

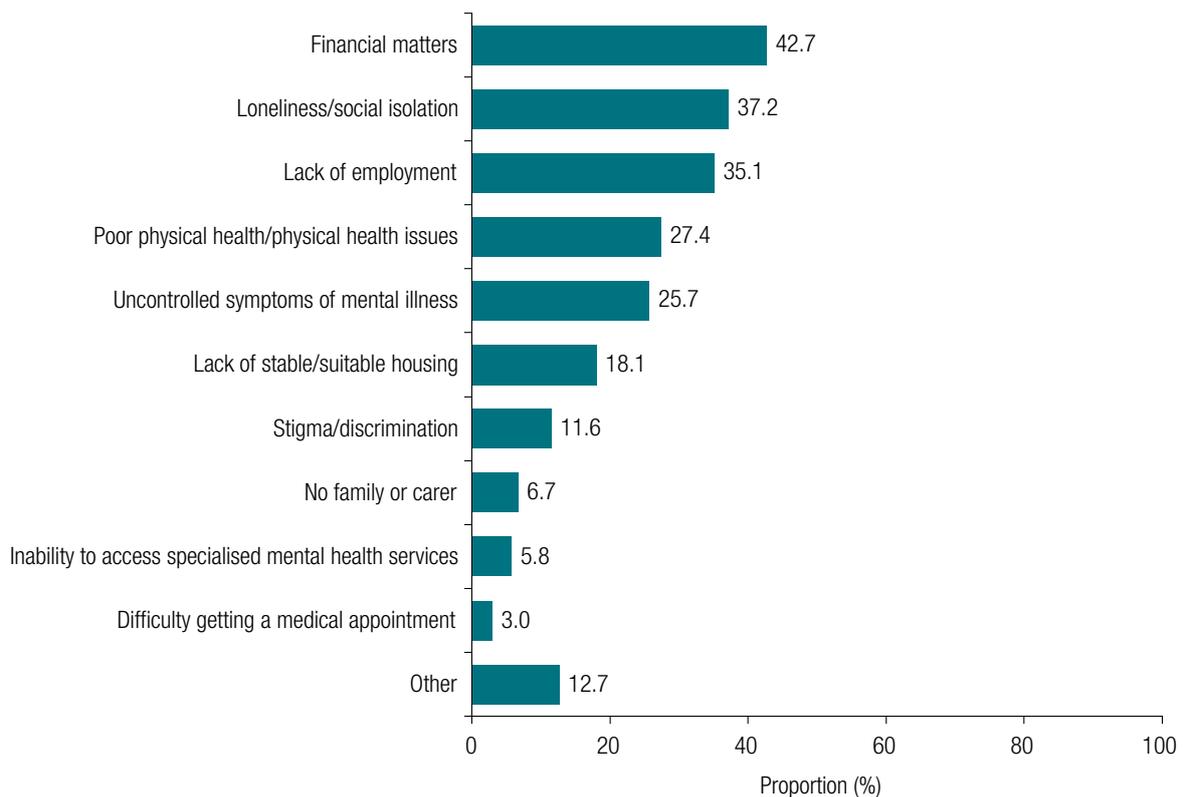
## 20 CONCLUSIONS

This is the largest and most comprehensive assessment of psychotic disorders undertaken in Australia, and one of the most detailed undertaken internationally. The survey has provided a snapshot of people living with psychotic illness, the circumstances in which they live and the services they receive. The results confirm that psychosis is associated with substantial and persistent disability. Apart from the psychiatric features of psychosis, these disorders impact on physical health, education, employment, and housing. Yet, in the face of disability, disadvantage, stigma and social isolation, people with psychotic disorder display resilience and tenacity.

### 20.1 Challenges for people with psychosis

People with psychosis identified the most important challenges for them in the coming year (Figure 20-1). The three top challenges were not health-related. They were financial problems (42.7%), loneliness and social isolation (37.2%) and lack of employment (35.1%). Health-related issues were ranked next, with 27.4% naming physical health issues and 25.7% naming the uncontrolled symptoms of mental illness. Housing was ranked sixth, at 18.1%.

**Figure 20-1. Most important challenges for the coming year**



Overall, the six top-ranked challenges were the same for males and females, and for the younger and the older age groups. Notably, however, younger people ranked unemployment issues first (44.5%). When participants' general practitioners were asked a similar question, they endorsed the same top five challenges for their patients (Table 17-4).

## 20.2 Quantifying the challenges identified by people with psychosis

The 2010 psychosis survey furnishes abundant evidence quantifying the extent to which people with psychosis are currently facing these challenges in the areas of mental and physical health, income, employment, housing and social isolation.

