

Summary of the 2003-2004 survey of consumer & carer experience of Victorian public adult 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 aged between 18 and 64 years of age and had used an adult mental health service (AMHS) 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 18 to 64 years who had used AMHS. 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 21 AMHS (13 metro and 8 rural). Target sample sizes for 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 AMHS (3 metro & 4 rural) involved.

2.3 Response rates

Overall, there were 1,586 respondents that included 908 consumers and 678 carers with a response rate of 15.1%. The response rates for consumers ranged from 7.3% to 26.0% between services, with an average of 14.2%. The carer response rate ranged from 9.8% to 26.5%, with an average of 15.8%.

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 AMHS questionnaires contained four sets of questions with one or two summary questions for each set. 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 | 67% | 56% |
| Understandable information about rights & responsibilities | 67% | 55% |
| Enabling access to help | 72% | 57% |
| Getting help when needed | 71% | 58% |
| Provision of treatment information when needed | 58% | 47% |
| Understandable treatment information | 57% | 45% |
| Meeting individual needs | 63% | 49% |

For consumers:

There were no significant differences in net positive responses for the seven key indicators of service quality by location, age, length of contact with service or the existence of a Community Treatment Order (CTO).

Consumers who had been admitted to hospital in 2003 rated their service less positively on most key indicators compared with consumers whose most recent admission was during or prior to 2002, which was a theme throughout the survey. Female consumers were less positive than males on getting help when needed (68% compared to 75%), and generally throughout the survey. Consumers with a preferred language other than English (LOTE) compared to English speaking consumers were more positive about their service on understandable information about rights & responsibilities (80% compared to 66%), provision of information about rights & responsibilities when needed (80% compared to 66%) and enabling access to help (84% compared to 71%).

For carers:

Overall, carers were less positive about their experiences with AMHS than consumers and compared to carers of child & adolescent (CAMHS) and aged persons (APMHS) mental health services.

Metropolitan services were rated more positively compared with rural services on enabling access to help (60% and 52% respectively). LOTE compared to English speaking carers were more positive about AMHS across all key indicators. In addition, there were trends throughout the survey for older carers (65 years or more) who were generally more positive compared to younger carers; female carers who were generally less positive than male carers; and carers in contact with the service for more than 5 years who were generally less positive about the service.

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 53% to 74%
- Highest net positive response ratings were for:
 - Letting you know about your right to privacy (74%)
 - That you can speak to someone in your preferred language (72%)
 - That you should feel safe where you are seen by the service (72%)
 - Letting you know what the service can do for you (72%)
- Lowest net positive response ratings were for:
 - Letting you know how to comment or complain about the service (53%)
 - How to participate in overall service planning, improvement & review (57%)
 - When you can choose who is told that you use the service (66%)
 - That you can speak to a male or female staff member (67%)

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 (79%)
 - Being easy to travel to (78%)
 - Making you feel safe where you were seen by the service (76%)
 - Letting you know who you should talk to (75%)
- Lowest net positive response ratings were for:
 - Providing opportunities for you to participate in overall service planning, improvement & review (61%)
 - Allowing you to comment or complain about the service (63%)
 - Asking for your opinion about your needs (64%)
 - Listening to your opinion about your needs (66%)

4.3 Information about treatment and support

- Net positive ratings ranged from 47% to 64%
- Highest net positive response ratings were for:
 - Providing information about your illness or condition (64%)
 - Providing information about the medication you are taking (64%)
 - Providing information about the range of treatments available (60%)
 - Providing information about other services that may help (60%)
- Lowest net positive response ratings were for:
 - Providing information about the Mental Health Act, including CTOs and the Mental Health Review Board (47%). Note that 44% of consumers on a CTO rated the service as poor or average on this indicator.
 - Providing information about the discharge process (49%)
 - Providing information about the assessment process (51%)
 - Providing information about the treatment planning & review process (52%)
 - Providing information about other treatment (not medication) you are receiving (55%)

