Services are expected to consider the strengths and areas for improvement highlighted in the survey findings, together with other sources of performance information. Other sources of information may include local consumer and carer feedback/complaints processes, key performance indicators, incident monitoring, etc.

Reflective questions may include:

- What do we know about our current performance in these areas? Do we need to gather further information? This guides a process for validating strengths and issues for improvement.
- What assurances for quality currently exist in these areas? It is important to ensure that governance processes and systems provide a source of regular and valuable feedback for continuous improvement.
- What can improve the experience of consumers & carers in these areas? Planning for improvement guides action.