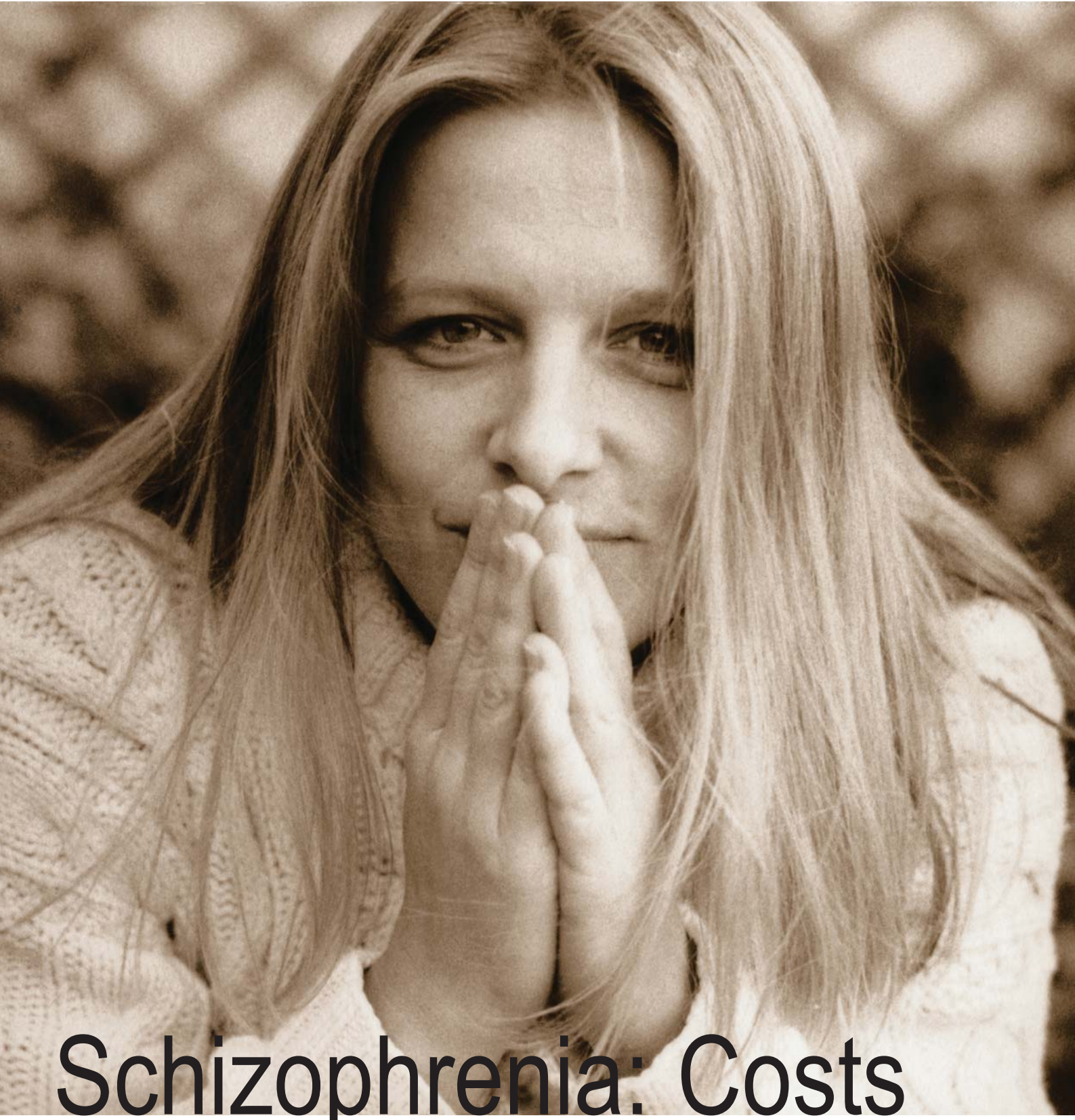

Schizophrenia: Costs

An analysis of the burden of schizophrenia and related suicide in Australia

An Access Economics Report
for SANE Australia 2002

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AUSTRALIA

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Contents

1 Executive Summary

Schizophrenia is a costly illness. The direct and indirect costs of schizophrenia and associated suicides are enormous. Real financial *costs of illness* totalled $1.85 billion in 2001, about 0.3% of GDP and nearly $50,000 on average for each of more than 37,000 Australians with the illness. Over one third of this cost is borne by people with the illness and their carers.

– Direct health system costs were $661 million in 2001, including 60% hospital costs, 22% community mental health services, 6% medical costs (GPs and specialists), 4% nursing homes and 2% pharmaceuticals.
  – This represents nearly $18,000 per person with schizophrenia, over six times the spending on the average Australian's health care and 1.2% of national health spending. Even so, it is clear that public health spending in Australia is at the low end of the international spectrum (1.2% of health spending compared to 1.6% to 2.6% in other comparable countries)
– Real indirect costs were $722 million, including $488 million of lost earnings from people unable to work due to the illness, $94 million due to premature death (the net present value of the mortality burden), $88 million of carer costs and $52 million of prison, police and legal costs.
– Transfer costs were $190 million of lost tax revenue (patients and carers) and $274 million in welfare payments, primarily comprising disability support pensions.

Moreover, the *burden of disease* – the pain, suffering, disability and death – was greater for schizophrenia than for ovarian cancer, rheumatoid arthritis or HIV/AIDs, and of similar magnitude to leukaemia and melanoma.

– 22,616 years of healthy Australian life were lost to the illness in 2001, including 3,323 years lost due to suicide and self-inflicted injury – 55% of the burden of disease was borne by males and 74% by young people aged 15-34.
– Suicide is a prominent cause of premature death – in 2001, best estimates suggest that at least 129 Australians who died due to the illness took their own lives. People with schizophrenia also disproportionately suffer other chronic illnesses, so that the risk of death is 2.5 times that of the average Australian.

These tragic figures are conservative estimates – while the one-year prevalence is relatively low (1.92 per 1000 in a global range of 1 to 7.5), lifetime prevalence is around 10 per 1000; direct costs are likely to be underestimated for pharmaceuticals; indirect costs do not include accommodation or the value of NGO services; and the burden of disease does not estimate the suffering of families as they care for their loved ones with the illness.

Part of the reason why public health spending in Australia is low is because many Australians with schizophrenia are missing out on effective treatments, rather than gaining full access to them.

Cost-effective interventions that should attract more dedicated investment include:
– prevention and early intervention programs;
– newer improved medications;
– carer education and training;
– psychosocial rehabilitation programs;
– suicide prevention strategies;
- treatment of co-existing substance abuse; and
– research into causes and more effective treatments.

Without such investment, in the coming decade direct health costs will top $1 billion, and many people with schizophrenia will still be living on the edge of Australian society, with only limited opportunities to be healthy and participating members of the community.

2 Schizophrenia and Suicide

2.1 Schizophrenia – a clinical picture

2.1.1 What is schizophrenia?

Swiss psychiatrist Eugen Bleuler introduced the term 'schizophrenia' to medical language in 1908 to describe a serious, often persistent form of psychotic illness.

Diagnosis of schizophrenia is typically complex and cautious, based on observation of behaviour and the thinking process in accordance with criteria from the DSM-IV or ICD-10 classifications (see Appendix).

*Misnomer: Schizophrenia is **not** 'split' or 'multiple' personality.*

Symptoms, which vary widely between individuals and even within the same individual at different times, can be *positive* (additional) or *negative* (missing) include most commonly:

- ***Hallucinations*** – hearing voices, tactile hallucinations (eg, something creeping under the skin) and visual hallucinations (seeing people or things that aren't there);
- ***Delusions***[1] – especially false beliefs (eg, 'My liver is made of gold', 'I came to Earth on a star'), and ideas of grandiosity or persecution (eg, being spied on);
- ***Disordered thinking*** – usually inferred from abnormalities in language, loose associations, speech digression, poverty of speech content and use of idiosyncratic expressions (eg, 'My divorced wife has an albigisty of conscience which she has terpolated with the Security Forces'); and
- ***Abnormal affect*** – including depressed mood[2], low motivation, withdrawal, and difficulty or inappropriateness expressing emotions (eg, laughing at sad news).

Onset of schizophrenia can be defined as *acute* – a florid psychotic state develops within days or weeks – or *insidious*, where there is a gradual transition. Acute onset is more common in developing countries – 70-80% compared with less than 50% in the US and Europe, with a more benign disease course and better outcome in developing countries (Jablensky et al, 1992). Onset tends to be *earlier in males* with a peak incidence in the early twenties in contrast to early thirties in females, with a milder course and better prognosis in females (Barbato, 1997).

Schizophrenia is the most common type of **psychosis**, representing over half of all psychotic patients. In Australia, the 1997-98 Low Prevalence Disorders Study (LPDS) showed, according to ICD-10 criteria, that 53.8% of people with psychoses had schizophrenia, 10.8% schizoaffective disorder, 11.8% bipolar disorder and/or mania, 8.4% depressive psychosis and 15.3% other psychoses.

2.1.2 Aetiology

Schizophrenia is a group of brain disorders that share certain clinical features. Like other complex disorders (such as diabetes and cancers), there is much still to learn about the causes underlying the disorder. There is now strong evidence that genetic and environmental factors that impact on early brain development lead to an increased risk of developing schizophrenia as an adult. Potential risk factors are discussed below.

Heredity/genetics: There is robust evidence demonstrating that genetic factors increase the susceptibility to schizophrenia (Kendler and Diehl, 1993). People with a close relative with schizophrenia are at significantly higher risk – an identical twin has a 40-50% risk of developing the illness if the other twin has schizophrenia, while a child of a person with schizophrenia has about a 10% chance, compared to the

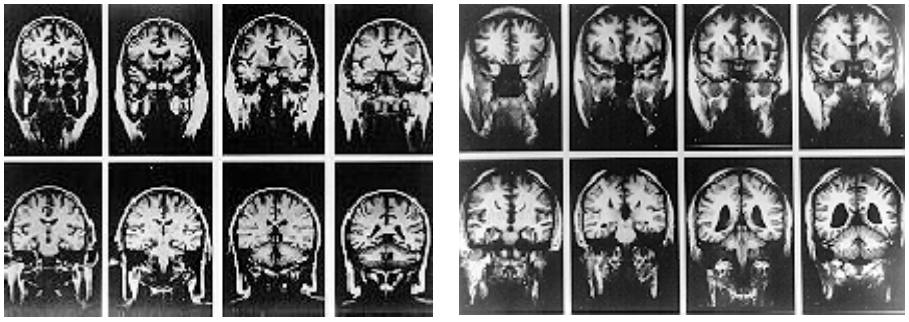
[1] Hallucinations and delusions occur in 96% of cases of psychosis according to Jablensky (2000).

[2] Depression and loss of pleasure occurs in 73% of cases of psychosis according to Jablensky *ibid,* with thoughts of suicide in 68% of cases.

general population risk of 1%. Scientists are investigating several regions of the human genome that may confer susceptibility to schizophrenia. It appears likely that multiple genes, each of small effect, may underlie the genetic pre-disposition to developing the disorder.[3]

Physical abnormality of the brain: Technological advances in neuro-imaging have found that, at the group level, people with schizophrenia have various alterations in brain shape, as shown in Figure 1 below from Green (2002). However, these findings relate to the group level, not the individual level, and thus these changes cannot be used as a 'diagnostic marker' of schizophrenia.

Figure 1: MRI scans of control and patients with schizophrenia



Left: Control subject, and *Right*: Male patient with schizophrenia.
Taken from *Problem-Based Psychiatry* Scans by Professor Nancy Andreasen.

Chemical imbalance: Some research, based mainly on features of medication, has indicated there may be an imbalance of the complex inter-related chemical systems of the brain, perhaps involving the neuro-transmitters *dopamine* and *glutamate*.

Environment: Schizophrenia is not a stress-related illness. Stressful life events and use of drugs (such as marijuana, cocaine, speed, ecstasy, amphetamines or LSD) may, however, precipitate a psychotic episode or first onset of schizophrenia. Researchers are also examining prenatal infection and maternal nutrition as candidate risk factors.[4] Environments that involve a lot of negative criticism, over-involvement by certain others and expressed hostility are unfavourable to recovery from schizophrenia. Close interpersonal relationships, especially marriage, appear to act as a protective factor, although many people with schizophrenia are single *because of* the illness (Barbato, 1997). There is a higher prevalence of schizophrenia in lower urban socio-economic areas, explained by the *selection-drift* hypothesis – i.e., people with schizophrenia drift to these areas because of the disease, as well as the reverse causation.

*Misnomer: Schizophrenia is **not** caused by 'bad' parenting.*

2.1.3 Illness progression, morbidity and mortality

Before the illness can be recognised there may be a *'prodromal' phase*[5] in the late teenage years, with social isolation, interest in fringe cults, social withdrawal (eg, living alone with minimal contact) and even earlier with *'neurological soft signs'* such as late walking, speech development problems, clumsiness or

[3] The US National Institute of Mental Health has established a *Schizophrenia Genetics Initiative* involving a large number of families of people with the illness.

[4] Research has shown there is a 10% higher chance of developing schizophrenia if born in Spring (February to April) in the northern hemisphere.

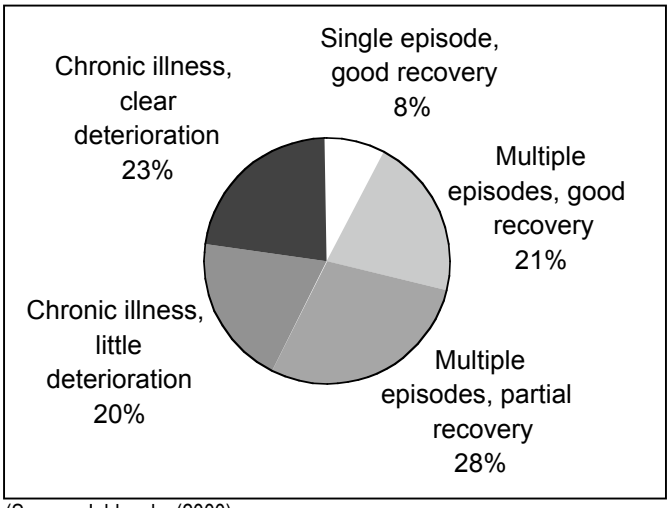
[5] Prodromal symptoms (McGrath and Davies, 1999, p18) include:
Cognitive changes – poor concentration, vague or woolly thinking, suspiciousness, odd preoccupations;
Mood changes – an anxious feeling that something in oneself or the world has changed. This experience, sometimes referred to as 'delusional mood', may be relieved the moment the person first develops a delusional explanation for what is happening;
Behavioural changes – interpersonal withdrawal, loss of old friends, loss of interest in social activities, problems at work or in a course of study, deterioration in self-care, drug taking (sometimes in an attempt to self-medicate) and estrangement from family;
Premorbid personality – people with schizotypal personality traits are at higher risk of developing a psychotic illness.

movement disorders in childhood, preferring to play alone[6]. The active phase of disease coincides with the obvious onset of psychotic symptoms. There is a critical period between two and five years after the first psychotic episode when most of the impairment and disability arise, which highlights the need for early and active intervention at this stage of the illness (McGrath and Davies, 1999).

> *'Most of the impairment, disability and handicap of schizophrenia arise between 2 and 5 years after the first psychotic episode.' McGrath and Davies (1999)*

After an active episode there may be a complete return to normal function, but there is a high probability of further episodes where function and personality may be damaged. The damage may worsen over time, with features of a poor prognosis being: insidious earlier onset, neurological soft signs, lack of education, past psychiatric history, history of violence, long duration of first episode, long duration of untreated psychosis, emotional blunting, social withdrawal, poor psychosexual functioning and significant co-morbidities (especially substance abuse).

