

People living with psychotic illness

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A SANE Response

People living with psychotic illness

A SANE Response



Knowledge is power.

The better we understand the impact of psychotic illness, the better evidence we have to improve services – and to advocate for improved services.

The *People Living with Psychotic Illness 2010* study is the largest of its kind ever carried out in Australia. It is one of the most detailed undertaken anywhere in the world. Commissioned by the Australian Government, Department of Health and Ageing, it was conducted by a team of experts which spanned the country. Interviews were conducted with thousands of people with psychotic illness and many of those who provide care for them, including staff in mental health services and non-government organisations (NGOs) as well as general practitioners (GPs).

(The study focused on clients of public mental health services, and did not include people who were solely clients of private health services or were not currently receiving treatment.)

The study provides an extraordinarily comprehensive insight into the impact of psychotic illness on the lives of Australians today, and how this has changed since the previous *People Living with Psychotic Illness* study conducted in 1997-98. It describes how many are affected and their demographic characteristics. It examines the effects on physical and mental health, as well as the care people receive from clinical and non-clinical services. It details, too, the day-to-day lives of those affected: where they live, whether they have a job, their concerns, and the profound impact which the associated social exclusion has on many of their lives.

SANE Australia is proud to have been an active partner in this project from its inception.

The authority of the *People Living with Psychotic Illness* study provides compelling evidence of the need to radically improve Australia's mental health and community support services. *A SANE Response* is intended not only to promote the key findings of the study, but also to outline what action is needed in response to them.

With health reforms being planned in a range of areas, including mental health, now is the time for Australian governments to 'seize the day' and make a real difference to the lives of people living with psychotic illness.



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The challenge



How many are affected?

How many are affected?

Psychotic illness affects around one in 200 Australians every year.

64,000

Number of adult Australians (18-64) with a psychotic illness who are in contact with public mental health services in a year.



males

Psychotic illness is more common in males: 60% of people diagnosed (around 3.7 cases per thousand).



females

Psychotic illness is less common in females: 40% of people diagnosed (around 2.4 cases per thousand).

- ▶ The *People Living with Psychotic Illness* study focused on clients of public mental health services; the total number of people affected by psychosis, including clients of private mental health services and those not being treated, is likely to be 25-50% higher.
- ▶ Males aged 25-34 have the highest rate of psychotic illness.
- ▶ Prevalence is more even among females across all age groups.
- ▶ The most common psychotic illness is schizophrenia (47% of all cases).
- ▶ The mean age of onset is between 23 and 24 years of age.
- ▶ Two in three experience their first psychotic episode before the age of 25 (64.8%).
- ▶ One in three experience onset of the illness on or after the age of 25 (32.3% of males; 38.2% of females).

6 months

The onset of psychotic illness is often very gradual. For many people (42.2%) it develops slowly over a period of more than six months.



Action

The Australian Government's 2011 Mental Health Reform package includes a national network of specialist centres to treat people with psychosis as soon as possible. This is especially welcome, given the lengthy duration of untreated psychosis (DUP), revealed in this study, which can have such a serious impact on long-term outcomes, as well as causing such distress to those affected, including family and friends.

The community needs to be educated (through schools and other channels) to identify people who may be in need of assessment, so that treatment and support can be provided as soon as possible for all who need it.

It is also essential that the new centres collaborate with local adult mental health and other services in order to ensure continuity of care.

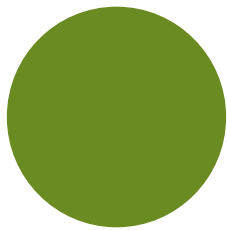
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Who is affected?

Who is affected?

People living with psychotic illness are more likely to be male, to be living alone, and to have low educational qualifications, although almost half have TAFE or trade qualifications.



In a relationship general population

Around two-thirds of Australians have a partner (married or de facto): 61% (ABS 4102.0, 2009).



