

Summary of the 2003-2004 survey of consumer & carer experience of Victorian public child & adolescent 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 13 to 18 years and had used a child & adolescent mental health service (CAMHS) 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 years or less who had used CAMHS in 2003. This included family members, next of kin, friends and neighbours, but not paid carers employed by the service.

2.2 Sampling strategy

Passive parental or guardian consent was required for consumers aged 13 – 18 years to take part in the survey. The exception was for those consumers who were using the service without a parent's or guardian's knowledge.

Survey questionnaires were distributed to a random sample of consumers and carers at all 13 CAMHS (5 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 8 CAMHS (4 metro & 4 rural) involved.

2.3 Response rates

Overall, there were 728 respondents that included 313 consumers and 413 carers with a response rate of 15.7%. The response rates for consumers ranged from 7.2% to 29.9% between services, with an average of 14.5%. The response rates for carers ranged from 10.0% to 30.4% between services, with an average of 19.4%.

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

3. Key indicators

The CAMHS questionnaires contained three 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

Provision of treatment & support including related information

- Meeting consumer/carer needs

Table 1 illustrates the net positive responses of consumers and carers across the five 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	71%	68%
Understandable information about rights & responsibilities	74%	66%
Enabling access to help	76%	67%
Getting help when needed	77%	62%
Meeting individual needs through treatment and support	77%	59%

For consumers, there were no significant differences in net positive responses for the five key indicators of service quality by age, gender, length of contact with the service or most recent hospital admission. There were significant differences in net positive responses between consumers of **metropolitan & rural services** for providing understandable information about rights and responsibilities (68% and 79% respectively).

For carers, there were no significant differences in net positive responses by location, age or gender. Carers who had **contact with the service for less than a year** were significantly more positive about the help they received to understand rights and responsibilities information (72%), compared to carers in contact with the service for more than 1 year but less than 5 years (60%).

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 51% to 84%
- Highest net positive response ratings were for:
 - Letting you know about your right to privacy (84%)
 - That you can speak to someone in your preferred language (82%)
 - When you can choose who is told that you use the service (77%)
 - That you should feel safe where you are seen by the service (77%)
 - When you can choose to have others involved in your care (73%)
- Lowest net positive response ratings were for:
 - How to comment or complain about the service (51%)
 - How to be involved in how the overall service runs (55%)
 - That you can speak to a male or female staff member (65%)

4.2 Accessibility & responsiveness

- Net positive ratings ranged from 59% to 84%
- Highest net positive response ratings were for:
 - Making you feel safe where you were seen by the service (84%)
 - Respecting your cultural beliefs and practices (82%)
 - Letting you know how & when they can be contacted (82%)
 - Listening to your opinion about your needs (82%)
 - Arranging for you to speak to someone in your own language (81%)
- Lowest net positive response ratings were for:
 - Giving you the chance to be involved in how the overall service runs (59%)
 - Being available when you need them (66%)
 - Making it easy to contact the person you need to talk to (69%)
 - Allowing you to comment or complain about the service freely (69%)

4.3 Provision of treatment and support including related information

Note: This section of the CAMHS questionnaire was structured differently to AMHS and APMHS to simplify the format whilst retaining consistency in content.

- Net positive ratings ranged from 56% to 78%
- Highest net positive response ratings were for:
 - Talking to you about the different ways to help you feel better (78%)
 - Involving you in decisions about your treatment (76%)
 - Helping you to understand your illness or problems (75%)
 - Discussing your opinion about the effects of your treatment (75%)
- Lowest net positive response ratings were for help to access:
 - Helping you to prepare for when you no longer use the service (56%)
 - Providing opportunities for you to use other services that may help (66%)
 - Helping you to use services to get or keep work (66%)
 - Helping you to know when you are starting to feel worse (67%)

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

- 84% made comments
- Attitudes & characteristics of staff (33%) – described as compassionate, supportive, caring, reassuring, helpful, friendly and non-judgemental
- Being able to talk to someone & discuss issues (25%)
- Coping strategies & suggestions (23%)

5.2 Service weaknesses

- 78% made comments
- Nothing that they did not like (19%)
- Felt excluded & unable to have input into key decisions (6%)
- Lengthy waiting lists/periods to access the service (5%)
- Not given appropriate coping strategies or suggestions (5%)
- Lack of staff continuity (4%)

5.3 Areas for improvement

- 73% made comments
- Nothing needs to change (15%)
- More timely access to services (5%)
- Increase staff levels (4%)
- More understanding, caring, compassionate & supportive staff (4%)
- Stronger focus on outcomes & coping strategies (4%)
- Choice of staff member (4%)
- Better communication about the condition, progress & treatment and inclusion of carers (3%)
- Better follow-up after discharge (3%)
- Easier to contact (3%)

