

# Summary of the 2004 survey of consumer & carer experience of Victorian psychiatric disability rehabilitation & support 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 care they received.

The aims of the 2004 consumer & carer surveys conducted in psychiatric disability rehabilitation & support services (PDRSS) 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 2003, the Department commissioned the Australian Institute for Primary Care (AIPC) to develop PDRSS consumer & carer surveys in collaboration with consumers, carers and service providers. The survey methodology is a mail-out mail-back semi-structured questionnaire, which was adapted from the questionnaires developed for use in clinical mental health services.

The items in the survey reflect the needs, priorities and expectations of services identified by consumers and carers. The survey items are 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.

## 2. Implementation

### 2.1 Data collection

Statewide data collection occurred from 12<sup>th</sup> January to 3<sup>rd</sup> March 2004. In total, 88 services distributed questionnaires and respondents from 56 services returned completed surveys by the closing date.

3 semi-structured questionnaires were used to collect information:

- Consumer Experience of PDRSS – completed by people with a mental illness who receive services
- Carer Service Users Experience of PDRSS – completed by people who care for someone with a mental illness and currently use a PDRSS for themselves
- Carer Experience of PDRSS – completed by people who care for someone with a mental illness

## 2.2 Response rates

Overall, the survey response rate was 21% (1,874 returns). The response rate for consumers was 25% (1,527 returns), carer service-users 16% (142 returns) and carers 12% (205 returns).

Some services chose not to distribute carer questionnaires, which seemed to reflect the philosophy of the individual service rather than a trend according to program type. As a result, it is unclear how much of the poor response rate was due to carers choosing not to participate or not being asked to participate in the survey.

## 3. Survey findings

### 3.1 Reporting

In April-May 2004, participating services received an individual service report, which included their both their service data and relevant statewide data. A statewide report is also available.

### 3.2 Key results

Overall, 84.1 per cent of the consumer respondents indicated that the service was either a "great deal of benefit" or "quite a lot of benefit" to them, compared with 80.3 per cent of carer service-user respondents and 64.2 per cent of carer respondents.

For common items across all 3 surveys, there was a consistent trend where larger proportions of carer respondents rated the items as "poor", compared with consumer respondents and carer service-user respondents.

- For choice of female or male support person, 9.2% of consumers rated this item as "poor", compared with 7.1% of carers and only 2.9% of carer service-users. More carer service-users rated this item as either "very good" or "excellent" (42%), compared with consumers (39.9%) and carers (38.2%).
- For how well the service made the respondent feel safe where they attended or received services, 5.6% of carers rated this item as "poor", compared with 2.1% of consumers and 3% of carer service-users. Fewer carers rated this item as either "very good" or "excellent" (49%), compared with consumers (69%) and carer service-users (62%).
- For how easy it was to contact the person they needed to talk to, 11% of carers rated this item as "poor", compared with 2.9% of carer service-users and 2.4% of consumers. Fewer carers rated this item as either "very good" or "excellent" (48.5%), compared with consumers (62.5%) and carer service-users (56%).
- For how good the service was at asking about their views and concerns, 14.1% of carers rated this item as "poor", compared with 8.7% of carer service-users and 4.8% of consumers. Fewer carers rated this item as either "very good" or "excellent" (44.4%), compared with consumers (60.3%) and carer service-users (59.4%).
- For how good the service was at listening to and discussing their views and concerns, 9.5% of carers rated this item as "poor", compared with 5.9% of carer service-users and 3.7% of consumers. Fewer carers rated this item as either "very good" or "excellent" (50.7%), compared with consumers (63.6%) and carer service-users (61.8%).

### 3.3 Consumer respondents

- For the information provision domain, the most positive experience of consumer respondents was being able to get information when needed (39.2% stated this was "excellent"). The most negative experience related to being told whether or not they can view their own records (11.9% stated this was "poor").
- For the service delivery domain, the most positive experience of consumer respondents was feeling safe at the service (42.7% stated this was "excellent"). The most negative experience was in relation to the service's ability to make consumers aware and feel comfortable about making complaints or comments (5.3% stated this was "poor").

- For the assistance with daily living domain, the most positive experience of consumer respondents was being able to get related information when needed (32.3% stated this was “excellent”). The most negative experience was in relation to the assistance provided in preparing consumers for when they are no longer in the program (7.6% stated this was “poor”).
- In relation to the positive experiences outlined above, in each case a smaller proportion of respondents from Psychosocial Rehabilitation Day Programs (PRDP) compared with the Home-Based Outreach Support (HBOS) and Mutual Support & Self-Help (MSSH) respondents marked these items as “excellent”.
- In relation to the negative experiences outlined above, in each case a larger proportion of respondents from PRDP compared with the HBOS and MSSH respondents marked these items as “poor”.
- There was a tendency for females and 18-24 year olds to be represented in highest and lowest ratings, although any differences between gender and age categories were typically small.

### **3.4 Carer service-user respondents**

- For the information provision domain, the most positive experience of carer service-user respondents was being able to get information about the range of services available (33.8% stated this was “excellent”). As was the case with the consumer respondents, the most negative experience for carer service-users related to being told whether or not they can view their own records (23.3% stated this was “poor”).
- For the service delivery domain, the most positive experience of carer service-user respondents was being able to get information from the service about mental illness (43.5% stated this was “excellent”). The most negative experience related to being asked by the service for their opinion about their needs (8.7% stated this was “poor”).
- Results cannot be broken down by program type, age or gender because of insufficient numbers of respondents between categories.