Figure 2: Course of illness, psychoses, Australia



(Source: Jablensky (2000).

Illness progression may be categorised into types and the World Health Organisation (Barbato, 1997) reports that 45% of patients have complete or partial recovery after one or more episodes – the 'good and OK' outcomes; there are unremitting symptoms and increasing disability in 20% – 'poor' outcomes; while about 35% show varying degrees of remission and exacerbation – 'mixed' outcomes. The LPDS in Australia showed comparable results, 'good' outcomes in 29% of cases, 'poor' outcomes in 23% and 'mixed and OK' outcomes in 48% – see Chart 1.

Morbidity

Disability: Disability is experienced in relation to self-care (personal hygiene, dressing and feeding – 30% in the LPDS suffered impairment, including 3.6% where this amounted to self-neglect); relations and interactions (with family, friends and society generally – 49% for those within families and 59% overall in relation to socialising outside the home); and occupational performance (studying, paid work, housework – 46% dysfunction of the 38% who indeed could state a 'main occupational role' – i.e., 80% dysfunctionality overall). After musculoskeletal disorders, psychiatric disorders are the largest cause of people being on the Disability Support Pension, comprising approximately 20% of the total who receive it (HFS, 1996).

> *'Schizophrenia permanently disables more young people than any other illness.' OHS Net (2000)*

***Work and educational limitations, socio-economic disadvantage*:** People with schizophrenia tend to be socio-economically disadvantaged. Over 70% of people with psychosis in Australia do not work at all. Lack of rehabilitation programs also seriously limits work potential. Nearly half have no school qualification, while for the Australian population as a whole this figure is about 37%. Moreover, of the 28% in the LPDS who had any formal employment, 53% had lost nearly 15% of their work-weeks during the year due to illness-related absenteeism (Jablensky et al, 1999).

[6] It should be noted that most children with late developmental milestones will not develop schizophrenia.

***Social stigma*:** Social mistreatment takes many forms including negative labelling, use of pejorative language, and barriers to housing, employment, social services and social interactions/friendships, resulting in lower self-esteem and reluctance to obtain treatment. De-stigmatising psychotic illness represents a major challenge in Australia.

***Social isolation*:** People with psychosis in Australia tend to be isolated – 31% live alone, 59% have an impaired ability to socialise, 35% have no frequent face-to-face contact with a close relative, 39% have no best friend with whom to share thoughts and feelings and 12% have no friends at all. 64% are single and 50% had no sexual relations in the previous year (Jablensky et al, 1999).

***Violence/criminality*:** People with schizophrenia are not especially prone to violence – more typically they are withdrawn and prefer to be left alone. As with the community generally, the rate of violence is increased if there is substance abuse or a history of criminal violence (before onset of the disease). Risk also increases if there are paranoid and psychotic symptoms and medication is discontinued. When violence does occur, it is most frequently targeted at self, or at family members or friends, and more often takes place at home. There is an elevated risk of criminality, however, with 10.2% of Australians with psychoses in the LPDS arrested for a criminal offence (Jablensky et al, 1999). Worldwide, people with psychoses are over-represented in the prison system with 3.7% of male prisoners and 4.0% of female prisoners having a psychotic illness, several times the population prevalence (Fazel and Danesh, 2002). People with schizophrenia are also more likely to be the victims of crime (see Section 4.4).

Co-morbidities

People with schizophrenia have a higher risk of having ***other mental disorders*** including a 25-30% chance of clinical depression. Depression may result as people assess the impact that the illness has on their life plans, or they may know another person with schizophrenia who has died by suicide. Anxiety symptoms are also more likely—for example a fear of being attacked due to persecutory delusions or worry about having another episode (SANE Australia, 2000a).

There is also evidence that people with schizophrenia are more prone to some ***physical disorders***, especially cardiovascular disease (due to unhealthier lifestyles and the effect of anti-psychotic drugs) and HIV infection (Jeste et al, 1996). A recent Western Australian study of people with mental illness showed that they are 30% more likely to die of cancer, over three times more likely to develop HIV, over four times more likely to develop hepatitis and their death rates are 2.5 times higher than the norm (Lawrence et al, 2001).

***Substance abuse*:** People who have schizophrenia often abuse alcohol (30%) and/or drugs (25%), and may have particularly bad reactions to them. Symptoms may worsen and treatment plans are less effective when substance abuse is also a problem (Regier et al, 1990). In Australia, the LPDS (Jablensky et al, 2000) showed lifetime diagnosis of alcohol abuse or dependence at 39% for men and 17% for women, compared with 9.4% and 3.7% in the population generally. Lifetime diagnosis of drug abuse or dependence in the LPDS was 36% for men and 16% for women, over ten times the corresponding rates in the general population of 3.1% and 1.3%.

***Smoking*:** Nicotine is the most common form of substance abuse for people with schizophrenia, with three to four times the prevalence (75-90%) of the general population (now close to 20%). Smoking interferes with the effectiveness of anti-psychotic drugs, quitting may be difficult for people with schizophrenia, and of course the habit worsens other health risks (cancer, heart disease etc). The Australian LPDS (Jablensky et al, 1999) showed smoking in 73% of men and 56% of women, compared to the national averages of 27% and 20% respectively reported in the 1995 ABS National Health Survey. Similar findings (68% men and 54% women) were revealed in a study of clients of four Area Mental Health services in Melbourne (Davidson et al, 2001). Another study by Professor Ann Crocker at Flinders Medical Centre, Adelaide, showed 80% of people with schizophrenia smoke.[7]

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[7] *"Most people with schizophrenia smoke tobacco, says research"* 9 April 2001 on www.mydr.com.au

Mortality

Death rates of people with schizophrenia are at least twice as high as those in the general population, even though it is not a 'fatal' disease. In the past, when people with schizophrenia were institutionalised and infectious diseases were a significant cause of death, many people with the illness died from communicable diseases such as tuberculosis. Today, the pre-eminent cause of death is suicide and accidents.

'One in six people with schizophrenia die by their own hand, often in response to psychotic symptoms eg, second person auditory hallucinations telling them to kill themselves.' (Green, 2002)

2.2 Suicide

The World Health Organisation calculates the lifetime risk of suicide globally for people with schizophrenia as 10-13%, which is twelve times the population risk (Barbato, 1997). A Swedish study found the ratio as high as 20% in men and 17% in women (Litton and Kahl, 2001).

Over 40% of people with schizophrenia will attempt suicide at least once – 60% of males and 20% of females. Completed suicide is more common in males.[8] Suicidal ideation is common in 70% of people with schizophrenia. The highest risk of suicide is usually within a year or two of symptoms starting (SANE Australia, 2000a).

Suicide is a high risk for people with schizophrenia who experience depression when in remission from a psychotic episode. Most at risk are young males with good pre-morbid function and high expectations who show self-reported or perceived hopelessness (Caldwell and Gottesmann, 1990). A study of individuals with the illness who made serious suicide attempts reported that 81% of them had 'positive psychotic symptoms at the time of attempting suicide' (Nieto, 1992). This was reinforced in an American longitudinal study, which showed an elevated risk of suicide when paranoia, suspiciousness and delusions are present and significantly lower risk of suicide (only 1.5%) with predominantly negative symptoms (Fenton et al, 1997).

There are suggestions in several research studies that suicide is more likely to occur in people with schizophrenia who are not treated or not adequately treated (Heila, 1997). De-institutionalisation has increased the risk of failure to treat, and the suicide rate has also risen markedly since de-institutionalisation began – it is at least four times higher today than in studies from the period 1913-1960 (Stephens, 1999).

A recent UK study found that psychiatric patients who took their own lives were more likely to have had their care reduced at the last appointment in the community before death. Suicide was also associated with a history of self-harm, with suicidal thoughts during aftercare and with the initial hospitalisation. The key conclusion of the study is that reductions in care are strongly associated with suicide by people with mental illness, and may be contributory, so maintaining care beyond the point of clinical recovery is important in protecting high risk individuals (Appleby et al, 1999).

SANE Australia (2002) also note that people with schizophrenia are especially vulnerable to suicidality in the period after hospital discharge (especially in the twelve months after discharge from a psychiatric ward) or when treatment in the community has been reduced – when they have reached a point of 'clinical recovery'. Continuity of care after discharge and improved community support are recommended.

[8] See www.schizophrenia.com, Suicide Information.

Box 1: Lori Schiller's story

The first time Lori heard derogatory voices was as a teenager. She didn't know what was happening and battled 'strange, ominous voices and sights'. Life seemed dark, scary and fragmented. She wanted to die desperately 'in an effort to be free from this world'.

For many years, Lori was afraid to tell anyone about the voices, which repeated things like: 'You must die. You will die.' Eventually, she was diagnosed with schizophrenia.

At this stage, she felt her whole life would be 'like living under cobwebs in an old attic – I'd be a nobody.' A 'me-murder' was her answer, and her imagination became infested with them – including jumping from a bridge and overdosing on pills. Suicidal scenarios all held for Lori a perceived ending of tranquillity and eternal peace.

Lori had many experiences while in hospital that were so frightening at times she became physically sick. Her behaviour often left her 'acting out', necessitating medications and restraint. Sometimes, she would be in her room and afraid to leave because there were 'creatures sitting on my bed and coming through my window. I couldn't leave and I couldn't stay, so I'd 'freak out' and smash my fist into a wall or window safety screen. I did learn, however, from repeated psychotherapy sessions over many years, that the voices and sights are a part of me.'

Lori used to dread every morning for what was going to transpire that day. Every night when she went to bed, she was afraid that the voices would leave her sleepless. With the assistance of a new medication and the comfort and support from her psychiatrist and others, Lori has been able to make distances down her path to recovery.

She is now involved in working part-time in a gift shop and part-time as a counsellor in a halfway house. She has also written a book telling her story and co-leads a class once a month (with two nurses) about schizophrenia.[9]

2.3 Prevention, treatment and care

For many years there was considered no treatment for schizophrenia, which meant that many people with this illness were kept in mental hospitals for most of their lives. Today, with early and ongoing treatment and care, the majority of people with schizophrenia can live in the general community and lead relatively normal lives.

2.3.1 Preventive interventions

Primary preventive interventions (to reduce incidence) are limited in schizophrenia because causation and risk factors are not sufficiently understood to allow intervention. More research is required in this area.

Secondary prevention aims at early identification of prodromal symptoms to reduce morbidity through prompt treatment. McGrath and Davies (1999) emphasise the importance of early detection and treatment of schizophrenia in Australia, and how GPs can assist in this. They note that many people experience a significant delay (about a year) between symptom development and treatment, in which time many have contacted their GP but not gained access to psychiatric care. *The longer the delay in treatment, the worse the prognosis.* This is due to the adverse effects of untreated illness on neurobiological mechanisms – it is 'bad for the brain' – as well as on psychosocial functioning.

Early detection and treatment can be achieved through community education programs about early warning signs, with primary care and mental health services and intensive home-based assessment and

[9] For Lori 's book about her triumph over schizophrenia and suicidality – see Schiller (1996). Lori is also working on another book on the value of music therapy for schizophrenia.

interventions targeted at people with risk factors and at key persons in their social networks to enhance stress management strategies and problem-solving skills (Birchwood et al, 1997).

Suicide prevention is an important element of any preventive program. Suicide is becoming recognised worldwide as a leading cause of death, one of the top three causes of death for people aged 15-35. Suicide rates have increased 60% worldwide in the past 45 years, with one death now every 40 seconds. Suicide attempts are 20 times more frequent (one every two seconds) than completed suicides. Moreover, mental disorders are associated with 90% of suicides (WHO, 2002).

Effective prevention strategies (WHO, 2000) tend to involve:

– restriction of access to common methods of suicide eg, firearms (and avoidance of media reporting of the detail of suicides);
– multi-sectoral approaches – eg, community crisis centres, crisis phone lines, GP training, school-based interventions, prison programs, mentoring programs, family involvement (often it is only family or friends who are aware of risk factors emerging, eg, talking about suicide);
– adequate prevention and treatment of depression, psychotic illness, alcohol and substance abuse through pharmaceutical and psychosocial management (eg, anti-depressant medication);
– education and awareness programs – eg, crisis management, self-esteem enhancement, coping skills, healthy decision-making, group therapies; in the case of schizophrenia, awareness of high risk times and patients – namely, young, single, unemployed, male, educated, paranoid/suspicious, depressed, frequently relapsing, early in illness when confused/fearful of deterioration, early in relapse when disappointed (felt they'd overcome but symptoms recur), early in recovery especially soon after discharge from hospital (feeling vulnerable).

Table 1: Suicide prevention: do's and don'ts

Do	**Do Not**
Listen, show empathy, be calm	Ignore the situation
Be supportive, caring and take the situation seriously	Be shocked, embarrassed or panicky
Assess risk – ask about previous attempts and suicide plan	Say that everything will be all right
Explore possibilities other than suicide	Challenge the person to go ahead
Buy time – make a contract; remove the means, if possible	Make the problem appear trivial
Identify other supports	Give false assurances
Take action, tell others, get help	Swear to secrecy
If the risk is high, stay with the person	Leave the person alone

Source: WHO (2000).

2.3.2. Pharmaceutical treatments

Traditional ('typical') and novel ('atypical') anti-psychotic medications are described below. The balance between the two has changed markedly in recent years in favour of the newer drugs. Of these, clozapine has superior efficacy with respect to positive symptoms; the other atypical medications have equal efficacy compared to traditional medications, some benefit on cognitive performance, and fewer side-effects. Antipsychotics tend to be introduced in low doses and then gradually increased. While agitation can settle within hours or days of medicating, positive symptoms may take weeks to settle. Higher than recommended doses only produce more side-effects, not quicker or better outcomes. Medications may be prescribed to counter side-effects. Maintenance medication is required to reduce the risk of relapse (McGrath and Davies, 1999). The same medication can affect different people quite differently, so a period of trial-and-error may be inevitable to work out which drug and dose are best. Atypical medications should be prescribed when someone is newly diagnosed or has persistent symptoms or side-effects with current medication.

Traditional ('typical') anti-psychotic medications available since the 1950s do not provide cures but relieve symptoms including hallucinations, delusions and thought disorder by assisting the brain to restore its usual chemical balance, generally by blocking dopamine D_2 receptors. Trials show that 75% of patients show substantial improvement in 6-14 weeks (Dixon et al, 1995), with first-year relapse reduced to 20% from 60%. Traditional medications tend to be less effective with and may worsen negative symptoms such as social withdrawal and loss of drive and emotional expression. They may lead in 70% of cases to 'extra-pyramidal' side-effects including anxiety, irritability, an inability to feel comfortable and movement disorders such as involuntary trembling or stiffening of muscles, and the risk of developing *tardive dyskinesia,* a disabling movement disorder which develops over the long term in around 20% of people on the traditional drugs as maintenance, and which does not respond to treatment. Severe cases of these side-effects may result in aggressive or suicidal acts (Barbato, 1997). Other distressing side-effects are sedation, cardiovascular and endocrine effects, anticholinergic effects (eg, dry mouth, blurred vision), weight gain, skin and eye effects, and the rare but potentially fatal neuroleptic malignant syndrome. Poor compliance can be a big issue with these therapies (50% of outpatients fail to take them).