4.4 Provision of treatment and support

- Net positive ratings ranged from 44% to 64%
- Highest net positive response ratings were for:
 - Respecting your opinion about your treatment (64%)
 - Helping you to improve or maintain links with your GP (63%)
 - Discussing the effects/outcomes of your treatment with you (61%)
 - Helping you to identify early signs of deterioration in your illness or condition (61%)
- Lowest net positive response ratings were for:
 - Helping you to access employment services (44%)
 - Helping you to access education & training courses/facilities (45%)
 - Helping you to prepare for when you no longer use the service (47%)
 - Helping you to access leisure/recreation groups or services (50%)
 - Helping you to access financial services (50%)

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

- 87% made comments
- Attitudes & characteristics of staff (43%) – understanding, compassionate, supportive, caring, reassuring, helpful, friendly and non-judgemental
- Being able to talk to someone & discuss issues (13%)
- Coping strategies & suggestions (9%)
- Nothing that I liked (9%)
- Help available when needed (8%)

5.2 Service weaknesses

- 80% made comments
- 17% indicated that there was nothing that they did not like
- Attitudes & characteristics of staff (8%) – rude, unhelpful, lacked compassion & understanding (this was more common with consumers who had been admitted in 2003 and consumers who had used the service for 5yrs or more)
- Felt excluded & unable to have input into key decisions (5%)
- Lack of communication & feedback about the condition, progress & treatment (5%)
- Lack of staff continuity (4%)

5.3 Areas for improvement

- 79% made comments
- 15% indicated that nothing needs to improve
- More understanding/caring/compassionate/supportive staff (9%)
- Increase staff levels (6%)
- Greater willingness to listen to concerns (5%)
- More focus on strategies & advice on how to cope (5%)
- Communication about the condition, treatment and progress and inclusion of carers (4%)

6. Consumer use and ratings of service types

- **Continuing care/community clinic services:** Of the 64% of respondents who used these services, 70% rated positively
- **Mobile Support & Treatment Services:** Of the 28% of respondents who used these services, 67% rated positively
- **Crisis Assessment & Treatment Services:** Of the 47% of respondents who used these services, 64% rated positively
- **Acute inpatient services:** Of the 31% of respondents who used these services, 53% rated positively
- **Primary Mental Health & Early Intervention Services:** Of the 25% of respondents who used these services, 62% rated positively
- **Dual Diagnosis Services:** Of the 17% of respondents who used these services, 54% rated positively and 25% rated as poor
- **Community Care Units:** Of the 26% of respondents who used these services, 65% rated positively
- **Secure extended care inpatient services:** Of the 19% of respondents who used these services, 56% rated positively

7. Consumer characteristics

- **Location:** 56% metro compared to 44% rural
- **Gender:** 54% female compared to 44% male
- **Preferred language:** English was the preferred language spoken for 90% (and of the 8% who spoke a LOTE, 13% were metro compared to 2% rural)
- **Age:** 85% were aged between 25 & 64 years; significantly more consumers in metro (14%) compared to rural (6%) were aged between 18 & 24 years; significantly more consumers in rural (38%) compared to metro (29%) were aged between 45 & 64 years
- **Length of contact:** 40% had been in contact with the service for more than 5 years; 27% for more than 1 year but less than 5 years; 33% for less than a year
- **Last face-to-face contact:** At a community clinic/centre for 51% (significantly more common for metro than rural, with rural more likely to have had their last contact at home)
- **Time of last contact:** 65% had their last contact with the service in the previous month; 10% in the last 2 months; 8% in the last 3 months; 9% in the last 6 months; 8% more than 6 months ago
- **Last inpatient admission:** All indicated an inpatient admission and of that 46% had been admitted during 2003, 20% during 2002 and 34% prior to 2002
- **CTO:** 19% were currently on a CTO (more likely for metro than rural and females than males); 62% were not on a CTO; 19% were unsure (more likely for those aged 18-34yrs than 35yrs or more)
- **Completion of the questionnaire:** 20% needed some form of assistance to complete the questionnaire

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 46% to 78%
- Highest net positive response ratings were for:
 - Your right & that of the person you care for to speak with someone in your preferred language (78%)
 - Your right & that of the person you care for to privacy (71%)
 - Your right & that of the person you care for to confidentiality (71%)
 - Your right & that of the person you care for to written information in your preferred language (70%)
- Lowest net positive response ratings were for letting you know:
 - How to participate in overall service planning, improvement & review (46%)
 - How to comment or complain about the service (47%)
 - What they expect from you & the person you care for (57%)