### 20.2.1 Impact of psychosis

Psychosis impacts on individuals not only in terms of the symptoms of the illness, but from side effects of medication used to treat psychosis, as well as other associated impairments such as limited capacity to undertake activities of daily living, dysfunction in socialising and cognitive impairment. The prevalence of suicidal thinking and behaviour is very high in people with psychosis.

- While the majority of people with psychosis reported multiple episodes of illness with either good recovery or partial recovery in between (61.5%), almost a third (30.5%) experienced a continuous, chronic illness.
- Over a lifetime and currently, delusions and hallucinations were prominent, along with depressed mood, loss of pleasure, poor concentration and, to a lesser extent, abnormally elevated mood and irritability.
- Symptoms associated with anxiety/phobia and with depression were common: 59.8% and 53.1% of people with psychosis, respectively, reported having these symptoms over the past year.
- Over 90 percent (91.6%) were taking prescribed medication for their mental illness and the majority said that they got relief from the medications they were using.
- While most people with psychosis were on antipsychotic medication, the majority were not receiving adjunctive psychosocial therapies despite evidence-based guidelines for their concurrent use in the management of symptoms and impairments associated with psychotic illness.
- Over the past year, almost one third (30.5%) had received counselling, group therapy or other talking therapies, only one in five (22.3%) had had cognitive behavioural therapy and only one in ten (11.4%) had had family therapy.
- Three quarters (77.4%) complained of medication side effects. The most common side effects included daytime drowsiness, drier or more watery mouth, weight gain (an average of nine kilograms in the past six months), inner restlessness, trembling or shaking of limbs and inability to relax.
- Sixty percent (61.0%) had impairments attributed to medication side effects. Almost one third (29.9%) said the impairments had a moderate or severe impact on their daily lives.
- Nine out of ten reported deterioration in social, occupational or emotional functioning after the onset of their illness.
- One third (32.3%) was rated as having marked impairment in self care in the four weeks prior to interview.
- There was evidence of some cognitive impairment in people with psychosis prior to illness onset that was amplified in the years after illness onset.
- One half (49.5%) of people with psychosis had attempted suicide at least once at some point in their lives compared to 3.7% of the general population.
- Two thirds (67.0%) had had serious thoughts about taking their own life in the past and one in ten (11.5%) was thinking seriously about taking their own life currently.

## 20.2.2 Physical health

People with psychosis are affected by physical conditions at rates well above those for the general population. This amplifies the burden of ill health that they already carry. In particular, rates of cardiometabolic risk factors are high, predisposing this group to increased risk of metabolic disorders, cardiovascular disease and premature death. High levels of substance use contribute to poor health. Smoking rates remain very high and unchanged for over more than a decade, with lifetime drug and alcohol use or dependence disorders also well above population estimates.

- Levels of lifetime physical health morbidity were higher among people with psychosis than general population levels for a wide range of conditions.
- Half (49.9%) met criteria for metabolic syndrome, a risk factor for cardiovascular disease and type 2 diabetes.
- One quarter (24.0%) had a high absolute risk of cardiovascular disease in the next five years, or already had cardiovascular disease.
- Almost one half (45.1%) had a body mass index in the obese range compared to 20% of the general population.
- One third (33.5%) had no or very little daily physical activity and almost all the rest (62.9%) reported low levels of activity. The figures for the general population were 19% and 54% respectively.
- Two thirds (66.1%) of people with psychosis were currently smoking. Despite a fall in tobacco use in the general community, the proportion smoking had not changed since the first national psychosis survey in 1997-98. The rate was two and a half times the population rate of 25.3%.
- The lifetime rate of alcohol abuse or dependence, at 50.5%, was double the population figure of 24.7%.
- The lifetime rate of any drug abuse or dependence, at 50.8%, was almost six times the population figure of 8.9%.
- The majority of people using cannabis in the past year was using it at least once a week (58.5%), with 38.1% using it daily or almost daily.

## 20.2.3 Income, employment and housing

### Income

People with psychosis have levels of income well below the national average.

- Three-quarters of people with psychosis had earned less than half the national estimated average disposable income.
- The main source of income for 85.0% of people was the Disability Support Pension.

### Employment

Not only is paid employment an important source of income, it is a key form of community engagement and a factor that contributes to self-worth. However, employment rates are low among people with psychosis. Most of those with any employment are working part-time only, with a substantial minority preferring more hours of work.