Novel ('atypical') anti-psychotics[10]: In recent years a new generation of anti-psychotic medications has become available including the first one, clozapine (*Clozaril*, *Clopine*), followed by risperidone (*Risperdal),* olanzapine (*Zyprexa*), quetiapine (*Seroquel*) and amisulpride (*Solian*). All five of these have been approved by the Therapeutic Goods Administration for use in Australia, and have been accepted for Commonwealth Pharmaceutical Benefits Scheme listing. The newer medications reduce psychotic symptoms with a lower incidence of extrapyramidal side-effects. There is also some evidence they are effective against 'negative' symptoms, helping people to feel less withdrawn and more motivated. However there may still be other side-effects – for example, the possibility of headache, dizziness, weight gain, low blood pressure, increased salivation, or urinary problems. People prescribed clozapine also require regular blood monitoring to detect a potentially fatal reduction in white blood cell count, which affects a small number of those taking the medication. [11]

Although these newer medications are up to ten times more expensive than traditional drug therapies, they reduce the need for other treatments, as Professor Martin Knapp of the London School of Economics notes (Doctor's Guide, 2000). A 1996 Canadian study showed that the new generation antipsychotics could save C$8,000 per annum per patient by decreasing hospital admissions, length of stay and physician visits (Anderson, 1996). A 2001 Canadian study concluded that:

> 'Clozapine might save $38,879/year while producing 0.04 more QALYs . . . Clozapine appears to be a very cost-effective therapy in patients with treatment-resistant schizophrenia compared with haloperidol and chlorpromazine.' (Iskedjian et al, 2001).

There is also evidence that clozapine is associated with a reduction in suicide attempts (Meltzer, Anand and Alphs, 2000).

[10] For more information on atypical anti-psychotics see SANE Australia (2000b).

[11] "*Novartis adds heart warning to Clozaril*", 1 April 2002, on www.psychminded.co.uk/news

Third wave anti-psychotics: New drugs for treatment of schizophrenia are currently in clinical development[12]. These aim to better identify protein and gene abnormalities in the brain, with more targeted molecular interventions (University of Maryland, 1999). The hope is to further reduce side-effects and increase the ease of administering in home and community care settings, to improve compliance rates.

2.3.3 Medical, family and other psychosocial interventions

In addition to medication, effective treatment for schizophrenia includes ongoing clinical support (primary care, psychiatric, hospital and community services), education about the illness and how to deal with it, psychosocial rehabilitation, accommodation support, and a range of other services. Carers also need accurate, easily understood information about medication and other aspects of treatment, so they are best able to support the person with the mental illness to lead as independent a life as possible.

Doctors: In Australia, 75% of ***GPs*** care for people with schizophrenia, two thirds of whom being in shared care with mental health services (Carr et al, 2002a). Carr found that people with schizophrenia being treated by a GP have fewer symptoms, better functioning and lower service use than those treated by community mental health clinics (direction of causation not speculated). The AIHW (2002, p14) found that 5% of schizophrenia problems managed by GPs were referred on to private psychiatrists, the highest on-referral of all mental disorders (depression was second at 3.4%). ***Psychiatrists*** are referred to for specialist schizophrenia diagnosis, in acute cases and for ongoing treatment with the GP and/or other carers.

Community mental health services: These include all specialised public community-based residential and non-residential psychiatric services, excluding services for admitted patients. Residential services are 24-hour staffed units established in community settings that provide specialised treatment, rehabilitation or care for people with schizophrenia or other psychiatric disability. Non-residential services provide assessment, treatment, rehabilitation and care for non-admitted patients (AIHW, 2002). Models of 24-hour supported accommodation services and their costs are outlined in SANE Australia (1997). The increasing reliance on community mental health services and social supports goes hand in hand with briefer and fewer hospital admissions.

> *'It is now regarded as preferable for people to be treated in their home surroundings under the care of a Community Mental Health Service, with a specialist local clinic and mobile teams of mental health workers available ideally 24 hours a day. If needed, longer term support providing help with day-to-day activities may also be available, and is often supplied by community organisations.'*
> *SANE Australia (2000a), p36*

Hospitalisation is necessary in acute cases of schizophrenia, with the first episode, during relapse and when risk of suicide (or risks to others) is high. The LPDS found that in Australia over half of people with psychotic illness had used inpatient services in the year prior to the study, and that hospitalisation was voluntary in over half of admissions. Most admissions were to a psychiatric unit in a general or psychiatric public hospital, with 16% to general medical facilities, 7.5% to private inpatient facilities and 2.6% to public drug and alcohol units. The average length of stay (ALOS) in hospital for schizophrenia and schizoaffective disorder patients was 16 weeks (the highest of all psychotic disorders)—the median was lower as the distribution is skewed by a small proportion of very long stay patients (Jablensky et al, 2000). The ALOS is tending to reduce Australia-wide – most hospital stays are trending to 1-2 weeks.

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[12] "*Titan Pharmaceuticals and Novartis announce Positive Results from Zomaril Phase III Clinical Trials*" 25 September 2000, on www.biospace.com. These Phase III trials of iloperidone (*Zomaril*) are being conducted at the University of Maryland School of Medicine and involve patients from more than forty centres in the US, Europe, Canada, South Africa and Australia.

With de-institutionalisation, **family interventions** are now viewed, in most cases, as a long-term support measure. The World Health Organization (Barbato, 1997) suggest that these interventions include:

– Engagement of the family in the treatment process in a 'no-fault' atmosphere;
– Education about schizophrenia – the 'vulnerability-stress' model, risk factors, variation in prognosis, rationale for various treatments, suggestions for coping;
– Communication (eg, listening skills, affirmation, conflict resolution) and problem-solving training (eg, goal setting); and
– Crisis intervention if necessary.

Psychoeducation and counselling (including cognitive behaviour therapy) has been found to be a useful approach in addressing misbeliefs (delusions) and in learning to adapt and not *respond* to hallucinations (as illustrated in the recent motion picture film 'A *Beautiful Mind')*. A Victorian clinical research project, *Cognitively Oriented Psychotherapy for Early Psychosis (COPE)* has focused on management of older adolescents and young adults experiencing their first episode of psychosis. The project analysed how the person was adjusting to the experience of a psychotic episode and the possibility of an ongoing vulnerability or continuing symptoms, the effects of this knowledge on self-perception, and the promotion of an adaptive recovery style from psychosis. The research forms part of strategies to prevent or manage secondary morbidity such as depression, anxiety and stigma – all influences on self-esteem – that may develop secondary to psychotic disorders.

Vocational rehabilitation traditionally provided through hospitals or clinics and later involving sheltered employment programs, has not been as successful as more recent developments such as disabled workers' cooperatives (Savio and Angelo, 1993), the creation of self-sufficient enterprises ('social firms') and supported employment programs.

'Rehabilitation and disability support are the most time consuming components of the management of long term illness.'
McGrath and Davies (1999)

Psychosocial rehabilitation *eg, through* ***day programs*** aims to achieve community integration, independence and rewarding relationships, using role playing, behaviour reversal, feedback and homework techniques, among others. SANE Australia's Gap Project, commissioned by the Commonwealth Government in 1998, found that there is a 'rehabilitation gap', with over 80% of those who might benefit from psychosocial rehabilitation not attending programs. The study found that in the great majority of cases (92%), psychiatrists did not refer for rehabilitation and indeed only 17% of people with a psychiatric disability attended programs.[13] 'Given the demonstrated effectiveness of rehabilitation, this represents an enormous opportunity to improve the quality of life and health outcomes of a great many people living with mental illness' (SANE Australia, 2001a, p5).

Rehabilitation refers to the services and technologies made available to disabled people so they might learn to adapt to their world and, as such, is different from *recovery,* which is the real life experience of people as they accept and overcome the challenge of disability. Rehabilitation has three stages – assessment, planning and intervention, with many positive benefits (see Section 3.4):

– reduction in the frequency and severity of symptoms;
– cost savings to public health systems;
– improved quality of life;
– respite for carers and support for the carer relationship.

There are a variety of approaches to providing rehabilitation. SANE Australia (2001a) details two broad approaches – the Livings Skills Centre approach and the Day Program approach, as well as principles for good practice in Australia. State health departments are now the main practical source of funding for programs.

[13] Only 19.1% of persons with psychosis in the LPDS reported participating in a rehabilitation or day hospital program in the previous 12 months (Jablensky et al, 1999).

There is still a great unmet need in Australia for all of these psychosocial interventions for people with schizophrenia. There is a lack of programs and a lack of choice, particularly outside the Sydney and Melbourne metropolitan areas.

2.4 Health and social impacts

The Australian Bureau of Statistics shows that, in just ***two weeks*** (prior to the National Health Survey 1995[14]), of all the people with self-reported psychoses:

- 3.1% were hospitalised;
- 13.0% visited casualty or outpatient clinics;
- 16.6% visited the doctor (GP and/or specialist);
- 15.1% visited another health practitioner;
- 53.8% used prescribed or over-the-counter medication, including 46% reporting use of anti-psychotics, 11% on anti-depressants and 8% on hypnotics/sedatives;
- 1.2% used natural remedies (herbal/vitamins etc);
- 8.9% had reduced activity days; and
- 2.3% took days off work or school due to their illness.

Table 2 show how Australians with psychoses are under-represented in the workforce, with extremely low participation rates – only 36.5%, less than half the 73.8% in the general population of working age (15-65 years). For those who seek work, unemployment rates are higher (and employment rates lower) for both males and females. As found in the LPDS study also and noted in Section 2.1.3 above, fewer than 30% are employed (only one third – 35% – of these full time) of which nearly 8% of work is lost due to absenteeism. 4.6% of the total were studying and 5.7% described home duties as their main occupation (Jablensky et al, 1999).

Table 2: Employment status by gender (aged 15-65)

	People with psychosis (%)			**Total population (%)**		
	Male	**Female**	**Total**	**Male**	**Female**	**Total**
Employed	33.4	23.6	29.6	76.9	60.3	68.7
Unemployed	7.6	5.8	6.9	6.4	3.9	5.2
Not in labour force	59.1	70.6	63.5	16.7	35.8	26.2
Total	*100*	*100*	*100*	*100*	*100*	*100*
Participation rate	*40.9*	*29.4*	*36.5*	*83.3*	*64.2*	*73.8*

Source: ABS NHS 1995.

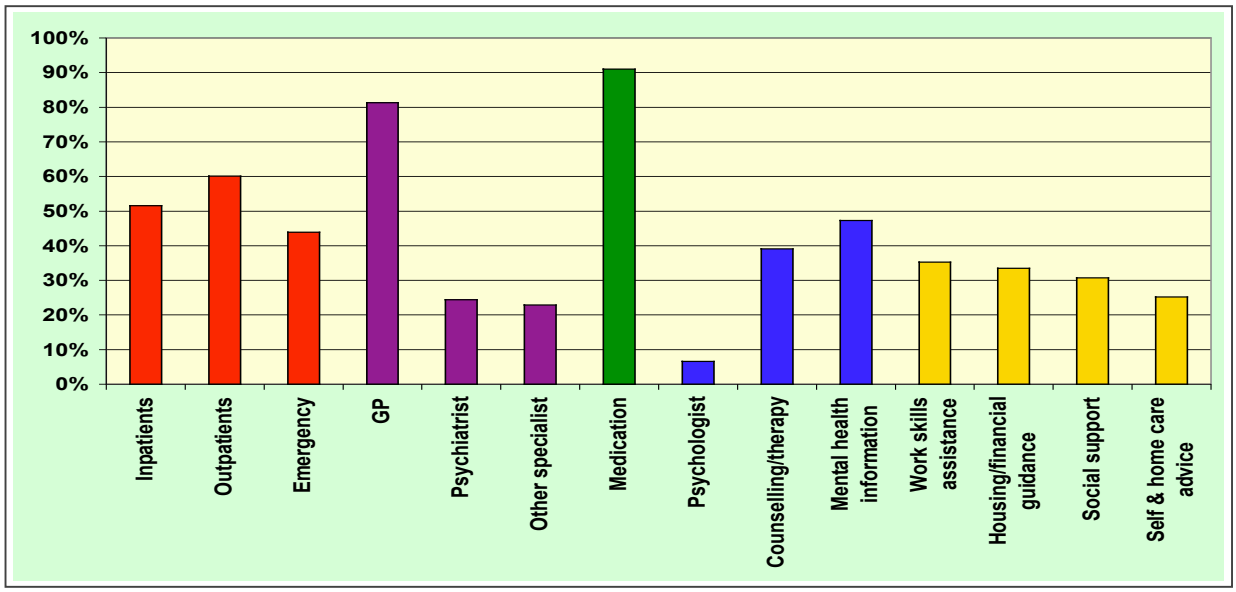
The LPDS also provides data on service utilisation for the full ***twelve months*** prior to the survey, finding (Jablensky et al, 1999) that for people with psychoses in Australia:

- 51.6% were inpatients at least once (in public or private hospitals or psychiatric units);
- 43.9% used emergency services (psychiatric and general);
- 22.6% of those using emergency services reported substance abuse/overdose or other self-inflicted harm;
- 60.1% used outpatient services (mainly community mental health clinics and psychiatric outpatient clinics in general hospitals) and the average number of outpatient attendances was 17 for schizophrenia;
- 90% of outpatients saw a doctor/psychiatrist; 33.6% saw a nurse; 16.1% saw a social worker; 12.7% saw a psychologist; 7.8% saw an occupational therapist and 0.8% saw a drug/alcohol counsellor;
- outside of inpatient and outpatient services, 81.3% saw a GP (an average of 12 times), 24.4% saw a private psychiatrist (most went at least six times in the year), 22.9% saw a medical/surgical specialist at least once, and 6.6% saw a private psychologist;

[14] Special ABS data request – schizophrenia cannot be separately identified from other psychoses (see Methodology).

– 91% received prescription medicines;
– 39% received counselling/therapy, 47% received mental health information, and 25%-35% received each of a variety of social services including help improving work skills, housing/financial and home/self-care advice and direct support, and;
– 13.2% had private health insurance (compared with a national average of 32%).

Figure 3: Health & social service utilisation for people with psychoses, Australia



Source: Derived from LPDS data, Jablensky et al (1999).

Since de-institutionalisation, most people with schizophrenia receive treatment for psychotic illness in the community. SANE Australia (1999a) reports that the vast majority value their independence, and want to live in and be part of the community to have the potential for greater normalcy of life. However, as the above data highlight, too many miss out on the community services and supports that they need:

– over half are not receiving information on mental health;
– nearly two thirds do not receive counselling;
– less than one fifth attend rehabilitation programs; and
– of the 91% who receive medication, one third are still on older, more toxic medications.

Hence, heavy demands are placed on crisis and emergency services, churches and non-government organisations (NGOs) because many have trouble getting clinical treatment or disability support. Table 3 shows impacts on social infrastructure and community networks as identified in the LPDS, with the Department of Social Security, churches and community organisations ranking highest and meeting needs best.

Table 3: Agencies contacted by people with psychoses and adequacy of service

Agencies contacted	**Contacted agency (%)**	**Needs met, if contacted (%)**
1. Department of Social Security	68.5	87.0
2. Church	36.7	85.8
3. Other community organisations *(Salvation Army, St Vincent de Paul, Red Cross)*	25.8	88.5
4. Commonwealth Employment Service	25.4	57.4
5. Government department: Housing	24.5	70.8
6. Mental health self-help organisations	17.3	72.9
7. Government department: Legal Aid	14.9	62.3
8. Community counselling services	12.8	64.0
9. Local council	11.9	59.8
10. Government department: Community Services	8.8	47.7
11. Ethnic services	5.8	36.8
12. Family Court counsellors	4.7	15.2
13. Government department: Veterans' Affairs	4.3	11.9

Source: Jablensky et al (1999), p55.

3 Prevalence and Direct Health Costs

3.1 Prevalence of schizophrenia

The World Health Organization ten-country study showed an incidence rate of schizophrenia (new cases per year) of between 0.1 and 0.4 per 1000 population (Jablensky et al, 1992). Lifetime prevalence – the number of people in the population who will suffer from schizophrenia in their lifetime – ranges between 1 and 18 per 1000, hence the commonly quoted statistic that schizophrenia affects 'about 1% of the population.' One-year point prevalence is lower, in the range between 1 and 7.5 per 1000 (Warner and de Girolamo, 1995). A summary of international prevalence studies is provided in Jablensky et al (1999).