In a relationship people with psychosis

Around one in five of Australians with a psychotic illness have a partner (married or de facto): 17%. Among males the proportion is closer to one in ten: 12%.

- ▶ The majority (59.6%) of people with psychosis are male.
- ▶ Over half (56.2%) of females have children of any age.
- ▶ Around a quarter (25.9%) of males have children of any age.
- ▶ Around one in six (14.7%) of people with psychosis are carers for another person.
- ▶ One third (33.7%) had left school with no qualifications, compared to 24.9% in the general population.
- ▶ Around half (48.9%) of people with psychosis have a TAFE or trade certificate, or higher post-school qualification.

one in five Almost one in five (18.4%) people with psychotic illness report difficulty with reading and/ or writing.



Action

The lower-than-average level of qualifications and relationships revealed in this study reflect the disturbance of education and learning of social skills during adolescence and early adulthood, as well as ongoing disability and lack of opportunity to address this.

These findings provide strong evidence of the need for more access to psychosocial rehabilitation/ recovery programs, and for these to be more tightly-focused on improving cognitive and social skills so that people can continue education and get a job. Action is also needed to improve support for families and friends of people with psychosis, including children and young people who have a parent with the illness.

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What are the effects?

What are the effects?

Psychotic illness often has a severe impact on ability to function in daily life.

90%

Percentage of people with psychotic illness who report a deterioration in their ability to function in daily life.

The most common symptoms of psychotic illness are **delusions** and **hallucinations**. **Thinking** processes, **perception** and **emotional response** may also be affected.



Delusions four out of five

Four out of five (86.7%) have experienced delusions.

Half of these (41.3%) currently experience delusions.



Hallucinations four out of five

Four out of five (78.9%) have experienced hallucinations.

Half of these (37.5%) currently experience hallucinations.

- ▶ The majority of people with psychotic illness also experience anxiety (59.8%).
- ▶ Over half of people with psychotic illness also experience depression (54.5%).
- ▶ One in three (32.3%) have significant difficulty in looking after themselves, with 18.4% unable to complete a simple task such as cleaning their room.
- ▶ Two out of three (63.2%) have significant difficulty in their capacity to socialise.



Action

Current treatments, including medication, do not help everyone nor are they effective enough. Many people with psychotic illness continue to experience symptoms and ongoing disability, despite the treatments they receive.

Mental health services need to provide more focused assistance to clients in managing, as well as reducing, symptoms – for example, through cognitive behavioural therapy and other psychological and social support. Continued research is also needed to improve the effectiveness of treatments, including antipsychotic medication.

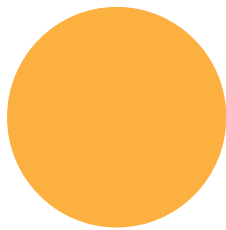


Physical health

People living with psychotic illness ⁴

Physical health

People with psychotic illness experience very poor physical health. They are also far more likely to harm themselves and to attempt suicide than the general population.



smokers people with psychosis

Two in three (66.1%) of people with a psychotic illness smoke tobacco. This rate has remained unchanged for over ten years.



smokers general population

Only one in four (25.3%) of the general population smoke, a rate which continues to fall steadily.

- ▶ People with psychotic illness experience higher rates of chronic physical conditions than the general population, including: back or other pain (31.8%), asthma (30.1%), and heart or circulatory conditions (26.8%). One in four (24%) are at high risk of cardiovascular disease.
- ▶ Very few people with psychotic illness are physically active. Over nine out of ten (96.4%) were classified as sedentary or undertaking low levels of exercise, compared to 72% of the general population.
- ▶ Almost half (45.1%) of people with psychotic illness are obese, double the rate of the general population. This high rate is associated with medication side-effects, as well as poor diet and reduced physical activity.
- ▶ Abuse of alcohol is far higher than in the general population. The majority of males (58.3%) and four out of ten females (38.9%) have alcohol abuse or dependence at some time in life.
- ▶ Abuse of drugs is far higher than in the general population. The majority of males (63.2%) and four out of ten females (41.7%) use cannabis at levels regarded as abuse or dependence.

one in two Around half (49.5%) of people with psychotic illness have attempted suicide at some time. This is over ten times the rate in the general population (3.7%).