8.2 Accessibility & responsiveness

- Net positive ratings ranged from 50% to 79%
- Highest net positive response ratings were for:
 - Respecting your cultural beliefs & practices (79%)
 - Arranging for an interpreter when needed (76%)
 - Making you feel safe where you were seen by the service (75%)
 - Being easy to travel to (72%)
- Lowest net positive response ratings were for:
 - Providing opportunities for you to be involved in service planning, improvement & review (50%)
 - Being available when you needed them (54%)
 - Making it easy for you to find the person you needed to talk to (58%)

8.3 Information about treatment and support

- Net positive ratings ranged from 39% to 57%
- Highest net positive response ratings were for:
 - Providing information about illness or problems (57%)
 - Providing information about other services and supports that may help the person you care for (49%)
 - Providing information about the range of treatments available for mental illness or problems (48%)
- Lowest net positive response ratings were for:
 - Providing information about the discharge process (39%)
 - Providing information about the Mental Health Act, including the Mental Health Review Board and CTOs (41%)
 - Providing information about the assessment process (42%)
 - Providing information about treatment planning & review (43%)

8.4 Provision of treatment and support

- Net positive ratings ranged from 36% to 60%
- Highest net positive response ratings were for:
 - Providing opportunities to discuss the person's illness or problems (60%)
 - Providing opportunities to discuss the person's medication (57%)
 - Respecting your opinion of what might help the person you care for (55%)
 - Providing opportunities to discuss other treatment (not medication) (53%)
- Lowest net positive response ratings were for:
 - Help to prepare for when the person no longer uses the service (36%)
 - Providing opportunities for you to access other services and supports that may help the person you care for (43%)
 - Providing opportunities for you to access available services and supports for carers (44%)
 - Help to recognise and manage early signs of deterioration in the person you care for (45%)

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

- 83% made comments
- Attitudes & characteristics of staff (38%) – described as understanding, compassionate, supportive, caring, reassuring, helpful, friendly and non-judgemental
- Help available when needed most (10%)
- Being able to talk to someone & discuss issues (9%)
- Coping strategies & suggestions (7%)
- Nothing that I liked (7%)

9.2 Service weaknesses

- 78% made comments
- 12% indicated that there was nothing that they did not like
- Lack of communication & feedback about the condition, progress & treatment (11%)
- Lack of support/help/empathy for carers (11%)
- Felt excluded & unable to have input into key decisions - more likely in rural compared to metro services (7%)
- Lack of staff continuity (7%)
- Staff shortages (6%)

9.3 Areas for improvement

- 79% made comments
- Nothing needs to improve (7%)
- More communication about condition, treatment & progress, and inclusion of carers (17%)
- Increase staff levels (9%)
- More focus on strategies & advice on how to cope (8%)
- Keep in touch/follow-up (6%)
- More support & respite for carers (6%)

10. Carer use and ratings of services types

- **Continuing care/community clinic services:** Of the 61% of respondents who used these services, 65% rated positively
- **Mobile Support & Treatment Services:** Of the 29% of respondents who used these services, 66% rated positively
- **Crisis Assessment & Treatment Services:** Of the 50% of respondents who used these services, 67% rated positively
- **Acute inpatient services:** Of the 33% of respondents who used these services, 61% rated positively
- **Primary Mental Health & Early Intervention Services:** Of the 19% of respondents who used these services, 68% rated positively
- **Dual Diagnosis Services:** Of the 14% of respondents who used these services, 55% rated positively
- **Community Care Units:** Of the 23% of respondents who used these services, 73% rated positively
- **Secure extended care inpatient services:** Of the 17% of respondents who used these services, 63% rated positively