Based on the WHO prevalence ranges, lifetime prevalence estimates for schizophrenia in Australia may likely be around 194,213 (10 per 1000) or possibly even up to 349,583 (18 per 1000, the upper limit) in 2001. As far as cost of illness is concerned, one-year prevalence is more important. A current picture of schizophrenia one-year prevalence by demographic group can be obtained by reconciling the ABS National Health Survey and the LPDS data, and extrapolating to 2001 (see Methodology). Results are shown in Table 4.

Table 4: Prevalence of schizophrenia by gender and age, 2001

People	**Male**	**Female**	**Total**
under 18	1,576	553	2,129
18-24	1,922	728	2,650
25-44	12,819	5,878	18,698
45-64	4,653	5,656	10,309
Total 18-64	*19,394*	*12,262*	*31,657*
Over 65	843	2,603	3,447
Total	***21,814***	***15,419***	***37,233***
Rate per 1000 pop'n			
under 18	0.65	0.24	0.45
18-24	1.97	0.78	1.39
25-44	4.35	1.99	3.17
45-64	2.07	2.55	2.31
Total 18-64	***3.14***	***2.01***	***2.58***
Over 65	0.80	1.94	1.43
Total	***2.26***	***1.58***	***1.92***

Source: Access Economics estimates based on NHS and LPDS data.

Table 4 shows that the prevalence of schizophrenia is highest in males aged 25-44. Males have higher prevalence in the younger age groups, while females have higher prevalence in the older age groups. Two possible contributing factors here are (1) the later onset for females of the disease, and (2) higher mortality of males due to suicide and other causes of premature death.[15] Overall, the prevalence for males is higher (2.3 per 1000) than for females (1.6 per 1000). Across the whole population, the one-year point prevalence in Australia is estimated at 1.9 per 1000, while in the working age population, the one-year point prevalence is 2.6 per 1000.

The ABS National Health Survey also looked at the prevalence of psychoses in rural and urban areas. Table 5 shows the distribution in urban centres (with a population over 100,000), and in the rural/remote remainder of the State/Territories). People with psychoses are over-represented in the urban centres. However, more disaggregated data would be useful here (eg, by RRMA).

[15] The more stable nature of the illness in females may also suggest some bias towards statistical under-reporting of females from the two data sources (see Methodology). Hence the male: female ratio may be closer to parity in reality.

Table 5: Rural-urban distribution of psychoses

	% with psychoses	% general population
Urban	87.1	84.8
Rural/remote balance	12.9	15.2
Total	*100*	*100*

Source: ABS NHS 1995.

3.2 Prevalence of suicide related to schizophrenia

Across the world, over a million people will die this year from suicide. It is one of the top ten causes of death in every country. The psychological, social and financial impact of suicide on the family and community is immeasurable. On average, a single suicide intimately affects at least six other people but can affect hundreds if it occurs in a public place.

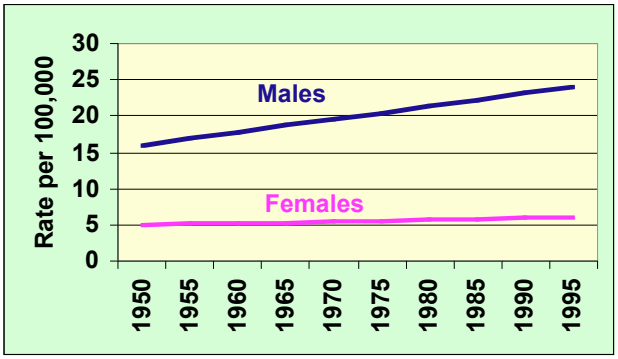
In 1998, the World Health Organization estimated suicide to be responsible for 1.8% of the total global burden of disease and injury and 2.3% in high-income countries like Australia – equal to the burden due to wars *and* homicide, and roughly twice the burden of diabetes (WHO, 2000).

'5-10% of all suicides are attributable to schizophrenia.' US Office of Technology Assessment

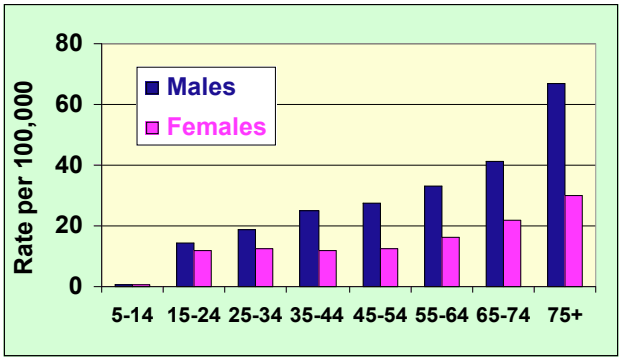
It is estimated that 5-10% of *all* suicides are attributable to schizophrenia (OTA, 1992). Worldwide, that equates to up to 100,000 deaths this year, as a result of the disease. Among people with the disease, suicide is the number one cause of premature death. In the US, the Office of Technology Assessment (OTA) estimates the age-adjusted suicide rate as 90 per 100,000 for women and 210 per 100,000 for men, chilling evidence of the distressing nature of the disorder. The higher rate of suicide among men with schizophrenia may be due in part to greater severity of symptoms for men as well as mirroring the general profile of completed suicide in the population, where men tend to use firearms and other means with higher probability of a lethal outcome.

Figure 4 shows the growth in world suicides and the age and gender distribution, with more young people now ending their lives than ever before – in 1950, 44% of suicides were by people under 45; but by 1995, 53% were in this age-group.

Figure 4: Increase in world suicide rates and demographic distribution



Left: Increase in rates, 1950-1995.
Source: WHO (2002).

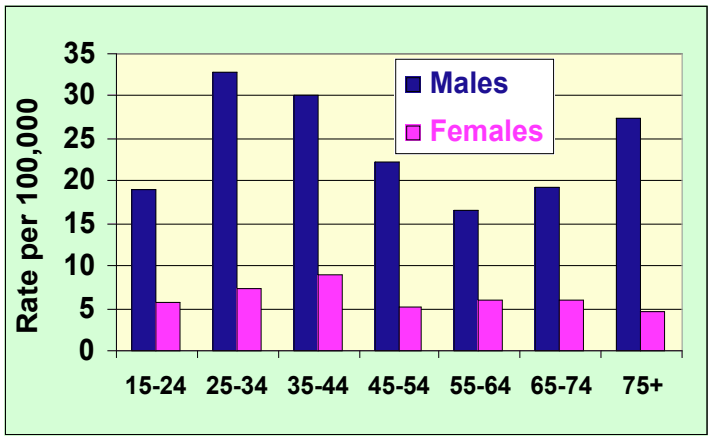


Right: Age-gender distribution, 1995.

In Australia, 1.8% of all deaths are due to suicide (ABS, 2001). The human and economic costs are enormous – apart from the loss of life, there are health care costs associated with attempted suicide and the circumstances surrounding death can be particularly difficult for family and friends.

In 2000, ABS data shows there were 2,363 suicides in Australia – 12.2 deaths per 100,000 Australians. 503 of these deaths were women and 1,860 (nearly four times as many) were men. Half the deaths were of Australians aged 25-44. The higher prevalence for the 25-34 year olds (20.1 per 100,000) and for 35-44 year olds (19.6 per 100,000) is shown in Figure 5. The age profile of suicide rates in Australia is quite different from that of the world as depicted in the previous Figure 4.

Figure 5: Suicide rates, Australia, by demographic group, 2000



Source: Derived from data in ABS (2001).

Table 6 over the page shows the proportions of deaths by suicide of total deaths in each age group, and the differences across States and Territories. The highest suicide rate in Australia is in the Northern Territory (20.1 per 100,000) and the lowest in the ACT (8.9 per 100,000). In young men aged 25-34 years, suicide accounted for over one quarter of all deaths. Hanging and shooting are the most common forms of suicide by young males; poisoning and hanging are the most common for Australian women (Harrison et al, 1997).

Table 6: Suicides, Australia, 2000 by state/territory and as % total deaths

Suicides as a % of total deaths by age-group in years and gender			State/ Territory	Suicides per 100,000
			ACT	8.9
	Males	**Females**	NSW	11.0
15-24	22%	16%	NT	20.1
25-34	26%	15%	QLD	15.2
35-44	18%	10%	SA	13.1
45-54	7%	3%	TAS	11.4
55-64	2%	1%	VIC	10.5
65+	<1%	<1%	WA	13.7

Source: Derived from data in ABS (2001).

Admission to hospital because of intentional self-injury is about ten times more common than death due to suicide in the 15-24 age group – nearly 4000 young Australians in 2000 were hospitalised. The ratio of admissions to deaths is much higher for females (34 to 1) than for males (5 to 1), and 3 females are admitted for self-injury for every 2 males. Poisoning is by far the greatest reason for hospitalisation, followed by cutting/piercing (Harrison et al, 1997).

Deaths by suicide for young males is now of the same magnitude as deaths due to motor vehicle accidents. As with the global trend shown in Figure 4, male suicide rates have been rising in Australia since WWII, with rates for females doubling in the early 1960s (epidemic of sedative suicides), but fairly constant after that. Aboriginal suicide rates are higher than the average, especially in the younger age groups.

Given these Australian suicide rates, the prevalence of schizophrenia in Australia, and the increased risk of suicide with schizophrenia, the number of suicides due to schizophrenia is conservatively estimated for 2001 as shown in Table 7. The total is 129 deaths, of which 104 were males and 25 females. Nearly half were males in the 25-44 group.

Table 7: Suicides due to schizophrenia, Australia, 2001

People	**Males**	**Females**	**Total**
under 18	5	1	*6*
18-24	9	2	*11*
25-44	59	12	*71*
45-64	22	6	*28*
Total 18-64	***90***	***20***	***110***
over 65	10	3	*13*
Total	***104***	***25***	***129***

Source: Access Economics estimates.

3.3 Direct costs of schizophrenia: 2001

The Australian Institute of Health and Welfare has utilised DCIS prevalence-based methodology to estimate direct costs of disease in 1993-94. This report extends and projects the AIHW work to estimate those costs attributable to schizophrenia in CY2001 (Table 8). The methodology is detailed in the Appendix.

Table 8: Direct costs of schizophrenia & other mental disorders, Australia, 2001

$ million	**Hospital**	**Medical**	**Pharma-ceuticals**	**Other health services**	**Other**	**Total**	**% of Total**
Dementia	158	16	3	13	837	1,027	23.6%
Affective disorders (inc. depression)	312	203	98	101	213	926	21.3%
Schizophrenia and SAD	**395**	**37**	**12**	**152**	**58**	**653**	**15.0%**
Substance abuse disorders	196	66	17	26	196	500	11.5%
Anxiety disorders	35	147	73	36	53	344	7.9%
Behavioural syndromes & other mental disorders	24	76	65	13	72	250	5.8%
Other non-drug psychosis	91	7	1	9	76	184	4.2%
Stress and adjustment disorders	40	39	10	45	27	161	3.7%
Disorders of childhood and adolescence	14	13	1	27	23	79	1.8%
Other mental disorders, prevention & screening	88	27	4	60	42	221	5.1%
Total	***1,353***	***631***	***285***	***482***	***1,596***	**4,345**	**100.0%**

Source: Access Economics based on AIHW (1999b).

Health system costs of schizophrenia including schizoaffective disorder (SAD) are estimated at $653 million in 2001. Table 8 shows that this means schizophrenia ranks as the third highest cost mental illness in Australia, after dementia and affective disorders (including depression), absorbing 15% of total spending on mental health. Schizophrenia also has the highest hospital costs of all mental illnesses ($395m or 29.1% of the total), and the highest cost of 'other health services' including community health services ($152 million or 31.5% of the total).

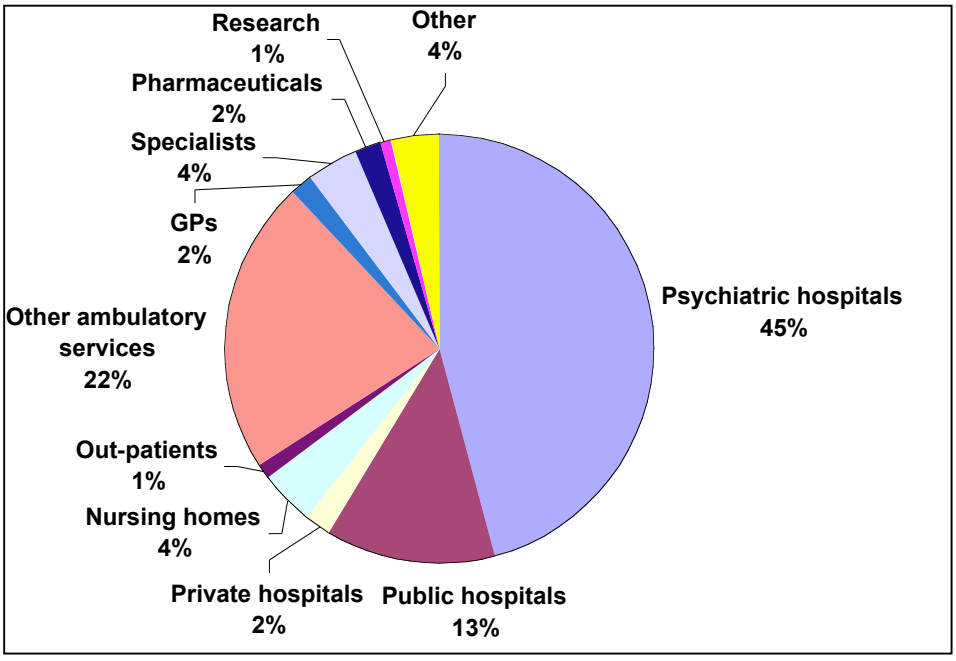
Table 9 and Figure 6 show the breakdown of cost components for schizophrenia. Psychiatric hospital costs dominate the profile at $299m (46% of the total). Second are other ambulatory services (including community mental health centres) at $145m (22%) followed by public hospital services at $83m (13%). Other big-ticket items are nursing home costs ($28m) and specialists – mainly psychiatrists ($26m). Private hospitals ($13m), pharmaceuticals ($12m) and GP costs ($11m) are relatively small. Only $6m was spent on research. Other costs (mainly administration) absorbed $23m.

Table 9: Components of direct health costs for schizophrenia, 2001.

Direct health cost	$m	% of total
Psychiatric hospitals	299.3	45.8%
Other ambulatory services	144.9	22.2%
Public hospitals	82.8	12.7%
Nursing homes	28.2	4.3%
Specialists	26.2	4.0%
Private hospitals	12.8	2.0%
Pharmaceuticals	11.7	1.8%
GPs	10.6	1.6%
Out-patients	7.1	1.1%
Research	6.1	0.9%
Other	23.4	4.0%
Total	***653.1***	***100.0%***

Source: Access Economics, based on AIHW special data request.

Figure 6: Components of schizophrenia costs, Australia, 2001



Source: Access Economics based on AIHW special data request.

The cost of suicide attempts and self-inflicted injury also imposes costs on the Australian health system. In 2001 the estimated cost of these was $104 million or 3% of the cost of all Australian injuries and accidents (see Table 10).

The cost of suicide and self-inflicted injury directly attributable to schizophrenia (including SAD) is an estimated $6 million, including $4 million in hospital costs in 2001.