Action

This study confirms that people with psychotic illness experience very poor physical health. Coordinated, systematic action is required by all health agencies involved to routinely assess risk factors (such as obesity, smoking, and low physical activity) and provide intervention and support, including referral to drug and alcohol agencies.

It is highly concerning that the smoking rate of people with psychotic illness has not gone down in over ten years despite significant reduction in the general population. Urgent action is needed by Quit smoking agencies to begin to focus resources on people with psychotic illness as a primary target group.

The extremely high rate of suicidal thinking among people with psychotic illness also demands an increased focus on them as a target group for suicide reduction strategies.

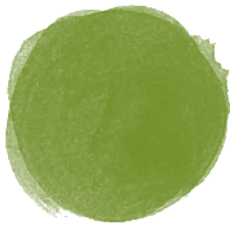
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Mental health services

Mental health services

People with psychotic illness are the predominant users of State-funded public mental health services.



intense service use

People with psychotic illness are heavy, regular users of mental health services, public hospitals, GPs, and a range of other health services and professionals. This intense engagement reflects the severe, ongoing impact of the illness on mental and physical health.

- In addition to using mental health services, most (81%) people with psychotic illness had used services for physical health problems in the past year.
- Two in five (41%) had visited a hospital emergency department in the past year, over half of these with a psychiatric problem.
- One in three (34.8%) had one or more psychiatric admission to hospital in the past year.
- One in five (20.7%) had at least one involuntary psychiatric admission to hospital in the past year.
- One in five (19.2%) were receiving treatment under a CTO (community treatment order) in the past year.
- As well as antipsychotic medications, 37.4% are taking antidepressant medication. Side-effects (such as weight gain, drowsiness, and dry or watery mouth) are common, with one in three (29.9%) reporting that their effect on daily life was moderate or severe.

40 days Average length of stay in hospital after a psychiatric admission.