6. Consumer use and ratings of service types

- **Community clinic services:** Of the 66% of respondents who used these services, 81% rated positively
- **Acute inpatient services:** Of the 11% of respondents who used these services, 63% rated positively
- **Intensive Mobile Youth Outreach Services (IMYOS):** Of the 8% of respondents who used these services, 71% rated positively
- **Mobile Adolescent Teams (MAT):** Of the 9% of respondents who used these services, 61% rated positively

7. Consumer characteristics

- **Location:** 40% metro compared to 58% rural
- **Gender:** 65% female compared to 34% male
- **Preferred language:** English was the predominant language spoken for 97% and 1% for a language other than English (LOTE), which was consistent across metro & rural regions
- **Age:** 45% were aged 13 to 15 years and 34% were aged 16 to 18 years
- **Length of contact:** 63% had been in contact with the service for up to a year; 36% for more than 1 but less than 5 years; 5% for more than 5 years
- **Last face-to-face contact:** Community clinic or centre for 76%
- **Time of last contact:** 48% had their last contact with the service in the previous week; 31% in the last school term (i.e. 6-8 weeks); 18% in the last year; 3% more than a year ago
- **Last inpatient admission:** 24% indicated an inpatient admission including 16% who had been admitted during 2003, 6% during 2002 and 2% prior to 2002
- **Completion of the questionnaire:** 40% needed some form of assistance

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 54% to 83%
- Highest net positive response ratings were for information about:
 - Your right & that of the person you care for to privacy (83%)
 - Your right & that of the person you care for to information in your preferred language (83%)
 - Your right & that of the person you care for to confidentiality (81%)
 - Your right & that of the person you care for to feel safe where you are seen by the service (80%)
- Lowest net positive response ratings were for letting you know:
 - How to comment or complain about the service (54%)
 - How to participate in overall service planning, improvement & review (56%)
 - That you can speak to a male or female staff member (62%)

8.2 Accessibility & responsiveness

- Net positive ratings ranged from 61% to 84%
- Highest net positive response ratings were for:
 - Making you feel safe where you were seen by the service (84%)
 - Respecting your cultural beliefs & practices (82%)
 - Being easy for you to travel to (78%)
- Lowest net positive response ratings were for:
 - Being available when needed (61%)
 - Providing opportunities for you to be involved in service planning, improvement & review (61%)
 - Providing written information in your preferred language (62%)
 - Arranging for you to see a female or male staff member if asked for (64%)

8.3 Provision of treatment and support including related information

- Net positive ratings ranged from 45% to 68%
- Highest net positive response ratings were for:
 - Involving you in decisions about the treatment of the person you care for (68%)
 - Involving you in the treatment program (67%)
 - Helping you to understand the illness or problems of the person you care for (66%)
 - Asking you what might help the person you care for from your experience and knowledge of them (66%)
- Lowest net positive response ratings were for:
 - Helping you to prepare for when the service is no longer involved (45%)
 - Helping you to recognise early signs of deterioration in the person you care for (51%)
 - Helping you to manage early signs of deterioration in the person you care for (51%)

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

- 84% made comments
- Attitudes & characteristics of staff (45%) – described as compassionate, supportive, caring, reassuring, helpful, friendly and non-judgemental
- Being able to talk to someone & discuss issues (14%)
- Coping strategies & suggestions (14%)

9.2 Service weaknesses

- 71% made comments
- Nothing that they did not like (14%)
- Difficulty & delays in initial access (13%)
- Lack of communication & feedback (8%)
- Lack of support & empathy for carers (7%)

9.3 Areas for improvement

- 79% made comments
- Nothing needs to change (9%)
- Better communication about the condition, progress & treatment and inclusion of carers (14%)
- More timely access to services (13%)
- Stronger focus on outcomes & coping strategies (6%)
- Increase staff levels (5%)
- Better follow-up after discharge (4%)

10. Carer use and ratings of services types

- **Community clinic services:** Of the 45% of respondents who used these services, 75% rated positively
- **Acute inpatient services:** Of the 11% of respondents who used these services, 58% rated positively
- **Intensive Mobile Youth Outreach Services (IMYOS):** Of the 8% of respondents who used these services, 45% rated positively
- **Mobile Adolescent Teams (MAT):** Of the 7% of respondents who used these services, 40% rated positively