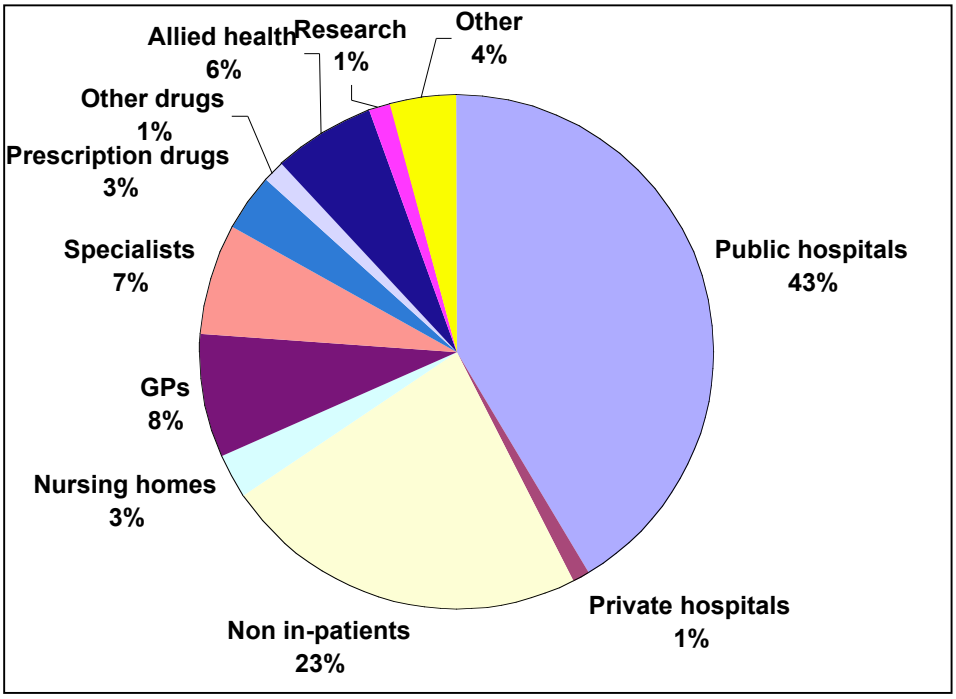
The importance of hospital costs is illustrated in Figure 7, which shows hospitalisation represents two thirds of the direct health costs of suicide attempts and self-injury.

Table 10: Direct costs of suicide and other injuries, Australia, 2001

$ million	**Hospital**	**Medical**	**Pharma-ceuticals**	**Other**	**Total**	**% of Total**
Accidental falls	720	161	46	239	1,165	31.1%
Road traffic & transport accidents	387	95	27	108	618	16.5%
Adverse effects of medical treatment	431	55	33	62	579	15.5%
Homicide and violence	104	35	10	29	180	4.8%
Suicide and self-inflicted injury	**69**	**16**	**6**	**16**	**104**	**2.8%**
Accidental fires, burns and scalds	59	12	4	6	79	2.1%
Machine accidents	39	12	3	10	63	1.7%
Accidental poisoning	29	1	1	4	37	1.0%
Accidental drowning	4	1	-	1	9	0.2%
Other unintentional injuries	548	178	52	125	906	24.2%
Total injury and poisoning	***2,390***	***565***	***183***	***600***	***3,740***	**100.0%**
Schiz'a-related suicide & self-inflicted injury	*4*	*1*	*0*	*1*	*6*	*0.15%*

Source: Access Economics based on AIHW (1999b).

Figure 7: Components of suicide costs, Australia, 2001



Source: Access Economics based on AIHW (1999a).

In estimating the full health system costs of schizophrenia, there is an additional small element for prevention and management ($2m), which forms part of the 'Other mental disorders, prevention & screening' category in Table 8.

In summary, Access Economics estimates the total health system costs for schizophrenia (including SAD) were $661m in 2001, comprised of:

- direct health system costs of $653m;
- suicide and self-inflicted injury related to schizophrenia ($6m); and
- suicide prevention and management ($2m).

This is $17,740 per person with schizophrenia – *6.3 times the spending on the average Australian's health care*. Nonetheless, direct health costs are conservatively estimated, coming in at 1.2% of national health system costs, while the WHO estimates this ratio globally at between 1.6% and 2.6% (Barbato, 1997), with 75% of the direct costs in inpatient or residential care and less than 5% on pharmaceuticals (64% and

1.8% in this study of Australia). By way of comparison, pharmaceutical spending has been estimated as 1.1% in the Netherlands, 1.6% in the UK, 2% in the Netherlands and 2.5% in the US (De Hert et al, 1998).

Upside risk[16] on pharmaceuticals: There is particular upside risk on the cost estimate of pharmaceuticals spending in this analysis, as the PBS listing and take-up of atypical drug therapies has not yet had flow-through effects to the official data. Carr et al (2002c), based on 'bottom-up' analysis as opposed to the 'top-down' DCIS methodology, estimates that medication for all psychotic illness in Australia may be now be as high as $44.5 million, implying the pharmaceutical cost attributable to schizophrenia and SAD would be around $28.7m or 4.3% of what would then be a higher direct cost of $670 million. Although this would be considerably out of line with the international comparisons above, it is possible that international proportions may now also be higher for the same reason. If drug costs are indeed this high now, then the cost per person with schizophrenia would increase to $17,999 on average.

3.4 Projections to 2011

3.4.1 Prevalence of schizophrenia and schizophrenia-related suicides

Based on demographic growth of cohorts, the prevalence of schizophrenia will increase by 10.7% (nearly 4,000 additional people with the illness) to 41,230 over the coming decade. 38% of this increase – 1,526 people – occurs in the cohort of 45-64 year old women with schizophrenia; this cohort grows 27% over the period. There is also projected strong growth in the over-65 group, in line with population ageing, but from a much lower base. Table 10 shows an estimated extra 304 men aged 25-44 with schizophrenia by 2011 (with growth slowing because of lower fertility rates).

Table 11: Projected prevalence of schizophrenia, Australia, 2011

	Prevalence 2011 Schizophrenia (inc. SAD)			Prevalence growth 2011:2001		
People	**Male**	**Female**	**Total**	**Male**	**Female**	**Total**
under 18	1,550	543	2,092	-1.7%	-1.8%	-1.7%
18-24	2,015	763	2,779	4.9%	4.8%	4.8%
25-44	13,123	5,966	19,060	2.4%	1.5%	1.9%
45-64	5,778	7,182	12,945	24.2%	27.0%	25.6%
Total 18-64	*20,916*	*13,912*	*34,783*	*7.8%*	*13.4%*	*9.9%*
over 65	1,105	3,194	4,355	31.0%	22.7%	26.3%
Total	**23,571**	**17,648**	**41,230**	**8.1%**	**14.5%**	**10.7%**

Source: Access Economics projections.

Suicides related to schizophrenia are estimated to grow in line with the prevalence of the illness itself. Hence six of the additional 14 annual suicides will likely be males aged 25-44, as illustrated in Table 11.

Table 12: Projected schizophrenia-related suicides, Australia, 2011

	Schizophrenia-related suicides, 2011			Change in suicides, 2011:2001		
People	**Males**	**Females**	**Total**	**Males**	**Females**	**Total**
under 18	5	1	6	1	0	1
18-24	10	2	13	1	0	1
25-44	65	13	78	6	1	8
45-64	24	7	31	2	1	3
Total 18-64	*99*	*23*	*122*	*10*	*2*	*12*
over 65	11	4	15	1	0	1
Total	**115**	**28**	**143**	**11**	**3**	**14**

Source: Access Economics projections.

[16] 'Upside risk' means that estimates are more likely to be under-estimated (conservative) than over-estimated, based on sensitivity analysis of factors that may be different from those assumed.

3.4.2 Projected direct health costs

Projected growth in health care costs (based on trends in the Health and Community Services GDP deflator) together with greater prevalence, will lead to significantly higher costs of treating schizophrenia by 2011 (see Methodology). All other things being equal, the direct health system costs of schizophrenia will grow 61% to $1.06 billion over the coming decade. Table 12 shows a breakdown of projected costs for 2011, with the main burden on the hospital system. Psychiatric hospital costs alone would approach $500 million.

The health care costs of schizophrenia are estimated to exceed $1 billion p.a. this decade.

Table 13: Projected components of direct health costs for schizophrenia, 2011

			Change
$ million	**2001**	**2011**	**2011:2001**
Psychiatric hospitals	299.3	481.1	181.8
Public hospitals	82.8	133.1	50.3
Private hospitals	12.8	20.5	7.8
Nursing homes	28.2	45.3	17.1
Out-patients	7.1	11.4	4.3
Other ambulatory services	144.9	232.9	88.0
GPs	10.6	17.0	6.4
Specialists	26.2	42.2	15.9
Pharmaceuticals	11.7	18.8	7.1
Research	6.1	9.9	3.7
Other	23.4	37.6	14.2
Total	*653.1*	*1,049.8*	*396.7*
Suicide/self-injury	5.7	9.1	3.4
Preventive costs	2.0	3.3	1.2
Full cost schizophrenia	***660.8***	***1,062.2***	***401.4***

Source: Access Economics projections.

The rogue variable is *pharmaceutical spending*, which may increase as the third wave drugs come on-line. However, this would be expected to have an offsetting effect on other medical costs, in particular hospitalisations.

Another important variable in projections is the policy response to the current inadequacies of *accommodation and rehabilitation programs*. If spending on these components is addressed in a significant way, there may be compositional and other effects on projected direct costs. A number of studies offer evidence of mental health and indirect cost savings from psychosocial rehabilitation, flowing from better health outcomes that diminish demand for clinical services and increased the likelihood of gaining employment. The Adelaide Study, conducted for the South Australian Health Commission, identified a range of savings including reduced frequency of psychiatric appointments (Ireland and Morgan, 1996).

Similarly, interventions such as *carer education and training* as well as early intervention and preventive programs have enormous potential to alter the cost structure and overall burden of schizophrenia in the years ahead (see Section 4.2). *Early intervention* is particularly important with schizophrenia, as the deterioration process almost always occurs in the early phases of the illness, which may last up to five years after the initial psychotic episode. Lieberman (1997) interprets recent research as suggesting that the active psychotic phase of the illness may signal an underlying pathological process that further injures the brain and, if not treated in time, can be irreversible.

In Australia, the Early Psychosis Prevention and Intervention Centre (EPPIC) in the western metropolitan region of Melbourne, has been able to demonstrate the cost-effectiveness of their model of early intervention and care for people aged 16 to 25 with emerging psychotic disorders. The average cost of one year of treatment for the non-EPPIC (general) patients was $24,074 but for EPPIC patients that cost was only $16,964 (70%). Treatment outcomes were far better in the EPPIC sample even when less money was used. For an average of $1,081, EPPIC patients' entry level SANS score decreased from 34.5 to 18.1 after 12 months. On the other hand, for an average cost of $12,671, non-EPPIC patients' entry level SANS score decreased from 29.7 to only 27.8 after 12 months. The implication is that future early intervention programs will be able to show cost effectiveness both by a reduction of costly inpatient and other services as well as an improvement in productivity through treatment outcomes that permit return to vocation or schooling.[17]

As highlighted in Chapter 5, these are important conclusions with implications for future policy directions.

[17] See 'Economic Impact of Schizophrenia' on www.mhac.org

4 Indirect Costs and Burdens

In addition to the direct health system costs estimated in the previous chapter, there are two types of indirect costs of schizophrenia estimated in this chapter:

– financial costs, which include earnings forfeited due to the illness, carer costs, welfare costs and the costs of criminality, each estimated individually; and
– non-financial costs from loss of healthy life – the pain, premature death and loss of life quality that results from the diseases; these are more difficult to measure, but can be analysed in terms of the years of healthy life lost, both quantitatively and qualitatively, known as the 'burden of disease'.

4.1 Loss of earnings

Lower participation/employment: People aged 15 to 64 years with psychosis have lower rates of employment than healthy people of the same age (as noted in Section 2.4), due to the functional disability of psychotic illness. Table 2 showed the employment rate for those with psychosis as 29.6% compared to 68.7% in the general population. If people with schizophrenia achieved the same employment rate, *ceteris paribus* there would have been an extra 13,210 people in the workforce in 2001, earning an average of $668 per week (see Methodology). This would have produced $459.8m in extra income.

This figure is a conservative estimate of the true loss as many people may reduce their workload rather than stop work completely, as a result of the health impacts of schizophrenia. Income losses of *carers* of people with schizophrenia who reduce or give up work in order to care for the person with the illness are identified in the next section.

Absenteeism: There were an estimated 10,001 people employed with schizophrenia in 2001, earning an estimated $348m. The LPDS showed that people with schizophrenia who work lose on average 8% of their work time due to their illness, amounting to $27.8m of lost production in 2001.

In total then, the loss of earnings from loss of employment and absenteeism is estimated for 2001 as $487.6m.

Potential tax revenue foregone: There are two sources of lost tax revenue that result from the lower earnings above—the potential income tax foregone and the potential indirect (sales) tax foregone. The latter is lost because, as income falls, so does consumption of goods and services. Table 14 summarises the tax losses of $138m in 2001, comprising $100m (72.5%) of personal income tax and $38m of indirect tax (27.5%).

Table 14: Potential earnings and tax revenue lost due to schizophrenia, 2001

Potential Earnings Lost	**$488 million**
Average personal income tax rate#	20.45%
Potential personal income tax lost	$100 million
Average indirect tax rate#	15.18%
Potential indirect tax lost	$38 million
Total potential tax revenue lost	**$138 million**

Source: AEM Model, Access Economics.

Mortality burden: In addition to the income foregone due to those with schizophrenia in the community who are unable to work due to their illness, there is also the income foregone of those who have died. This section provides an estimate of this 'mortality burden' of suicides related to schizophrenia, assuming that if those who died had lived and not had the illness, they would have been employed at the same rate as the general population (79 people in all). The average age of suicide is estimated as 34.7 years (i.e., with 30.3 years to retirement) and the income stream is discounted at the average real growth rate in AWE (0.8%

p.a.). This yields the net present value (NPV) of the mortality burden as $94.3 million. The NPV of taxation revenue sacrificed for the mortality burden is $26.6 million.

4.2 Carer costs

> *'As a result of the shift in delivery of mental health services from institutions to the community, much of the burden of care now falls on families.' McGrath and Davies (1999)*

The majority of people with schizophrenia receive treatment at home, rather than being long-stay hospital inpatients. Section 2.3 discussed the psychiatric and other mental health services that these people access through their community centres and GPs. The provision of day-to-day care and support, however, is left very much to family and friends (Schene et al, 1996). Society, and our public sector health and welfare budget, relies increasingly on the support that such carers provide.

Carers Australia estimates there are at least 2.3 million Australians (one in every five households) providing care for family members or friends with a disability, chronic condition or who are frail aged. Nearly 20% (450,900) of these are 'primary' carers, of which 70% are female. Conservative estimates show that the 'invisible workforce' saves the economy $16 billion annually and is the major provider of community care services, delivering 74% of all services to people needing care and support. The Home and Community Care (HACC) Program, worth over $800 million nationally, meets only 9% of this need.

Most primary carers (78%) are of workforce age (aged 18 to 64 years) yet paid work is usually not possible – 59% are not attached to the workforce. Over one-half of all full time carers reported incomes of less than $200 per week, while also experiencing the increased expenses of looking after another person. Forty percent of primary carers have been providing care for a decade or more, and 68% for more than 5 years. Care is mostly for a partner (43%), child (25%) or parent (21%), and most primary carers (54%) said that they provided care either because alternative care was unavailable or too costly, or because they consider they have no choice. Carers suffer from generally worse physical health, tiredness, stress, back/muscle problems, depression, anxiety and lack of respite.[18] For carers of people with schizophrenia, specific stressors according to Queensland researchers McGrath and Davies (1999) may include:

- mourning the loss of hopes and plans for the person with schizophrenia;
- feeling ashamed of the illness and possibly guilty that they may in some way have contributed to it;
- difficulty dealing with the demanding behaviours of the person and, at times, even being afraid for their own safety;
- fear of leaving the person alone, of taking holidays or having visitors to stay; and
- strain on marriages.