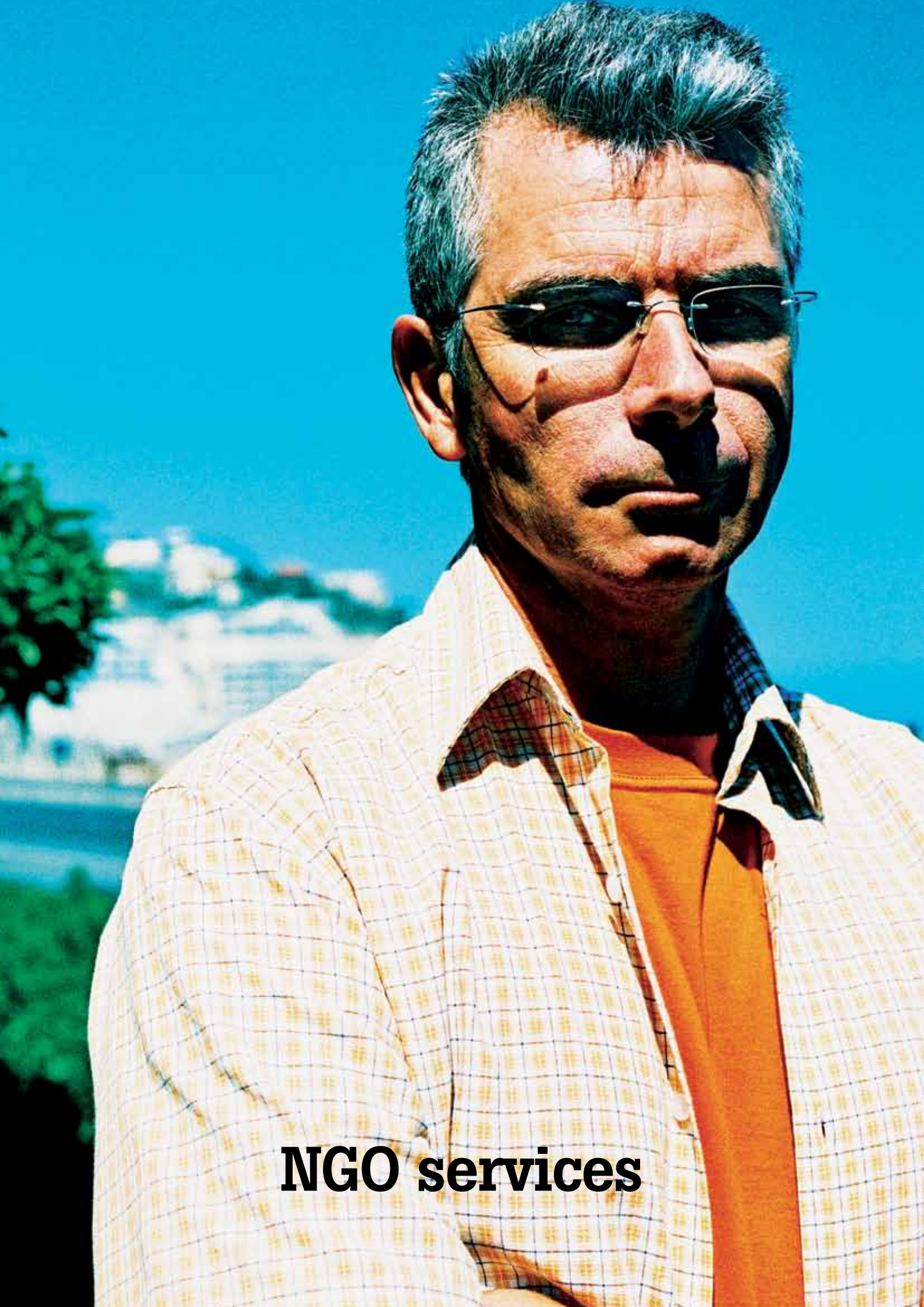


Action

The intense use of mental health services by people with psychotic illness revealed by this study explains in part why these services are often described as being in constant 'crisis management'. It also suggests the limitations of antipsychotic medication as what is, in practice, the sole treatment provided by many under-resourced services. In addition to greater resourcing to match the need, more emphasis is needed on providing other treatments besides medication to help people manage their symptoms.

The complexity of services available through a range of agencies can also be a barrier to getting help. Action is needed to ensure there really is 'no wrong door' and to make pathways to care easier to access and navigate. Together with earlier intervention and more community support programs, this will contribute to reducing 'crisis interventions' and presentations to hospital emergency departments.

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NGO services

NGO services

Mental health non-government organisations (NGOs) provide a range of services, and are highly valued by people living with psychotic illness.



a key component

NGO services are now a recognised and valued 'key component' of the mental health system in Australia.

NGOs provide a rich variety of services, including emotional **support**, help to **access** treatment, support and education, **information** about mental illness, **accommodation**, skills **training** and help to find and keep a **job**.

- ▶ The majority (74.3%) of people who attend NGO services are over 35 years old. They are less likely than other people with psychotic illness to have had an admission to hospital or attended an emergency department in the past year.
- ▶ The majority (77.8%) of those who attend NGO services report satisfaction with the level of contact.
- ▶ Two in three people with a psychotic illness had a case manager in the past year: 61.6% provided by public mental health services, and 20.2% provided by NGO services.
- ▶ Around two in three people with a case manager report they are 'very satisfied' with the service received.
- ▶ Personal Helpers and Mentors Services (PHaMS) supported 12.3% of people with a psychotic illness in the past year, assisting them to manage daily activities, accompanying them to appointments, providing referral for further support, and acting as an advocate where needed.

one in three

Only one in three (29.8%) people with psychotic illness used an NGO service in the past year.



