

## 18 SUPPORT, NEEDS AND SATISFACTION

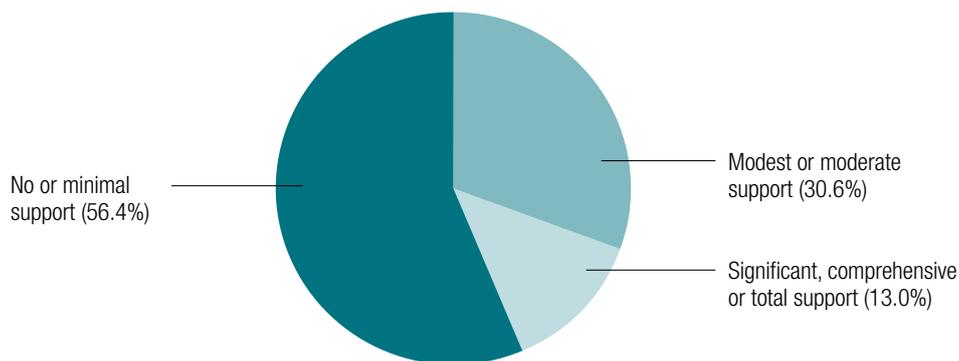
### 18.1 Level of support and its helpfulness

A number of sections in this report identified the roles that people with psychosis undertake in a variety of domains such as at home (including child care), at work and in study, and examined their performance in those roles. This section addresses the level of support that participants received to maintain their roles and to function effectively in the community setting.

The Multidimensional Scale of Independent Functioning<sup>9</sup> was used to provide a global measure of the level of formal and/or informal support from any source that participants had received in the four weeks prior to interview to maintain performance across the three domains of work, study and activities of daily living. It takes into account the frequency, quality and proximity of support, who provides this support (family, friends or professionals) and consequences if support was absent.

Just over half (56.4%) of participants reported receiving no or only minimal support to maintain role performance across these domains. One in three (30.6%) were receiving modest or moderate support and 13.0% were receiving significant, comprehensive or total support (Figure 18-1).

**Figure 18-1. Global level of support (home, work, study)<sup>9</sup>**



One quarter (24.5%) of the participants had support in the form of a carer. For two-fifths (40.8%) of those with carers, the carer was their mother and for one quarter (25.7%) it was their partner.

For another 5.4% of participants, this carer was their child, with more females being supported by their children than males (10.2% for females and 1.2% for males). The proportion cared for by a child was also higher for the older age group (9.0% for those aged 35-64 years). The age of the carer was not recorded.

One in eight (12.3%) participants had had a personal support worker at some stage over the past year.

The survey collected data on other forms of support received and the helpfulness of that support. These data are presented in Table 18-1. The most common form of support received was help with domestic responsibilities. Half (50.6%) the participants had received some help of this kind in the past four weeks. Almost everyone receiving this assistance (94.5%) found that the support provided was very or somewhat helpful, and one third (35.1%) said they would have had a lot of difficulty in maintaining their responsibilities without it.

**Table 18-1. Support in non-health related domains and its helpfulness**

|   | Proportion receiving support (%) | Proportion of those receiving support who found it helpful* (%) |
|---|----------------------------------|---|
| Socialising, past year                            | 29.5                             | 76.3  |
| Help with domestic responsibilities, past 4 weeks | 50.6                             | 94.5  |
| Help with financial management, past year         | 32.2                             | 86.2  |
| <b>Employment and study</b>                       |                                  |   |
| Employment support worker, past year              | 4.8                              | 84.1  |
| Other help to keep employment, past year          | 5.4                              | 82.9  |
| Help to find employment, past year                | 20.5                             | 58.7  |
| Help with study, past 4 weeks                     | 4.0                              | 95.9  |
| <b>Housing</b>                                    |                                  |   |
| State department of housing, past year            | 37.4                             | 61.1  |
| Other help with housing needs, past year          | 21.9                             | 83.7  |

\* Includes 'needs met adequately', 'helpful' and 'very helpful'.

The proportion receiving help was, however, low in a number of critical areas. For example, two thirds (63.2%) of participants were rated by interviewers as having obvious or severe dysfunction in socialising, but only 29.5% said they had received support in this area in the past year.

Only 7.6% had had an employment support worker or some other form of support to retain employment, although 24.4% had been in competitive employment in their main job in the past year. A higher percentage (20.5%) had received help in finding employment in the past year and 58.7% of those receiving this help said that the assistance they had been provided met their needs. Of those receiving this form of help, the most common sources of assistance were public employment services (42.9%), disability employment services (38.4%) and family and friends (31.7%), with 15.7% using a private recruitment company.

## 18.2 Who helped with mental health matters

People with psychosis were asked who was the person who spent the most time helping them with their mental health problems over the past year. One quarter (23.3%) of participants reported that this was their case manager and a similar proportion (23.1%) reported this was family or friends (Table 18-2). A further 14.7% reported it was their psychiatrist. Other persons named included: mental health nurse (7.5%), general practitioner (6.8%), other mental health professional (6.0%) and psychologist (5.5%).

**Table 18-2. Person spending the most time helping participants with mental health problems in the past year**

|  | Proportion (%) |
|--|----------------|
| Case manager                           | 23.3           |
| Family or friend                       | 23.1           |
| Psychiatrist (private or public)       | 14.7           |
| Mental health nurse                    | 7.5            |
| General practitioner                   | 6.8            |
| Other mental health professional       | 6.0            |
| Psychologist                           | 5.5            |
| Complementary or alternative therapist | 0.2            |
| Other                                  | 2.5            |
| No one                                 | 7.7            |
| Missing                                | 2.7            |
| <b>Total respondents</b>               | <b>1,825</b>   |

The professional most involved in providing counselling or talking therapies over the past year was a psychologist (named by 41.8% of those who had received counselling), followed by case manager (14.8%), psychiatrist (13.9%), other mental health professional (9.4%) and mental health nurse (7.7%).