There can also be substantial effects on siblings of people with schizophrenia, as the illness impacts on the whole family. Siblings may experience stress-related problems, guilt, anger, pressure to do well, and isolation/shame (eg, in relation to bringing friends home), as well as other issues. Whole family therapy may be indicated.

Counselling, education, support and respite services are essential for carers, result in improved health outcomes for people with schizophrenia, and reduce demand on clinical mental health services, especially hospitalisations. The cost-benefit ratio of the two-year education and training multiple family group (MFG) program described by McFarlane et al (1995) showed:

- significant reduction in psychotic symptoms and episodes;
- significant reduction in relapse rates (16% cf. >65%); and
- cost-benefit ratio of 1:34 – for every dollar spent, $34 was saved in mental health costs overall.

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[18] Sources: AIHW, *Australia's Welfare: 1999 Services and Assistance;* Carers Australia, *Caring Costs*, 1998, Australian Bureau of Statistics, *Disability, Ageing and Carers: Summary of Findings*, 1998. Cited on Carers Australia website.

A comprehensive assessment of carer costs in Australia would require detailed survey work to assess the needs for care of all levels of people with schizophrenia. Even mild illness, characterised by low motivation and functional limitation, can present difficulties across the spectrum of self-care – personal hygiene, cleaning, cooking, washing, shopping and house/garden maintenance. Wherever these tasks are outsourced (to hired assistants, home services, and most often volunteer carers), the cost should be attributed as disease cost. Where disease severity is higher, with commensurate greater reliance on community services and volunteer carers, the value of the community service and income sacrifice of the carer plus the value of the carer's work in a paid setting should also be attributed as disease cost.

Carr et al (2002c) have used data from the LPDS to estimate the 'time-loss' costs of carers of people with psychoses as $51.5m, using a conservative approach. The methodology used here is not quite so conservative, imputing an element of lost income for carers who stay home to look after people with schizophrenia, plus the value of Carer Payment for those who receive it for people in their own homes. The Carer Payment ($205.25 per week in 2001) is a means-tested government payment to people who provide full-time care to a person at their home (but not necessarily living with them). These values are shown in Table 15 below.

Table 15: Value of carers of people with schizophrenia, 2001

People with carers at home (9.3%, LPDS)	3,463
Carers who may work otherwise (68.7%)	2,379
Carers lost earnings @ AWE	$82.8m
Tax foregone on carers' earnings	*$23.4m*
Carer payment (LPDS, 1% of total)	$5.3m
Total cost of carers	***$88.1m***

Source: Access Economics estimates utilising LPDS and ABS data.

The costing in Table 15, of $88.1m in 2001, is still on the low side, as it ignores the many hours of care that is not provided full-time or not by 'designated carers at home'. It also ignores the many hours of care provided by goodwill non-government organisations – churches and others – which is valued by Carr et al (2002c) as a further $7m for all psychoses.

4.3 Cost of welfare payments

Eighty-five percent of people with psychoses in Australia are reliant on welfare benefits as their main source of income (Jablensky et al, 1999). The Disability Support Pension is received by 79% of those on a benefit, Newstart or other unemployment benefits by 11.8% and Sickness Allowance by 5%.

Disability support pension
The disability support pension is the main means of income support in Australia for people who have disabilities that preclude them from supporting themselves by paid employment. The pension provides income support for people aged 16 years and over whose physical, intellectual or psychiatric impairment prevents them from working, or for people who are permanently blind.

Sickness Allowance
This allowance provides assistance for people who are employed and who are temporarily unable to work due to a medical condition or, in some situations, unable to continue their full-time study.

Newstart Allowance, Youth Allowance and Work for the Dole
- *Newstart Allowance* is the main means of income support in Australia for people who are unemployed and aged over 21 or people who are temporarily unable to work due to illness, injury or disability, to assist them while they are looking for work and allow them to participate in activities designed to increase their chances of finding work.
- *Youth Allowance* helps young people aged 16-24 who are full-time students or those aged under 21 who are undertaking training, looking for work, or sick.

– *Work for the Dole* aims to improve employment prospects by providing opportunities for work experience in local community projects such as heritage, the environment, community care, tourism, sport and restoring and maintaining community services and facilities. Work for the Dole may be voluntary or compulsory in some situations, and is remunerated an extra $20.80 per fortnight.

Table 16 provides a summary of the costs to government attributable to each of these transfer payments for people with schizophrenia. The largest item is of course the Disability Support Pension at $250m, and Sickness Allowance payments total $15m. Unemployment payments are only $9m, reflecting the fact that, although there were 3,734 people with schizophrenia on Newstart or other unemployment benefits in 2001, only 920 were 'extra' to the number expected due to the general population unemployment rate. Total welfare payments estimated here are $274m.

Table 16: Cost of welfare payments

	Disability Pension	**Sickness Allowance**	**Unemployment (Newstart etc)**
Weighted average payment p.w.	$191.85	$184.38	$184.38
Estimated #people on payment due to schizophrenia/SAD	25,002	1,582	920
Total cost ($m)	$250m	$15m	$9m
Total of welfare payments due to schizophrenia			***$274m***

Source: Access Economics estimates utilising LPDS data.

4.4 Cost related to forensic issues

Another aspect of the cost of mental illness is the cost related to forensic issues. Section 2.1.3 noted that people with psychoses are more at risk of criminality – both male and female prisoners are several times more likely to have psychosis than the general population. The over-representation of people with psychosis in the prison system has been studied in many countries, notably Fazel and Danesh (2002), who bring together the results of 62 international surveys. They conclude that, worldwide, one in seven prisoners in Western countries have psychotic illnesses or major depression and that the burden of treatable serious mental disorder is substantial – possibly with twice the number of patients with serious mental disorders in prisons compared to those in psychiatric hospitals. 'Given the limited resources of most prisons, however, it seems doubtful whether most prisoners with these illnesses receive appropriate care…' (Fazel and Danesh, 2002, p548).

The US National Advisory Mental Health Council estimates that, in the US, 40% of people with schizophrenia are not being treated on any given day, resulting in homelessness, victimisation, suicide, episodes of violence and incarceration. Of around 100,000 homeless people with schizophrenia in the US, quality of life is extremely poor, with 8% listing garbage cans as a primary food source and with many being victimised. Victimisation crimes against the mentally ill – including purse snatching, stealing disability cheques, rape and murder – may not be reported or actioned. People with untreated schizophrenia commit an estimated 500 homicides (2.5% of the total) each year in the US. Around 16% of the total prison inmate population have untreated mental disorders, with incarceration frequently for misdemeanour or felony charges caused by psychotic thinking. People with psychotic illness spend twice as much time in prison, and are more likely to die by suicide there. On average, each incarceration in the US costs US$50,000 p.a., including prison, court and police costs but not including the cost of damages to property, totalling a massive US$15 billion per year for all those with serious psychotic disorders (Treatment Advocacy Center, 2002).

The World Health Organization (2000) is concerned that inmates have higher suicide rates than their community counterparts – in pre-trial facilities suicide rates are ten times the outside population, and three times greater in facilities holding sentenced prisoners. Suicide is often the single most common cause of

death in correctional settings that often struggle with the problem of preventing suicide. Key contributing factors are untreated mental illness (particularly in young males with substance abuse) combined with the psychological stress impact of arrest and incarceration, poor access to mental health services, overcrowding and poor sanitation. There is a very high period of risk within the first 24 hours of being detained (especially if intoxicated) and a second period around the time of the court appearance, especially if a guilty verdict or harsh sentencing is anticipated. Other periods of risk are after 4-5 years of incarceration in older prisoners, especially after a conflict or family break-up, victimisation, or after a negative legal disposition such as loss of an appeal or denial of parole. Completed suicides tend to occur in isolation or segregation cells, mostly by hanging, often at night or on weekends when staffing is lowest. Key warning signs are voiced feelings of hopelessness, shame or guilt, and psychotic behaviour.

Prevention involves post-intake observation and monitoring strategies (eg, video surveillance), screening of high-risk inmates, training of and clear procedures for correctional staff, social interventions (eg trained 'inmate buddies'), removal of means (eg, eliminating hanging points in cells or dorms) and, very importantly, access to mental health treatment. WHO (2002, p10) concludes, 'criminal justice, mental health and health systems must be integrally linked in the service of suicide prevention in correctional settings… This may require multi-agency cooperative service arrangements with general hospitals, emergency services, psychiatric facilities, community mental health programmes and addiction programmes'.

In Australia, the Mental Health Research Institute of Victoria conducted a 1999-2000 study of the effects of deinstitutionalisation on criminal offending among people with schizophrenia. In collaboration with the Victorian Institute of Forensic Mental Health, two large groups were examined, one with people who were first admitted to treatment in 1975 – prior to deinstitutionalisation; the people in the second group began treatment after 1985 – when community care was becoming the norm. The findings showed a modest increase in total offending in those admitted in 1985 compared to 1975 but not, according to MHRI, out of line with general increases in criminal offending in community controls without schizophrenia. Rates of violent offending showed no significant increase between the 1975 and 1985 groups. Rates of offending were higher in people with schizophrenia than in community controls for every category of crime except sexual offending. Substance abuse in young men with the disorder accounted for much of the offending. The report concluded that:

> 'Mental health services face a real challenge in reducing the disturbed and sometimes criminal behaviour to which schizophrenia can, on occasion, contribute. Turning back the clock on deinstitutionalisation and returning to asylums is not the solution. Rather there needs to be more support and intensive treatment in the community for those at risk and more effective strategies for reducing alcohol and drug abuse in this vulnerable group.'

The LPDS found that 18% of people with psychotic illnesses reported being a victim of violence and 10% were arrested during the 12 months prior to the interview. Based on these figures, Carr et al (2002c) estimated legal costs at $1.44m in a year for all Australians with psychoses. Clearly this estimate excluded incarceration costs since none of the LPDS participants reported being imprisoned for the reported offences.

Table 17 estimates prison costs based on the prevalence of schizophrenia in the Australian prison population ABS (2002) – of which 93% are males – and applying to that the Fazel and Danesh average psychosis prevalence rates for females (3.7%) and males (4.0%). Of these, 64.5% (based on LPDS) are likely to have schizophrenia and schizoaffective disorder (SAD) – 500 males and 39 females. Total prison costs in 2001 were $1.265 billion (Productivity Commission, 2002) from which average costs per inmate – $56,341 – are derived. The total prison costs for males and females with schizophrenia and SAD are thus $28.2m and $2.2m respectively. An estimate can also be derived for the total prison, legal and police costs for the illness based on the American TAC data, which suggest the average cost per inmate in Australia for all these items would be over $96,000 and hence the total bill would be over $50 million.

Table 17: Prison costs of schizophrenia, 2001

	Males	Females	Total
All prisoners	20,960	1,498	22,458
Prevalence of all psychoses	3.7%	4.0%	
Prisoners with schizophrenia	500	39	539
Prison costs of schizophrenia	28.2	2.2	**30.4**
Prisons, legal & police costs	48.1	3.7	**51.8**

Source: Access Economics estimates utilising ABS (2002), Fazel and Danesh (2002), Productivity Commission (2002) and Treatment Advocacy Center (2002).

4.5 Burden of disease

In 2001, an estimated 153 Australians died from schizophrenia and from suicide related to schizophrenia. Thousands of others suffered from the disabling symptoms of psychotic illness and its pervasive impacts on loved ones.

Disease imposes burdens on people that go well beyond the financial costs. There is no objective way to ascertain a financial value for the pain, suffering and premature death from mental illnesses like schizophrenia, particularly over a lifetime. However, the internationally developed 'Burden of Disease' methodology (see Appendix) has earned recognition in Australia and overseas as a useful way of estimating the years of healthy life lost due to a disease. This method uses DALYs – or 'disability adjusted life years'—as the measuring stick. DALYs have two components:

– the years of life lost (YLL) due to premature death—the mortality burden; and
– the years of healthy life lost due to disability (YLD)—the morbidity burden.

DALYs, YLLs and YLDs provide indicators that are useful in measuring the impact of disease and exploring the effectiveness of health spending in terms of purchasing years of healthy life. The Australian Institute of Health and Welfare has provided some excellent analysis in this area. Mathers, Vos and Stevenson (1999) estimate the burden of disease in 1996 for a variety of disease and injury categories. Table 18 extrapolates their estimates for RA to 2001 using prevalence and demographic data, and also derives estimates for JCA.

Table 18: Burden of disease from schizophrenia including suicide, 2001

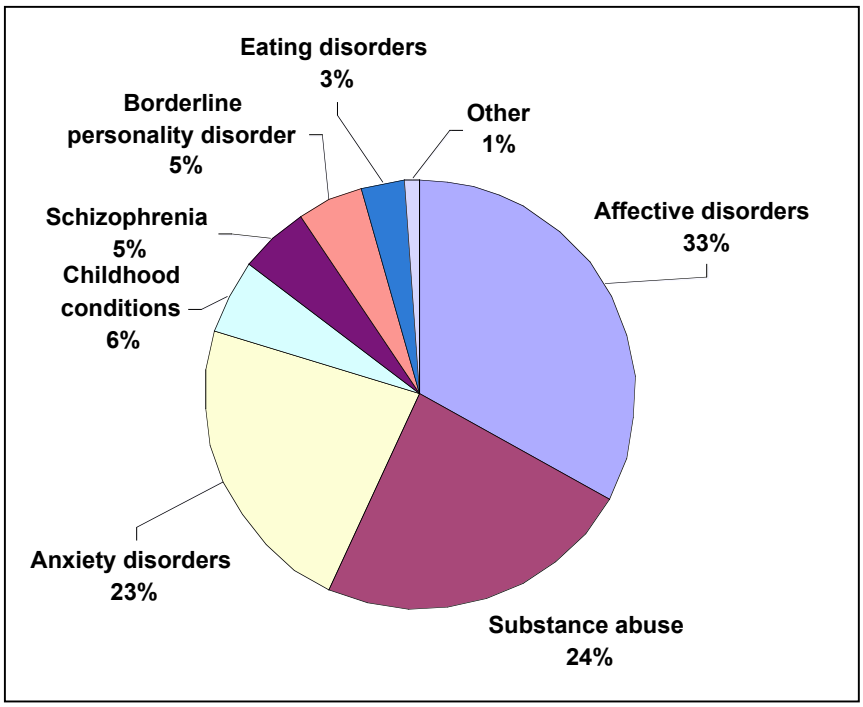
	Schizophrenia			Schizophrenia-related suicide & self-inflicted injury			Schizophrenia including suicide & self-inflicted injury		
	DALYs	YLL	YLD	DALYs	YLL	YLD	DALYs	YLL	YLD
Males	***9,773***	***123***	***9,650***	***2,721***	***2,705***	***16***	***12,494***	***2,829***	***9,666***
0-14	-	-	-	-	-	-	-	-	-
15-34	8,256	29	8,227	1,498	1,485	13	9,754	1,515	8,240
35-54	1,469	46	1,423	969	967	2	2,438	1,013	1,426
55-74	32	32	-	220	220	0	252	251	0
75+	16	16	-	34	34	0	50	50	0
Females	***9,520***	***175***	***9,346***	***602***	***591***	***11***	***10,122***	***765***	***9,357***
0-14	-	-	-	-	-	-	-	-	-
15-34	6,830	-	6,830	239	231	8	7,069	231	6,837
35-54	2,462	50	2,411	280	277	3	2,742	327	2,414
55-74	169	64	105	71	71	0	240	135	105
75+	60	60	-	12	12	0	72	72	0
Total	***19,293***	***298***	***18,996***	***3,323***	***3,296***	***27***	***22,616***	***3,594***	***19,023***
0-14	-	-	-	-	-	-	-	-	-
15-34	15,086	29	15,056	1,737	1,717	21	16,823	1,746	15,077
35-54	3,931	96	3,835	1,249	1,244	6	5,180	1,340	3,840
55-74	201	96	105	291	290	1	492	386	105
75+	76	76	-	45	45	0	122	122	0

Source: Access Economics estimates utilising data from Mathers, Vos and Stevenson (1999).