Action

The proportion of people who use NGO services has increased in recent years, yet two out of three people with psychotic illness still do not access them – predominantly those who are younger, and who experience more frequent episodes of psychosis.

Considering the range of practical support provided by NGOs, as well as their association with reduced use of hospital inpatient services, there is a strong case for boosting the funding and availability of their services to reach more people.

Closer, formal collaboration with clinical mental health, employment, and other services sharing the same clientele is also needed.

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GP services

GP services

GPs now play a central role in provision of mental health services as well as primary care to people living with psychotic illness.



a close relationship

People with psychotic illness see their GP nine times a year on average: almost twice as often as the general population.

Most people with psychotic illness (83.2%) see the same GP regularly. The doctor usually (86.5%) provides treatment in collaboration with the person's mental health service.

- ▶ One in three (32.2%) of people with a psychotic illness who visited their GP in the past year were treated for metabolic, cardiovascular or kidney disorders.
- ▶ One in three (31.3%) people with psychotic illness attended their GP for depression, and a similar proportion (30.3%) for an anxiety disorder.
- ▶ Nine out of ten (90.6%) people with psychotic illness had not been prescribed a mental health care plan by their GP.
- ▶ The most common (22.1%) difficulty noted by GPs in treating people with psychotic illness was non-adherence with medication.

unemployment
finances
social isolation

The top three challenges for people with psychotic illness, as reported by their GPs.



Action

GPs have an increasingly central role in treatment of people with psychotic illness. As well as providing primary care, they act as gatekeepers for a range of specialist services, including the Better Access and ATAPS initiatives. This role will only grow with the spread of the Medicare Local model of care.

The high rates of anxiety and depression suggest that more people could be prescribed mental health plans in order to access psychological treatments.

More systematic assessment of physical health risk factors is needed by GPs and other health professionals. GPs are also in an ideal position to make more routine referrals to local NGO and other community support services.

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A home and a job

A home and a job.

People with psychotic illness have a very high rate of unemployment and are at greater risk of homelessness.



gimme shelter

One in eight (12.8%) people with psychotic illness had periods of being homeless in the previous year.

- Around half (48.6%) are in rental accommodation, including 26.8% in public housing.
- Almost one in four (22.7%) are on a public housing waiting list.
- One in ten (11%) are in supported accommodation.
- Half (52.8%) had discussed accommodation needs before discharge from hospital, but 6.9% reported they had not been given any help, and were homeless on discharge.



no vacancies

General population in work **72.4%**

People with psychotic illness in work **21.5%**

The general working age population (15-64 years) employment rate is for the month of interview (ABS 6202.0, 2010). People with psychotic illness reported their work status in the week prior to interview.

- Government pensions are the main source of income for 85% of people.
- The majority (69%) of those in work have part-time jobs.
- Labouring is the most common occupation for men (48.5%) and women (26.5%).
- Just over half (56.2%) have disclosed their mental illness to their employer.



Action

Helping more people with psychotic illness to find a job addresses their three main concerns: unemployment, social isolation, and financial troubles. Government-supported initiatives have begun to make an impact in this area, but investment in these needs to be sustained and expanded, especially for innovative models which provide a genuinely supportive, flexible workplace in an open employment environment.

Finding a job is even more difficult if you do not have a home. Some progress has been made on accommodation in recent years, but key areas still need to be addressed, including: the need for more supported accommodation, the lack of sufficient, dedicated public housing, and the need to tackle homelessness among people with psychosis, especially young people.



Social isolation

Social isolation

Social exclusion is a distressing and deeply personal reality for many people living with psychotic illness.



a friendless life

Nearly a quarter of people with psychotic illness reported feeling socially isolated and lonely. One in eight (13.3%) had no friends at all. A similar proportion (15.4%) had never known someone they could confide in.

