What were the aims?
1. To estimate the number of people being treated for psychosis;
2. To describe the profile of people with a psychotic illness including personal, social and living circumstances, their mental and physical health;
3. To determine the use of services by people with psychotic illness; and
4. To assess the impact of psychotic illness and identify factors related to better outcomes and recovery.

For the first time it was possible to:
- establish the prevalence of psychosis in the NGO sector; and
- describe the characteristics of people with psychotic illness receiving services from NGOs funded to support people with mental illness.

Who participated?
- The survey took place in seven catchment sites across five Australian states, covering an area of around 62,000 square kilometres and a population of some 1.5 million people aged 18-64 years, approximately 10% of the Australian population in this age group.
- Over 10,000 people in contact with public specialised mental health services and NGOs funded to support people with a mental illness in March 2010 were screened for psychosis.
- All NGOs funded to support people with a mental illness within the site catchments were invited to participate in the screening, with 86% of individual centres within these NGOs participating.
- 1,825 people were randomly selected, gave consent and were interviewed.

Characteristics of participants
Aged 35-64 years .............................................. 58%
Male .......................................................... 60%
Born in Australia ........................................... 82%
Married or living in a de facto relationship ....... 17%
Women with children 18 years or under living with them 24%
Currently living in public or private rented housing 49%
In paid employment in the last 12 months ........ 33%
In paid employment at the time of interview .... 21%
Diagnosed with schizophrenia 30%
Taking medication for their mental health ... 92%
Met criteria for metabolic syndrome ............ 50%

How many people with psychosis are using mental health services?
An estimated 50,000 people aged 18-64 years with a psychotic illness were receiving treatment in March 2010 for their mental illness from public specialised mental health services or NGOs funded to support people with mental illness. While 44,000 people were seen by public specialised mental health services in March 2010 (Figure 1) an estimated 6,000 people were solely in contact with an NGO in the same period (Figure 2). Participants in both groups may have been seeing a GP, private psychiatrist or psychologist for their mental health.

Conclusions
People living with a psychotic illness are an optimistic group. Regardless of the difficulties they are facing, three out of four people believe their circumstances will improve over the next year. Like all Australians, people living with psychotic illness have the same needs for housing, good nutrition, employment and income. However, because of their mental illness, they face additional challenges. When asked about the challenges they face in the coming year, surprisingly, concerns regarding their mental illness were not their prime issues. They ranked financial issues, loneliness and unemployment as their most important challenges.

“Having a mental illness is a constant struggle and challenge.”

This is the largest and most comprehensive assessment of people living with psychotic illness undertaken in Australia. It has provided a snapshot of people living with psychotic illness, the circumstances in which they live and the services they receive. Information collected provides a solid foundation to guide policy development and service provision.

The full report People Living with Psychotic Illness 2010, is available at www.health.gov.au/mentalhealth
SANE Australia have been actively involved in SHIP. Their response to this survey ‘People Living with Psychotic Illness. A SANE response’ is available online at www.sane.org

We thank participating NGOs for their invaluable support and assistance.

ACKNOWLEDGEMENT
The comments in quotations were selected from the hundreds we received from participants in response to our final question ‘Are there any final comments you would like to make about living with a mental illness?’

People living with psychotic illness 2010
Summary of findings about services provided by Non Government Organisations (NGOs) funded to support people with mental illness
Funded by the Australian Government
Department of Health and Ageing
Supported by SANE Australia
NGO mental health support

The national Survey of High Impact Psychosis (SHIP) took place in 2010. There were two approaches to the collection of data on services provided by NGOs funded to support people with mental illness. 1. NGOs funded to support people with mental illness in the catchment sites were invited to take part in the census month screening. • 86% of NGOs participated • One in ten people (11%) interviewed were solely in contact with an NGO in the census month. Compared to people using public mental health services, people using only NGO services* in the census month were: • more likely to be in the older age group (35-64 years) (69% v 57%) • less likely to have had any inpatient admissions (33% v 46%) • less likely to have had a mental health admission (19% v 38%) • more likely to have attended a mental health outpatient clinic (54% v 90%) • more likely to have attended a mental health rehabilitation program in the last 12 months (74% v 37%). 2. All interviewed participants were asked about their use of a range of NGO services in the last 12 months. • Almost one in three participants (30%) had received help or support in the form of rehabilitation programs or one-to-one support for their mental health from an NGO funded to support people with a mental illness. • 37% of participants had accessed a variety of other community mental health support services such as counselling services for relationships, peer led support groups, telephone services for example Lifeline, or had attended a drop in centre for support. This brochure summarises the findings, from the 1,825 participants interviewed, of particular relevance to staff working in NGOs funded to support people with mental illness. “The help and support from the NGO has been very important and beneficial for me and my family.” *Participants may have been seeing a GP, private psychiatrist or psychologist for their mental health.

Case management

Effective case management is associated with better outcome. • Overall, 69% of participants had a case manager and 20% had a case manager provided by an NGO.

Those with an NGO case manager

<table>
<thead>
<tr>
<th>Frequency of contact</th>
<th>Proportion (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once every 1-4 weeks</td>
<td>30</td>
</tr>
<tr>
<td>More than once a week</td>
<td>64</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Contact as is often as preferred</th>
<th>Proportion (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somewhat satisfied</td>
<td>70</td>
</tr>
<tr>
<td>Very satisfied</td>
<td>20</td>
</tr>
</tbody>
</table>

“Everyone should have a case manager.”

Group-based rehabilitation program

NGOs are key providers of rehabilitation programs to people with psychotic illnesses: • One in four participants (22%) had been involved in NGO group-based rehabilitation programs.

One-to-one support

NGOs provide information and individualised support to people with mental illness and their families. • 69% of people with a psychotic illness supported by an NGO had received counselling or emotional support. • 16% had received a home visit from an NGO. • 91% were satisfied (very or somewhat) with the NGO assistance they had received.

“Good support from my NGO worker helps.”

Personal helper-peer supporter/mentor

Personal helpers/peer supporters/mentors assist people with a mental illness to manage their daily activities and live independently in the community. • 12% of participants had received assistance from a personal helper, peer supporter or mentor in the last 12 months. • 60% of people receiving this help had done so for a year or longer.

Challenges

Participants were asked to name the top three challenges that they faced in the coming year. The six top-ranked challenges were the same for men and women, and for younger and older people. However younger people (18-34 years) ranked lack of employment first.

“Don’t know where I would be now if not for NGOs.”

Other services

People had accessed a variety of other community services. • 22% had contacted a community organisation for financial or material aid. • 17% had used the internet to get help or information for their mental health problem. • 8% had used telephone services such as Lifeline or SANE helpline. • 5% had attended a community counselling service such as Relationships Australia.

Figure 3: Use of NGO rehabilitation programs in the last 12 months

Figure 3: Use of NGO rehabilitation programs in the last 12 months

Figure 4: Use of one-to-one support from NGOs in the last 12 months

Figure 4: Use of one-to-one support from NGOs in the last 12 months

Figure 5: Support provided by personal helpers/peer supporters/mentors

Figure 5: Support provided by personal helpers/peer supporters/mentors

*proportion is of those participants with a personal helper/peer supporter/mentor