In Australia in 2001, the burden of disease attributable to schizophrenia was estimated as 22,616 DALYs, of which 19,293 (85%) was due to the illness itself and 3,323 (15%) was due to suicide related to the illness. Morbidity was the major source of burden (19,023 YLDs were 84% of the total) although, clearly, mortality was dominant in the suicidal component (3,296 YLLs or 99%). Males bore 55% of the overall burden of disease – 51% of the burden due to the disease itself and 82% of the burden due to suicide and self-inflicted injury. Nearly three quarters (74%) of the burden of disease was borne by young people aged 15-34.

The burden of disease from schizophrenia alone (not including the impact of suicide) was greater than the burden due to ovarian cancer, epilepsy, rheumatoid arthritis, HIV/AIDS or homicide and violence, and of similar magnitude to leukaemia, bipolar disorder, cirrhosis of the liver and melanoma, according to Mathers, Vos and Stevenson 1996 comparisons. Schizophrenia accounted for 1.5% of the morbidity burden (YLL) of all disease and injury in Australia and 5% of all mental illness DALYs (see Figure 8).

Figure 8: Disease burden of schizophrenia and other mental disorders



Source: Access Economics, utilising data from Mathers, Vos and Stevenson (1999).

Worldwide, the loss in DALYs caused by schizophrenic disorders was estimated in 1990 at around 13 million, representing about 1% of the global burden of disease. By 2020, it is expected to account for 1.25% (Murray and Lopez, 1996). Moreover, because of the high comorbidity of schizophrenia, these estimates are likely to be considerably understated.

5 Conclusions

The direct and indirect costs of schizophrenia[19] are enormous. Total financial costs of the illness totalled $1.85 billion in 2001, about 0.3% of GDP, with indirect costs substantially outweighing direct health system costs. Transfer payments for schizophrenia (tax foregone and welfare payments) amounted to $0.46 billion (0.07% of GDP). Direct costs are estimated as $17,740 per person with schizophrenia, while real indirect costs are a further $19,385 and transfer payments $12,472. Most tragically, schizophrenia costs Australians 22,616 healthy life-years in 2001, including 129 lives lost through suicide. Table 19 summarises the costs as estimated in this paper.

Table 19: Summary of direct and indirect costs of schizophrenia, Australia 2001

	Real costs	Transfer payments	Total
Direct health costs			
Hospital	399.5		
Other	261.0		
Direct costs ($m)	**660.5**	**-**	**660.5**
Direct cost per person with illness			*$17,740*
Indirect costs			
Loss of earnings	459.8		
Absenteeism	27.8		
Mortality burden NPV	94.3		
Tax foregone, patients		165.7	
Subtotal patient earnings	*581.9*	*165.7*	*747.5*
Carer costs	88.1		
Tax foregone, carers		23.4	
Subtotal carers	*88.1*	*23.4*	*111.5*
Disability support		249.9	
Sickness allowance		15.2	
Newstart etc		8.8	
Subtotal welfare	-	*273.9*	*273.9*
Prison costs	30.4		
Police and legal costs	21.5		
Subtotal criminality	*51.8*		*51.8*
Indirect financial costs ($m)	**721.8**	**464.4**	**1,186.1**
Indirect cost per person with illness	*$19,385*	*$12,472*	*$31,857*
TOTAL FINANCIAL COSTS ($m)	**1,382.3**	**464.4**	**1,846.7**
% of GDP	0.21%	0.07%	0.29%
Cost per person with disease	$37,125	$12,472	$49,597
Cost per capita	$71	$24	$95

Burden of disease	**Schizophrenia**	**Related suicides**	**Total**
YLL	298	3,296	3,594
YLD	18,996	27	19,023
DALYs	**19,293**	**3,323**	**22,616**
Deaths	24	129	153

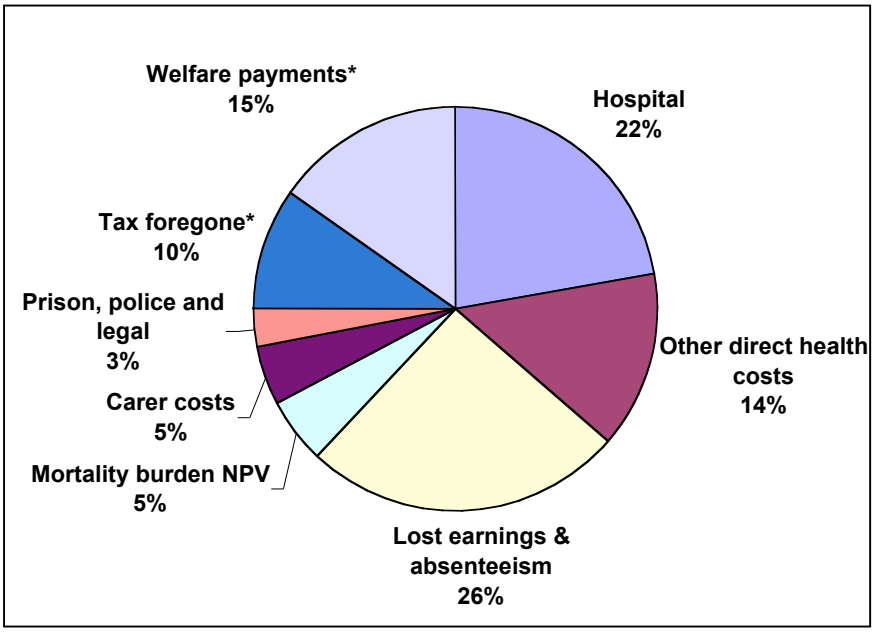
Source: Access Economics estimates.

Figure 9 shows the distribution of costs. Broadly, 36% are health system costs, dominated by hospitals (22% of the total); just over a quarter are lost earnings and another quarter are transfer payments (10%

[19] All costs in this section refer to schizophrenia and schizoaffective disorder, and suicides and self-injury related to schizophrenia as estimated in the paper.

government tax foregone and 15% welfare pensions. The net present value of the 'mortality burden' (the productive income streams lost due to premature death) is 5%, with the remaining costs for carers (5%) and criminality (3%). The total size of the 'pie' is $1.85 billion.

Figure 9: Distribution of schizophrenia costs, Australia 2001



Source: Access Economics. *Tax and welfare costs are transfer payments.

Comparison of results with other studies

The high costs per person with schizophrenia are confirmed by data from other international studies. If anything, the Australian estimates presented here are quite conservative.

- Prevalence estimation, based on the National Health Survey and the Low Prevalence Disorders Study, suggests a one-year point prevalence of 1.92 per 1000 or 37,233 people with schizophrenia and schizoaffective disorder. This is on the low end of global one-year prevalence range (of 1 to 7.5 per 1000).
- Direct health costs are also conservatively estimated, coming in at 1.2% of national health system costs based on AIHW methodology. One contributing factor may be conservative estimation of the take-up of atypical antipsychotics in recent years, although this would not have a substantial effect. Another interpretation is that Australia is at the low end of spending on schizophrenia. This is backed up by the estimates of Carr et al (2002b) that reveal a very similar estimate for direct costs ($667m) with average costs at $17,100 for people with SAD and $21,600 for people with schizophrenia excluding SAD.
- Estimates of the ratio of indirect to direct costs for schizophrenia varies considerably between countries and study methodology. In this analysis, indirect costs are 1.8 times the direct costs, including transfer payments at 70% of direct costs.
    - In the UK, indirect costs (£1.7 billion) have been estimated as *over four times* the direct costs (£396 million) in 1994, 'not counting the loss of earnings experienced by the 10% of families who have to give up work or have changed their lives to look after people with schizophrenia' (Davies and Drummond, 1994). In 1995-96 the official UK estimate had risen to £2.6 billion (see www.rethink.org)
    - On the low side, Rice and Miller's 1990 US study put indirect costs at then $US15.2 billion compared to direct costs at then $US17.3 billion (0.9:1), of which 70% was due to lost productivity, 16% to family carers, 9% to mortality, 4% to crime/incarceration, and

1% to social welfare (Rice, 1999).[20] The low ratio in the US study however, is due in part to quite a high estimate for direct health costs, at 2.5% of the annual US health budget (22% of mental illness spending) compared to 1.2% (15%) in this Australian study.

– Carr et al (2002b) again have comparable estimates for Australia – $1.63 billion for the total costs (government and social) compared to $1.85 billion estimated here (but including some different elements). The total costs per person per annum estimated by Carr et al (2002b) are $51,600 for people with schizophrenia excluding SAD and $47,900 for those with SAD, which compares very well with the analysis in this paper – $49,597 on average for both illnesses.

The Brain Dynamics Centre of Westmead Hospital and the University of Sydney, a provider of important Australian research into schizophrenia, has estimated the total cost of schizophrenia as $1.7 billion annually and states, 'Schizophrenia occupies 9% of all hospital beds, 11% of nursing home beds, and 40% of mental health facility beds.' [21]

The way ahead . . .

In Australia, people with schizophrenia and their carers are bearing a substantial portion of the financial cost of illness (at least 36%), compared to costs borne by the public purse. Patients and carers bear *the entire* burden of disease – the suffering, disability and years of healthy life lost, most tragically, in many cases due to suicide. Public health spending in Australia is at the low end of the international spectrum.

Moreover, the social and economic costs reflect a situation where too few people with schizophrenia in Australia are gaining access to the treatments and supports necessary to achieve stability and progress with the illness, and lead a fulfilling life. Many are living 'on the edge' of effective treatments, suffering profound and costly disability that could be reduced if such treatments were developed and introduced more systematically at onset and during the initial course of illness. Ongoing untreated or mistreated schizophrenia is extremely costly and will continue to impact on projected costs of illness in Australia into the future, unless alternative policy action is taken.

Public funding streams should become more dedicated to investing in treatments outlined in this paper that demonstrate effective outcomes, including:

– **early intervention programs** since most of the physiological and psychosocial impairment and disability of schizophrenia arises in the first 2-5 years – such as the Victorian EPPIC model, which indicates a 12-month savings of $6,603 per SANS score point decrease per person;

– **psychosocial rehabilitation programs** provide a range of cost savings, including reduced frequency of psychiatric care and other benefits – improved quality of life, respite and support for carers, and so on. However, there remains great unmet need in Australia for these services, with 80% of people with schizophrenia who might benefit from rehabilitation not attending programs. The gap for these, as well as cognitive behavioural therapy, assertive community treatment and supported accommodation and employment programs, needs to be addressed;

– **carer education and training** is also very effective in reducing psychotic symptoms, episodes and relapse rates with a cost: benefit ratio in the order of 1:34, i.e., saving $34 for every $1 spent;

– **newer improved medications**—atypical drugs can be extremely effective in reducing symptoms, episodes and side-effects and hence avoiding costly hospitalisations and other managements, saving in the order of $40,000 per annum per treated patient and producing better health outcomes;

[20] Re-estimates by Rice in August 2001 however, showed the ratio now in favour of the indirect costs by 1.1:1 at US$105 billion to $US92 billion, see 'Economic Impact of Schizophrenia' on www.mhac.org

[21] See www.brain-dynamics.net/research/clin_files/schizo.php

– **suicide prevention strategies** – suicide is the pre-eminent cause of death for people with schizophrenia, with 70% of Australians with schizophrenia in danger and a lifetime risk of completed suicide of 10-13%. Identification of high risk people together with effective prevention strategies are essential to reducing mortality and its burdens – equivalent to $21,425 p.a. on average for each person saved from suicide - and over 45 years of life; and
– **research** – more research into the causes of schizophrenia is essential in order to develop preventive measures and more effective treatments. Yet funding of Australian research centres is less than 1% of direct spending on the illness.

Without such investment, in the coming decade direct health costs will top $1 billion, and many people with schizophrenia will still be living on the edge of Australian society, with only limited opportunities to be healthy and participating members of the community.

Methodology

Prevalence, health and social impacts

The prevalence estimates are obtained from two data sources, the Low Prevalence Disorders Study, part of the 1997 National Survey of Mental Health and Wellbeing, and the Australian Bureau of Statistics National Health Survey 1995 data for psychoses (special data request). There are weaknesses with both data sets. The ABS data is likely to contain considerable under-statement of prevalence, as it is a household survey that relies on self-reporting and therefore has two forms of downward bias in relation to reporting psychoses. It does, however, contain data across all regions and demographic groups with no a priori reason why there would be more bias in one group compared to another.

The LPDS is a much better estimation of total prevalence, as it captures data in a two-phase process from four catchment areas across Australia and includes people with psychoses from hospitals, general practice and community mental health services, including some homeless people and those in marginalised circumstances. Moreover, some people were included who were not currently in treatment but had been up to three years prior to the survey (June-September 1997). Its limitations, while minor, are that it is restricted mainly to people in urban areas and to those aged between 18 and 65 years, and there may also be some minor bias towards more long-term illness rather than one-off episodes. It may therefore tend to have upside risk (i.e., underestimate prevalence) and is thus conservative. Nonetheless, it is the best data currently available for psychotic illnesses.

The two data sets were reconciled by applying the demographic splits of the NHS to the prevalence estimates of the LPDS, noting that schizophrenia and schizoaffective disorder (SAD) accounted for 64.5% of treated psychoses according to the LPDS after adjusting to take account of those in the LPDS who did not meet the criteria for psychosis (see below).

Disorder	LPDS (ICD-10)	Adjusted
Schizophrenia	52.0	53.8
Schizoaffective disorder	10.4	10.8
Bipolar disorder, mania	11.4	11.8
Depressive psychosis	8.1	8.4
Other psychosis	14.8	15.3
Did not meet criteria for psychosis	3.3	0
Total	**100.0**	**100.0**
Total persons	**980**	

Source: Jablensky et al (1999), Table 12.1, p35.

The projections to 2001 were based on the prevalence rates per 1000 for each demographic cohort projected to the estimated population in each cohort in 2001, as per ABS (2000). The 75+ age cohorts were anomalous due to high standard error so the 65-74 prevalence rates were extrapolated to the 75+ cohorts. All those with schizophrenia under the age of 18 were assumed to be 15 or over, as the likelihood of earlier onset is extremely low.

For the rural-urban comparisons in Section 3.1 and Table 5, unfortunately data was not available by RRMA group – the geographic 'section of state' classification used in the 1995 NHS was the same used in the 1991 Census. For further descriptions of the NHS methodology and LPDS methodology, see ABS (1997) and (Jablensky et al, 1999).

Suicide is defined in this paper as the deliberate taking of one's life: to be classified as a suicide, a death must be recognised as due to other than natural causes and must also be established by coronial enquiry as resulting from a deliberate act of the deceased with the intent of ending his or her own life (ABS, 2001).

Two approaches to estimating suicides due to schizophrenia were adopted, both based on completed suicides as reported in ABS (2001). The first approach applied the overall suicide rate in each demographic group, multiplied by 12 (since the WHO estimates suicide as twelve times more likely for people with schizophrenia) to the numbers of people with the illness in Australia in 2001. The second approach assumed that 7.5% of all suicides were due to schizophrenia (the midpoint of the US OTA estimates of 5-10%). Midpoints of the two approaches for each cohort were used as the final estimates. Better estimates of this important health area could be achieved if the ABS data on suicides specifically identified completed suicides of people with mental illnesses, preferably separately identifying psychoses in the collection process.