### **3.5 Carer respondents**

- For the information about services domain, the most positive experience of carer respondents was for being told by the service what it can do for them and the person for whom they have a caring role (26% stated this was “excellent”). The most negative experience related to being informed how to participate in the planning and improvement of the service (17.7% stated this was “poor”).
- For the service accessibility domain, the most positive experience of carer respondents was for the service enabling carers to obtain assistance when they needed it (31.2% stated this was “excellent”). The most negative experience related to how well the service asks carers about their views and concerns (14.1% stated this was “poor”).
- For the information provision domain, the most positive experience of carer respondents was the service’s ability to provide carers with information about mental illness (24.1% stated this was “excellent”). Carer service-user respondents similarly indicated the provision of such information as being one of their most positive experiences with the service. The most negative experience related to how well the service provides carers with information that assists them to recognise and manage early signs of deterioration in the person for whom they have a caring role (21.6% stated this was “poor”).
- For the service participation domain, the most positive experience of carer respondents was the service managing confidentiality and privacy issues between carers and the person with whom they have a caring role (29.1% stated this was “excellent”). The most negative experience related to how well the service helps carers prepare for when the person for whom they have a caring role no longer uses the service (21.3% stated this was “poor”).
- Results cannot be broken down by program type or age because of insufficient numbers of respondents (at least 50) between categories.
- There were no consistent trends when compared by gender, with any differences typically small.

## 4. Information about the samples

### 4.1 Information about the consumer sample (n = 1,527)

- **Program type (n = 1,024)**
  - Home based outreach support (HBOS) = 37.3%
  - Psychosocial Rehabilitation Day Program (PRDP) = 33.3%
  - Mutual Support & Self-Help (MSSH) = 15.9%
  - HBOS and PRDP = 3.7%
  - Residential rehabilitation = 3.7%
  - Planned respite = 3.1%
  - Multiple programs (not HBOS and PRDP) = 1.9%
  - Supported accommodation = 1.1%
- **First contact (n = 1,507)**
  - 1-5 years ago = 43.1%
  - Over 5 years ago = 32.8%
  - 4-12 months ago = 17.1%
- **Last contact (n = 1,479)**
  - 0-3 months ago = 91.8%
  - Over 12 months ago = 4.7%
  - 4-12 months ago = 3.6%
- **Frequency of contact (n = 1,499)**
  - Weekly = 79.9%
  - Monthly = 12.7%
  - 3 monthly = 2.9%
- **Gender (n = 1,160)**
  - Male = 52.8%
  - Female = 47.2%
- **Preferred spoken language (n = 1,185)**
  - English = 95%
  - Non-English = 3%
- **Age (n = 1,185)**
  - 45-64 years = 38.3%
  - 35-44 years = 31.9%
  - 25-34 years = 19.3%
  - 18-24 years = 7.3%
  - 65 years or more = 2.7%
  - Under 18 years = 0.4%

### 4.2 Information about the carer service-user sample (n = 142)

- **Program type (n = 132)**
  - Mutual Support & Self-Help (MSSH) = 54.5%
  - Multiple programs (not HBOS and PRDP) = 31.1%
  - Home based outreach support (HBOS) = 9.1%
  - Planned respite = 3.8%
  - Psychosocial Rehabilitation Day Program (PRDP) = 0.8%
  - Residential rehabilitation = 0.8%
- **Last contact (n = 138)**
  - 0-3 months ago = 78.3%
  - 4-12 months ago = 16.7%
  - Over 12 months ago = 5.1%
- **Frequency of contact (n = 130)**
  - Monthly = 43.8%
  - Weekly = 26.9%
  - 3 monthly = 20.8%
  - Annually = 8.5%

- **Gender (n = 121)**
  - Female = 78.5%
  - Male = 21.5%
- **Preferred spoken language (n = 128)**
  - English = 98.4%
  - Non-English = 0.8%
- **Age (n = 128)**
  - 45-64 years = 64.1%
  - 65 years or more = 18.8%
  - 35-44 years = 10.2%
  - 25-34 years = 7%

#### 4.3 Information about the carer sample (n = 205)

- **Program type (n = 138)**
  - Home based outreach support (HBOS) = 27.5%
  - Psychosocial Rehabilitation Day Program (PRDP) = 26.1%
  - Planned respite = 16.7%
  - Mutual Support & Self-Help (MSSH) = 8.7%
  - HBOS and PRDP = 8.7%
  - Multiple programs (not HBOS and PRDP) = 8%
- **Contact with PDRSS that the person cared for attends (n = 201)**
  - Yes = 82.6%
  - No = 17.4%
- **Frequency of contact (n = 173)**
  - Weekly = 34.7%
  - Monthly = 30.1%
  - Rarely = 16.2%
  - 3 monthly = 15.6%
  - Daily = 3.5%
- **Currently attending a PDRSS for carers (n=202)**
  - No = 71.8%
  - Yes = 28.2%
- **Contacted a PDRSS about your own needs as a carer (n = 202)?**
  - No = 61.4%
  - Yes = 38.6%
- **Relationship type (n = 198)**
  - Mother = 43.9%
  - Partner = 17.7%
  - Father = 13.1%
  - Son = 9.1%
  - Daughter = 7.6%
  - Sibling = 4.5%
  - Other = 4%
- **Gender (n = 158)**
  - Female = 67.1%
  - Male = 32.9%
- **Preferred spoken language (n = 162)**
  - English = 90.7%
  - Non-English = 6.8%
- **Age (n = 162)**
  - 45-64 years = 55.6%
  - 65 years or more = 27.8%
  - 35-44 years = 13%
  - 34 years or less = 2.7%

## 5. Action

The survey findings provide a source of reflection and potential for improvements in practice. It is important that services 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, particularly because of the low response rates.

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 and carers in these areas? Planning for improvement guides action.