The person most involved in providing mental health information was the case manager (named by 30.9% of those who had received such information), followed by psychiatrist (18.5%), mental health nurse (12.6%), other mental health professional (10.9%), general practitioner (7.4%) and psychologist (6.2%).

### 18.3 What helped the most

Participants had received many different forms of help, care and treatment for their mental and physical health in the year prior to interview. Toward the end of the interview, they were asked an open-ended question about what two forms of care they felt had helped them most. Qualitative responses were coded into categories (Table 18-3).

Mental health staff topped the list at 29.6%, with 11.9% of participants identifying case managers/key workers specifically and a further 9.0% identified psychiatrists and other medical officers as helping them most in the past year. One quarter (27.2%) reported that medication for their mental health and 18.8% reported that other forms of mental health care, such as counselling, education, rehabilitation and programs in non-government organisations, had helped them most. The two other commonly endorsed categories were: help and support from others (18.1%) and a category covering diet, sleep and physical activity (15.5%).

**Table 18-3. Participants' perceptions of who or what helped them most in the past year**

|   | Proportion (%) |
|---|----------------|
| Mental health staff   | 29.6           |
| Mental health medication  | 27.2           |
| Mental health treatment (e.g. counselling, education, rehabilitation, NGO programs) | 18.8           |
| Help and support from others (e.g. carer, family, friends)                          | 18.1           |
| Diet/sleep/physical activity  | 15.5           |
| Change in own behaviour/attitude  | 7.9            |
| Employment/housing/financial support and security                                   | 7.6            |
| Socialising; creative/leisure activities  | 5.5            |
| Other treatment (not mental health)   | 5.0            |

Three-fifths (59.5%) of participants reported in a separate question that religion and/or spirituality were important or very important aspects of their lives.

#### 18.4 Unmet needs

Just over one quarter of participants (27.5%) had had a need in the past year for one or more services that they had wanted and had not received. In response to an open-ended question, many named unmet needs related to treatment (55.5%) or treating services (26.9%), which were primarily but not wholly mental health related. A further 30.5% reported the need for assistance in other areas of their lives including, but not limited to, housing, finances, employment, legal assistance and practical assistance (for example, help with household goods), while 4.6% had socialising and leisure related needs.

In addition, in response to a question in the physical health section of the interview, 22.8% of participants said they had unmet physical health needs.

When asked the reason why they had not received the service they needed, 37.9% said it was not available, 31.3% reported that they could not afford it and 20.0% did not know how to access that service (Table 18-4).

**Table 18-4. Reasons for not receiving a service for which there was a perceived need in those with an unmet need**

|   | Proportion (%) |
|---|----------------|
| Not available   | 37.9           |
| Not affordable  | 31.3           |
| Did not know how or where to ask  | 20.0           |
| Waiting time too long   | 9.6            |
| Did not think anyone/anything could help                                  | 5.0            |
| Preferred to manage things themselves                                     | 2.0            |
| Afraid to ask for help, or of what others would think of them if they did | 1.2            |
| Did not get around to it  | 1.2            |
| Problems with things like transportation, childcare or scheduling         | 1.2            |
| Other   | 11.0           |

## 18.5 Overall satisfaction

Reflecting on the four weeks prior to interview, seven out of ten participants (71.9%) were satisfied or very satisfied with their own independence. Similarly, 71.1% never, rarely or only sometimes felt they were not in control of general life events, such as their personal life, health, work and finances.

When looking back over the past year, half (47.4%) were mostly or very satisfied with their lives, although one third (34.5%) had mixed feelings and 17.0% were mostly or very dissatisfied.

## 18.6 Challenges into the future

Surprisingly, concerns regarding the treatment and control of their mental illness were not the prime issues for most participants (Table 18-5).

While one quarter (25.7%) identified uncontrolled symptoms of mental illness and 5.8% identified lack of access to mental health services among their top challenges for the coming year, around two-fifths of participants identified financial matters and lack of employment as their top challenges (42.7% and 35.1% respectively). Lack of stable or suitable housing was reported as a challenge by 18.1% of participants.

For one quarter (27.4%) of participants, their physical health was one of the biggest challenges.

One in ten participants (11.6%) reported that stigma and discrimination were a challenge. Many more (37.2%) reported that loneliness and social isolation was one of their greatest challenges and 6.2% reported the absence of family or a carer as a challenge.

**Table 18-5. Challenges for the next 12 months**

|  | Proportion (%) |
|--|----------------|
| Financial matters                                      | 42.7           |
| Loneliness/Social isolation                            | 37.2           |
| Lack of employment                                     | 35.1           |
| Poor physical health/Physical health issues            | 27.4           |
| Uncontrolled symptoms of mental illness                | 25.7           |
| Lack of stable/suitable housing                        | 18.1           |
| Stigma/Discrimination                                  | 11.6           |
| No family or carer                                     | 6.7            |
| Inability to access specialised mental health services | 5.8            |
| Difficulty getting a medical appointment               | 3.0            |
| Other  | 12.7           |

Regardless of the difficulties facing them, three out of four (77.4%) people believed their circumstances would improve over the next year.