Direct Cost Estimation

Direct health system costs can be estimated in one of two ways – the 'bottom up' approach, calculated by adding actual (or imputed) costs for a representative cohort of patients, or the 'top-down' approach, which attributes total health expenditures to disease based on available information on the mix of diseases treated and the costs of treatment. While the former is sometimes more accurate in giving up-to-the-minute estimates for specific diseases, there can be problems in obtaining representative samples and representative cost patterns, and the advantage of the latter approach is that there will be consistency of coverage and estimates across diseases, which is more helpful for policy makers.

In this study, the top-down approach is adopted, based on the methodology developed by the Australian Institute of Health and Welfare (AIHW), in collaboration with the National Centre for Health Program Evaluation (NCHPE) for the Disease Costs and Impact Study (DCIS). This major study measures health services utilisation and expenditure for specific diseases and disease groups in Australia, in accordance with the Ninth Revision of the International Classification of Disease (ICD-9) published by the World Health Organisation (WHO). The DCIS methodology has been gradually refined to estimate direct costs of hospitals, GP and specialist medical services, allied professionals, pharmaceuticals, nursing homes, research and other costs (such as administration), primarily from hospital morbidity data, case mix data and the National Health Survey (NHS), as well as other sources. DCIS methodology is detailed in Mathers et al (1998).

Schizophrenia is quite simple to identify as it is wholly captured in ICD-9 Category 295, which also includes schizoaffective disorder (SAD) – see ICD-9/ICD-10 reconciliation below.

295 Schizophrenic psychoses: ICD-9/ICD-10 reconciliation	
ICD-9	**ICD-10**
295.0 Simple type	F20.6 Simple schizophrenia
295.1 Hebephrenic type	F20.1 Hebephrenic schizophrenia
295.2 Catatonic type	F20.2 Catatonic schizophrenia
295.3 Paranoid type	F20.0 Paranoid schizophrenia
295.4 Acute schizophrenic Episode	F23.2 Acute schizophrenia-like psychotic disorder F23.1 Acute polymorphic psychotic disorder with symptoms of schizophrenia F20.8 Other schizophrenia
295.5 Latent schizophrenia	F21 Schizotypal disorder
295.6 Residual schizophrenia	F20.5 Residual schizophrenia
295.7 Schizo-affective type	F25 Schizoaffective disorders
295.8 Other	F20.8 Other schizophrenia
295.9 Unspecified Schizophrenic reaction Schizophreniform psychosis NOS	F20.9 Schizophrenia, unspecified F23.2 Acute schizophrenia-like psychotic disorder F23.2 Acute schizophrenia-like psychotic disorder F23.1 Acute polymorphic psychotic disorder with symptoms of schizophrenia Consider also: F20.8 Other schizophrenia

The only limitation to the data might be that the AIHW used overseas figures for schizophrenia but local data for other psychotic disorders, although the existence or direction of bias from this is unknown. Data on costs for schizophrenia and suicide and self-inflicted injury were obtained through a special data request from the AIHW, as well as using existing data published in Mathers and Penm (1999) and Mathers, Vos and Stevenson (1999).

Projections to 2011

2011 population estimates were obtained from the ABS midpoint Series II projections for Australia (ABS, 2000). Each demographic cohort of people with schizophrenia was projected by the rate of change in population in that cohort, to reflect future one-year prevalence with demographic ageing. Thus, reflecting lower fertility, the number of people with schizophrenia in the under-18 cohort is expected to fall by 1.7% by 2011. This is more than outweighed however, by the growth in the older cohorts (18-24 and 25-44) with later onset of the disease, who age into the oldest cohorts (45-64 and 65+). This projection is the only one in this analysis with downside risk rather than upside risk, as the true progression of disease may favour the slower growth of the lower age groups more so than captured here. In other words, the prevalence rates in the higher age groups may in fact decline over the forecast period. More comprehensive age-of-onset data would enhance these projections.

Suicides are projected to grow in the same proportions as the number of people with schizophrenia, *ceteris paribus* (all other factors held constant). It is hoped, however, that policy interventions may reduce the numbers of suicides over the decade.

Direct cost projections are based on the prevalence changes together with projected growth in the Health and Community Services GDP deflator, which is expected to grow by 45.15% in nominal terms from 2001 to 2011 based on projections of historical growth over the 1990s (which averaged 3.80% p.a.). The upside risk of pharmaceutical spending, together with the various policy sensitivities outlined in Section 3.4.2, make the cost projections very much open to policy choices and directions of today.

Indirect costs

The World Health organisation and cost of illness studies in the past have typically classed indirect costs as all those costs that are not health system costs, the approach adopted here. More recently, there is a trend to separately identify costs that are borne by government as opposed to costs to individuals or society, an approach adopted for costing schizophrenia in Australia by Carr et al (2002b and 2002c). Measurement of indirect costs remains a matter of some debate and controversy.

***Lost earnings and production ('human capital')*:** This focuses on the loss of production or earnings associated with illness and premature death. The higher end of such estimates includes absenteeism costs plus the discounted stream of lifetime earnings lost. The lower end might include only the 'friction' period until the worker can be replaced, which would be highly dependent on labour market conditions and un(der)employment levels. The intermediate approach adopted in this paper comprises the lost production of one period due to exit from the workforce and absenteeism. In this case, it is reasonably assumed that, in the absence of illness, people with schizophrenia would participate in the labour force and obtain employment at the same rate as other Australians, and earn the same average weekly earnings (based on ABS Average Weekly Earnings end-June 2001 estimate of $668 per week, including full and part time earnings across all occupations and regions). The implicit economic assumption is that the numbers of such people would not be of sufficient magnitude to substantially influence the overall clearing of the labour market.

***Mortality burden*:** The mortality burden makes similar assumptions to those above if, in the absence of the illness, those people with the illness did not die (including from suicide) in 2001, but rather were well and participated in the labour force similarly to average Australians, and for the same expected duration. The average age of suicide (34.7 years) is derived from the demographic profile of suicides related to schizophrenia, with retirement at age 65. The discount rate for the net present value (NPV) of the future income stream – 0.81% – is based on the 30-year average growth of real AWE (with the Consumer Price Index as the deflator) for the period 1981-92 to 2011-12, including forecasts from the Access Economics

Macroeconomic Model. Thirty years were used as this is the number of years to retirement and because a long-term average is required due to the sensitivity of the results to the discount rate. Then:

NPV = $\sum Y(1+r)^i$ where Y=$34,803, r=0.81% and i=0,1,2……30
= $1.19m

The number of people who suicide under the age of 65 (116) is then multiplied by the employment rate (68.7%) to give the number of people (79) who suicided who would, if they were well, have been employed. This is probably a conservative estimate since males are over-represented in suicides and in employment rates. Overall, 79*$1.19m = $94.3m, the mortality burden. Average annual earnings ($34,803) multiplied by 79 divided by 129 gives $21,425 benefit per life saved (plus over 45 years of life!)

***Potential tax revenue foregone*:** People with schizophrenia who work less or retire early will not only forego income, but will also pay less personal income tax. The income tax foregone is a product of the average personal income tax rate and the foregone income. With schizophrenia and lower income, there will be less consumption of goods and services, estimated up to the level of the disability pension. Without schizophrenia, it is conservatively assumed that consumption would comprise 90% of income (the savings rate may well be lower than this). The indirect tax foregone is a product of the foregone consumption and the average indirect tax rate, as per the AE macroeconomic model incorporating changes from *A New Tax System* from 1 July 2000. Tax revenue sacrificed is included as a transfer payment (not a real economic cost) – interesting in terms of the overall government budget position.

***Carer costs*:** For many illnesses such as schizophrenia, the patient is supported and cared for by a spouse, parent, family member or significant other. Placing a value on the cost of volunteer care and community services is the one of the most difficult aspects of disease costing. It is nonetheless a hugely important indirect cost, and becoming more so as, in Australia, we increasingly cap hospital inpatient beds, discharge patients earlier, and move people with disabilities out of the hospital system. Greater emphasis is being placed on partnerships with community organisations, such as the Home and Community Care (HACC) program, and the proliferation of paid home help and domiciliary care services. The methodology for calculating carer costs is detailed in section 3.2 and, as discussed there, errs on the conservative side.

***Social welfare payments*:** The disability pension, sickness benefits and various unemployment benefits paid to those suffering from disease are costs to the tax-paying community, which could be put to alternative use. These are also income transfer payments rather than real economic costs, but again relevant to the public financial position. The disability support pension is the main item here for schizophrenia – this pension was previously known as the invalid pension and was introduced in 1910 as a result of the *Invalid and Old-age Pensions Act 1908*.

The weighted average payment per week in Table 16 is derived from the Centrelink website (www.centrelink.gov.au) for each of the various payments, with weights according to age as per prevalence and the split between singles and couples as per the LPDS. As an example, weights for weekly payments for the disability pension are shown below. People under 21 were assumed to live at home, for simplicity and because the difference is extremely small.

Pension Category	**Weight (%)**
Single, under 18, at home	6.3
Single, 18-20 years, at home	3.4
Single, over 21, max rate	57.8
Couple, over 21, max rate (each)	32.5

Other benefits (Sole Parents Allowance, Age Pension etc) are not related to the illness so not estimated here as part of the cost of illness. Special Benefit is paid in situations of severe financial need due to circumstances outside of a person's control and decided at the discretion of the Secretary of the

Department of Family and Community Services. Special Benefit may be related to psychotic illness but is a very small item so not included.

Accommodation: Finding a suitable place to live is essential for anyone with schizophrenia (SANE Australia, 1997). Although not estimated in this paper, rental assistance is another aspect of welfare payments attributable to psychotic illnesses such as schizophrenia. In the LPDS, 5.1% of patients reported living in group homes or supported housing. Carr et al (2002b) estimate the total costs of supported accommodation provided by government as $19.5m plus a further $5.7m provided by non-government organizations (NGOs) for all people with psychoses. $16.2m of this could be estimated here for people with schizophrenia or SAD.

Burden of disease: In recent years, the World Health Organisation (WHO), the World Bank and Harvard University have developed a methodology that provides a comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990 and projected to 2020 (Murray and Lopez, 1996). This approach has been adopted and applied in Australia by the AIHW with a separate comprehensive study in Victoria.

Mathers, Vos and Stevenson (1999) estimate the burden of disease in 1996. The schizophrenia component (pp88-90 and Annex tables) did not include associated suicides so these were attributed from the burden of disease data from the 'suicides and self-inflicted injury category' (pp91-93 and Annex tables), on the basis of the proportion of suicides due to schizophrenia as a proportion of total Australian suicides (5.5%). The YLD and YLL elements were then extrapolated to 2001 on the basis of 9.1% growth in schizophrenia prevalence over the period. The disability weight used by the AIHW team was 0.434 for all cases of schizophrenia.

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Appendix—Diagnosis and subtypes

DSM-IV and ICD-10 definitional diagnoses of schizophrenia

DSM-IV	ICD-10
A. Characteristic symptoms. Two or more of the following, each present for a significant portion of time during a 1-month period, or less if successfully treated: 1) Delusions, 2) Hallucinations, 3) Disorganized speech, e.g. frequent derailment or incoherence, 4) Grossly disorganized or catatonic behavior, 5) Negative symptoms, i.e. affective flattening, alogia or avolition. *Note*: Only one criterion A symptom is required if delusions are bizarre or hallucinations consist of a voice keeping up a running commentary on the person's behaviour or thoughts, or two or more voices conversing with each other. **B. Social/Occupational dysfunction.** For a significant portion of the time since the onset of the disturbance, one or more major areas of functioning such as work, interpersonal relations, or self-care are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic or occupational achievement). **C. Duration.** Continuous signs of the disturbance persist for at least 6 months. This 6-month period must include at least 1 month of symptoms (or less if successfully treated) that meet criterion A, i.e. active-phase symptoms, and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in criterion A present in an attenuated form (e.g. odd beliefs, unusual perceptual experiences). **D. Schizoaffective and mood disorder exclusion.** Schizoaffective and mood disorders have been ruled out because either (1) no major depressive, manic or mixed episodes have occurred concurrently with the active-phase symptoms or (2) if mood episodes have occurred during active-phase symptoms, their total duration has been brief relative to the duration of the active and residual periods. **E. Substance/general medical condition exclusion.** The disturbance is not related to the direct physiological effect of a substance (e.g. a drug of abuse, a medication) or a general medical condition. **F. Relationship to a pervasive developmental disorder.** If there is a history of autistic disorder or another pervasive developmental disorder, the additional diagnosis of schizophrenia is made only if prominent delusions or hallucinations are also present for at least a month (or less if successfully treated).	A minimum of one very clear symptom belonging to any one of the groups listed below as (a) to (d) or symptoms from at least two of the groups referred to as (e) to (i) should have been clearly present for most of the time during a period of 1 month or more. **a)** Thought echo, thought insertion or withdrawal and thought broadcasting **b)** delusions of control, influence or passivity, clearly referred to body or limb movements or specific thoughts, actions or sensations; delusional perception **c)** hallucinatory voices giving a running commentary on the patient's behaviour or discussing the patient among themselves, or other types of hallucinatory voices coming from some part of the body **d)** persistent delusions of other kinds that are culturally inappropriate and completely impossible, such as religious or political identity, or superhuman powers and abilities (e.g. being able to control the weather or being in communication with aliens from another world) **e)** persistent hallucinations in any modality, when accompanied either by fleeting or half-formed delusions without clear affective content or by persistent over-valued ideas, or when occurring every day for weeks or months on end **f)** breaks or interpolations in the train of thought, resulting in incoherence or irrelevant speech, or neologisms **g)** catatonic behaviour, such as excitement, posturing or waxy flexibility, negativism, mutism and stupor **h)** 'negative' symptoms such as marked apathy, paucity of speech and blunting or incongruity of emotional responses, usually resulting in social withdrawal and lowering of social performance; it must be clear that these are not due to depression or neuroleptic medication **i)** a significant and consistent change in the overall quality of some aspects of personal behaviour, manifest as loss of interest, aimlessness, idleness, a self-absorbed attitude and social withdrawal.

Differential diagnosis can be difficult early on, since the boundaries are ill defined between schizophrenia and other psychotic disorders such as delusional disorder, affective disorder, central nervous system diseases, acute transient psychosis and also drug-induced psychosis. A condition closely related to schizophrenia is *schizoaffective disorder*, similar in symptoms but also including mood extremes – mania or depression.

Schizophrenic conditions were previously known as *Folio circulaie* (Falvet, 1851), *Hebephrenia* (Hecker, 1871), *Catatonia* and *Paranoia* (Kahlbaum, 1874) and *Dementia praecox* (Kraepelin, 1878), reflecting what Bleuler himself postulated as a 'group of schizophrenias' characterised by the 'four A's' – Ambivalence, loosening of Associations, Autism and blunted Affect. In the 1970s, distinctions were made between 'positive' and 'negative' symptoms (Crow, 1980), with the latter characterised by social withdrawal, self-neglect and blunted affect. Multivariate analysis has suggested three symptom clusters – *reality distortion, disorganisation* and *psychomotor poverty* (Liddle, 1987). Nienhuis (1998) discerns four sub-types, which are not mutually exclusive and so defy convenient sub-classification:

- ***Simple* or *undifferentiated*** type: insidious, gradual reduction in external relations and interests; emotions lack depth; ideation is simple and concrete; progressive lessening of mental activity and a retreat to stereotyped forms of behaviour.
- ***Hebephrenic*** or ***disorganised*** type: shallow or inappropriate responses; bizarre behaviour, false beliefs (delusions) and false perceptions (hallucinations).
- ***Catatonic*** type: striking motor behaviour eg, a state of almost complete immobility, often assuming statuesque positions; mutism (inability to talk); extreme compliance and absence of voluntary actions (eg, inability to move through a doorway). May be preceded or interrupted by episodes of excessive motor activity and impulsive, unpredictable excitement.
- ***Paranoid*** type: characterised by delusions of persecution and/or grandeur (eg, being Jesus or Elvis) often accompanied by hallucinations.