11. Carer characteristics

- **Location:** 60% metro compared to 40% rural
- **Gender:** 70% were female compared to 27% who were male
- **Preferred language:** English was the preferred language spoken by 88%
- **Age:** 59% were aged between 45 & 64 years; 20% were aged 65 years or more
- **Age of person cared for:** 32% were 25-34 years; 24% were 35-44 years; 23% were 45-64 years; 16% were 18-24 years of age
- **Relationship:** 65% of carers were the parent; 17% the partner; and 18% other (i.e. a relative or friend)
- **Length of contact:** 47% had been in contact with the service for more than 5 years; 29% for more than 1 year but less than 5 years; 23% for less than a year
- **Last contact with the service:** Face-to-face for 62% and telephone for 36%
- **Time of last contact:** 51% in the previous month; 11% in the last 2 months; 9% in the last 3 months; 13% in the last 6 months; 15% more than 6 months ago
- **Completion of the questionnaire:** 8% needed some form of assistance

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

- Initial access:
 - Consumers and carers viewed AMHS as only accessible to people with a serious mental illness, with insufficient services to prevent a crisis or illness/relapse
 - Limited access to services was primarily attributed to staff shortages.
- Ongoing access:
 - Consumers and carers were generally pleased with access to services after a case manager had been assigned.
 - CAT services were generally described as accessible to people who had previously been registered with this service.
 - Former inpatients recognised and valued the role of CAT services and regular home visits by staff for preventing relapse & hospital admission, & reducing carer burden. However, greater backup & support needed during a crisis and with supervision of medication.
 - Availability of 24hr support was highly valued but limited access after hours
 - Consumers wanted more information & assistance with access to education and training, and employment services.
- Inpatient services:
 - Carers found acute inpatient units quite distressing, particularly the closed environment and behaviour of inpatients.
 - Carers felt that privacy was lacking and that the availability of interview rooms was not widely promoted
 - Former inpatients frequently reported boredom as a key source of frustration

12.2 Attitudes & responsiveness of staff

- Generally positive comments about the attitudes & responsiveness of staff
- Some felt that staff were more responsive to consumers & carers who asked questions and requested support, whilst overlooking those who were quiet and withdrawn
- Continuity of staff was very important to consumers in terms of trust, rapport & recovery
- Consumers most valued the following staff attributes:
 - Open & respectful communication, including a willingness to listen
 - Recognition that consumers are individuals with unique personalities & needs
 - Patience and genuine interest in helping consumers recover and rebuild their lives
 - Respect and compassion for people with a mental illness
 - A positive outlook, including feedback and encouragement about progress
 - An understanding and appreciation of the role of carers

12.3 Communication

- Consumers & carers viewed case managers as having a pivotal role in establishing effective communication with key stakeholders
- Communication & consistency in approach between staff was generally lacking from the perspective of consumers & carers who had been in contact with the service for a few months
- Consumers, particularly those being treated involuntarily, felt that it was important for staff to remain open to new information about their situation.

12.4 Provision of information

- Often viewed less positively by consumers & carers, particularly information about:
 - Medication and other treatment (i.e. purpose, side effects, alternatives & options)
 - Roles of various components of the service (i.e. CAT, inpatient & case management)
 - Discharge (relapse prevention, coping strategies, follow-up)
 - The Mental Health Act including review and appeal processes
 - Carer and family understanding of mental illness & availability of support
- Important that information be tailored to the individual needs of consumers & carers & their ability to digest information at the time
- Whilst written information was valued, it was considered a poor substitute to having someone talk through the information and answer questions that arise. This was particularly pertinent during the inpatient admission process.

12.5 Involvement in treatment

- Whilst consumers acknowledged that there are times when they may not be well enough to make decisions about their treatment, they felt that it was important for them to be involved in treatment planning. This enhanced their ownership, empowerment & compliance with treatment, as well as trust & respect for staff.
 - Consumers who had ongoing contact with services and a positive relationship with their case manager, were more likely to report input to treatment decisions
 - Former involuntary inpatients and consumers on CTOs often felt excluded from decisions about their treatment. Formal 'debriefing' sessions in which staff explain why treatment decisions were made on the consumer's behalf and encourage them to talk about their experiences and feelings, were identified as important for establishing or rebuilding trust in the therapeutic relationship.
- Whilst carers accepted regulations around privacy and confidentiality, they clearly wanted to be more involved in key decisions that affect them or the person they care for.

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.