11. Carer characteristics

- **Location:** 36% metro compared to 64% rural
- **Gender:** 90% female compared to 10% male
- **Preferred language:** English was the predominant language spoken for 99% with 1% preferring a language other than English (LOTE)
- **Age:** 94% were aged between 25 and 64 years (including 35% aged 45-64 years; 45% aged 35-44 years; 14% aged 25-34 years)
- **Relationship:** 86% were the parent of the person being cared for
- **Length of contact:** 54% had been in contact with the service for less than a year; 39% for more than 1 year but less than 5 years; 7% for more than 5 years
- **Type of last contact:** face-to-face for 67% and telephone for 30%
- **Time of last contact:** 39% had their last contact with the service in the previous week; 37% in the last school terms (i.e. 6-8 weeks); 19% in the last year; and 4% more than a year ago
- **Completion of questionnaire:** 3% 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 understanding of mental illness, particularly how it differed from 'normal' teenage behaviour (and subsequently the 'justification' or 'right' to access CAMHS)
 - Carer reluctance to admit they need help for fear of being labelled a 'bad parent'
 - Both consumers & carers felt that understanding of mental health issues & awareness of mental health services was poor amongst relevant professionals (including GPs, school counsellors & paediatricians) and the general community (including children & adolescents). Promotion efforts need to focus on reducing the stigma of mental illness, identifying early warning signs of mental illness, and raising awareness of services.
 - Lengthy waits for access to services and feedback on referral progress/outcomes
 - Lack of prevention and early intervention when initially referred for service
 - Concerns about privacy & confidentiality when accessing services, particularly in rural areas
- Ongoing access:
 - Both consumers & carers usually pleased with the accessibility of services after they had been accepted for ongoing case management
 - Limited flexibility around school & work commitments – shortage of late afternoon/early evening appointments for consumers & carers
 - Some experienced difficulty in getting to/from appointments on time; being accessible by public transport and close to home and school were significantly valued by both consumers & carers
 - Availability of 24hr support highly valued but awareness and ability to get through to the service after hours were variable
- Inpatient Services:
 - Ward programs highly valued, particularly outings but need to be more closely tailored to what consumers are missing out on at their own schools
 - Need for stricter rules and security on the inpatient unit to manage disruptive behaviour
- Other:
 - Access to respite services varied significantly from region to region
 - Carers expressed interest in respite care but were often unaware of services or somewhat ashamed to admit they needed a break.

12.2 Attitudes & responsiveness of staff

- Generally positive comments about the attitudes & responsiveness of staff; more likely to complain about issues related to understaffing
- Ability to relate to children and adolescents and make them feel comfortable & relaxed was highly valued by both consumers & carers
- Continuity of staff was very important to consumers, particularly in terms of trust, rapport and recovery
- A positive attitude of staff towards life and the consumer were highly valued
- Former inpatients felt that staff tended to be more responsive to consumers who broke the rules or were disruptive, whilst overlooking the needs of those who were quiet and withdrawn.
- Consumers valued the ability to choose between a female or male staff member
- For carers, the ability to talk openly & honestly with staff was very important, particularly without fear of being labelled a 'bad parent' or repercussions.
- Both consumers & carers raised the importance of staff setting clear boundaries from the outset & consistently reinforcing them

12.3 Communication

- Communication between staff within the service was important, particularly with staff handover/turnover to avoid having to repeat their story.
- Carers highly valued support & guidance from staff in communicating with external service providers including schools, GPs, paediatricians, etc. It was viewed as reducing carer burden & improving treatment outcomes.
- Consumers & carers emphasised the importance of being involved in any decisions relating to communication with external service providers, particularly schools.

12.4 Provision of information

- Consumers & carers were generally pleased with the information provided EXCEPT for those who had been 'turned away' or placed on a waiting list.
- Carers reported that it is difficult for the general public to find out what types of help & services are available.
- Written information highly sought by carers & to a lesser extent consumers, relating to:
 - Key aspects of the service including availability and staff roles
 - Links to other services & supports that may help
 - 'Do's & don'ts' for inpatients & visitors to inpatient units
 - Coping strategies & advice, including guidance for carers in setting boundaries, supervising and intervening
 - Mental illness & treatment options, including medication & side-effects
 - Discharge information including coping strategies, follow-up procedures, useful services & emergency contacts
- Whilst written information was valued, it was considered a poor substitute to having someone talk through the information and answer questions that arise.
- Important that information be tailored to the individual needs of the consumer & their ability to digest information at the time.

12.5 Involvement in treatment

- Being involved in key decisions regarding treatment was very important to consumers for a sense of ownership and control of their lives and their futures.
- In most but not all cases, consumers valued having their families involved in treatment through family therapy sessions as well as individual sessions. However, clear rules on what information is communicated need to be established upfront and agreed upon with all.
- Some carers reported a lack of communication and feedback from staff about their child's needs and progress, and how the service could be of assistance
- Carers reinforced their need to be involved in treatment planning to ensure that it addressed the impact on the whole family.

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, clinical audits, 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.