- Two in three (69.3%) said that their illness made it difficult to maintain close relationships.
- One in four (24.5%) reported having a carer, usually a close family member or friend.
- Over half (56.4%) reported receiving no or minimal support from any source.
- Two in five (37.9%) reported experience of stigma or discrimination in the past year.
- One in four (24.8%) had been victims of assault in the past year – five times the rate for the general population (4.8%).
- Over half (55.5%) reported unmet needs in relation to their treatment.
- Two in three (68.6%) had not attended any social programs run by NGOs.
- One in three (30.5%) reported unmet needs in areas of life such as housing, finances, employment, legal assistance, and other practical support.

unemployment
finances
social isolation

The top three challenges faced by people with psychotic illness.



Action

Social exclusion is one of the cruellest consequences of having a psychotic illness. While the proportion of people visiting NGO services has risen, there is scope for a dramatic increase in use of these programs and systematic referral to them by GPs and mental health services. Improved support and training for families is also needed.

It is notable that the three main challenges reported by people with psychotic illness are not clinical, and are the same as those observed by GPs: unemployment, finances, and social isolation. Of these, it is employment which holds the key to the others: it is work – a meaningful occupation, with appropriate, flexible support – which gives people the dignity of a place in society and links them to others, while also providing an income.

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People living with psychotic illness 10

The challenge

People Living with Psychotic Illness provides sobering evidence of the severe, sometimes savage, impact of psychosis, leading to substantial and persistent disability for many people. There is an impact, too, on physical health, education, employment, and housing. Yet, as the authors of the study state, 'in the face of disability, disadvantage, stigma and social isolation, people with psychotic disorder display resilience and tenacity'.

The study does reveal changes in the delivery of mental health services since the previous survey in 1997-98: principally related to the ongoing, if uneven, shift from hospital to community-based care.

There have been modest but real improvements in other areas. While the majority of people had multiple episodes of psychotic illness, more (29.3%: up from 21.3%) reported periods of good recovery in between. Involuntary admissions decreased by a third. There has been a 60.7% increase in the number of people using NGO rehabilitation programs. The number of people who had been homeless in the previous 12 months has more than halved since 1998, from 13% to 5%. Some services have only become available in recent years and are still growing in reach, such as the PHaMs (Personal Helpers and Mentors) programs which now helps 12.3% of people with psychotic illness and received a substantial funding boost in the 2011 Budget. This has also had the consequence of unlocking the potential of the many peer workers who work in the PHaMs programs, through providing practical help and advice to others.

There remains, nevertheless, vast scope for improvement in delivery of mental and physical health services, support and rehabilitation, to promote recovery for people living with psychotic illness so that they are able to live meaningful, satisfying lives – included in, contributing to, and valued by society.

The Gillard Government's Mental Health Reform package builds substantially on the 2006 COAG initiative under the Howard Government, and offers real hope of progress. As well as additional funding and the expansion of initiatives such as the Early Psychosis Prevention and Intervention centres, the package includes a commitment to improve partnership with the States and Territories in service delivery, and to develop a *Ten Year Roadmap* for mental health services. It is just such a national strategic vision which has been missing for many years, and allowed progress in mental health reform to atrophy. This process also occurs in the context of a changing health landscape, including implementation of the Medicare Local model and work to introduce a National Disability Insurance Scheme. There is a real danger that an already complex system will be made even more complicated by all these changes, and ensuring this does not happen must be a priority in any planning.

The People Living with Psychotic Illness study provides compelling evidence of the need to improve our mental health services, and recommendations based on this are spelled out under *Action* on every page of *A SANE Response*.

The challenge for all Australian Governments is to carry this out in a way that genuinely helps people who live with psychotic illness with such courage, endurance and hope.



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A U S T R A L I A

A national charity
working for a better life
for people affected by mental illness

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