- One in three (32.7%) people with psychosis had been in paid employment in the past year.
- One in five (21.5%) were in paid employment at the time of interview.
- Of those working in the past year, for their main job:
  - The majority (74.8%) was in open, competitive employment.
  - Over two thirds (69.0%) were working part-time only.
  - The average number of hours worked per week was 23.
  - One quarter (27.5%) would have preferred more hours of work.

## Housing

While half of the people with psychosis are very satisfied with their housing, residential mobility is high and one quarter is on public housing waiting lists. Moreover, many fear becoming homelessness and for many this is a reality.

- Half (48.6%) of people with psychosis were living in rented housing, 19.1% were in a family residence and 13.1% were in their own residence at the time of interview.
- One in ten (11.0%) was living in supported accommodation.
- One quarter of people with psychosis (25.0%) worried about becoming homeless.
- One in twenty (5.2%) was homeless at the time of interview compared to 0.5% of the general population.
- Up to one in eight (12.8%) had been homeless at some time over the past year.
- One quarter (27.4%) had changed accommodation at least once over the past year and 6.7% had moved three or more times.
- Almost one quarter (22.7%) was on a public housing waiting list.

### 20.2.4 Loneliness and social isolation

#### Loneliness and social isolation

Loneliness and social isolation are recurring themes among many people with psychosis. Social support is a key factor in facilitating recovery, but people with psychosis often have impairments in the social skills necessary for forming supportive social networks. Added to this, continuing symptoms of illness and stigma impact on their capacity to develop and maintain social relationships.

- Two thirds (63.2%) of people with psychosis were rated as having marked impairment in socialising over the past year.
- Two thirds (69.3%) said their illness made it hard for them to maintain a close relationship.
- Almost half (48.8%) had never been married or in a long term de facto relationship.
- Almost half (47.5%) said they needed and would like more friends.
- Almost one quarter (22.4%) felt socially isolated and lonely.
- In terms of contact with friends, 13.3% reported having no friends at all, 14.1% had no-one to rely on at times of serious need and 15.4% had never had anyone to confide in.

## 20.3 Other important findings

### 20.3.1 Educational profile

Poor school and post-school completion rates observed for many people with psychosis further detract from their employability and compound the effects of cognitive impairment associated with psychosis. These rates reflect the impact of early onset of illness in late adolescence and early adulthood at a critical stage for education and training, and for the consolidation of life skills.

- For almost two thirds (64.8%) illness onset was before the age of 25 years and, for a substantial minority (39.4%) it was under the age of 20 years.
- Only one third (31.5%) of people with psychosis had completed year 12 schooling compared to over half (53.0%) of the general population.
- Less than half (47.1%) had a post-school qualification compared to 59.4% of the general population.
- One in five (18.4%) had difficulty reading and/or writing.

### 20.3.2 Parenting

Many people with psychosis are parents. This is of considerable consequence from a service perspective, creating an imperative for services to identify the needs of these families and ensure that affected parents and their children are well supported.

- Just over half the women with psychosis (56.2%) and one quarter of the men (25.9%) were parents with children of their own.
- One quarter of the women (23.6%) and 5.5% of men had dependent children living at home with them.
- Just 44.8% of the mothers with dependent children at home were in a relationship, either married or defacto.
- The majority of parents with dependent children at home were parenting very well, however, almost one quarter (23.1%) were rated as having obvious or severe dysfunction in their provision of care for their children.

### 20.3.3 Victimisation

High victimisation rates highlight the vulnerability of people with psychosis.

- Almost two-fifths (38.6%) of people with psychosis had been a victim of an offence such as theft or assault over the past year.
- One quarter (24.8%) had been a victim of an assault in the previous year compared to 4.8% of the general population.

## 20.4 Conclusion

Like all Australians, people with a psychotic illness have the same requirements for good nutrition, adequate housing, worthwhile employment and sufficient income to meet basic needs. They express a similar yearning for social interaction and meaningful relations with others. Many have partners and children and some are carers for others with a disability who rely on them.

Because of their illness, people with a psychotic illness face additional challenges. Many of these challenges are not health issues, but relate to employment, income, housing, social contact and the need for social support. Indeed people living with psychosis in Australia in 2010 ranked social and economic disadvantage and loneliness and social isolation above their very profound physical and mental health needs.

These challenges highlight the importance of an integrated approach to service provision for people with psychosis to ensure that their living requirements and needs for social participation are met, as well as meeting their very considerable mental and physical health needs.

The population-level data collected as part of the 2010 national psychosis survey provide a solid, empirical foundation to guide policy development and service provision around all aspects of the lives of people living with psychosis.

