

**Editor's note:** The following paper by Professor McGorry was the 70th Beattie Smith Lecture, delivered in 2004. This series of lectures was made possible by an endowment from William Beattie Smith (1853–1921), a psychiatrist, lecturer at the University of Melbourne and medical superintendent of Kew Asylum. The first Beattie Smith Lecture was given by Victorian Lunacy Department Pathologist, Dr William Lind, in 1925.

## **‘Every me and every you’: responding to the hidden challenge of mental illness in Australia**

**Patrick McGorry**

**Objective:** *To show that mental illness affects everyone in society, describe some of the main obstacles to better outcomes, and build confidence that they can be overcome.*

**Methods:** *A review and analysis of relevant evidence and experience combined with personal advocacy.*

**Results:** *Mental illnesses are common and seriously under-treated, reform of the system of care has completely stalled, and insidious reinstitutionalization of the modernized system is occurring. A number of contributing factors and possible solutions are identified, including mental health literacy and advocacy campaigns, a focus on young people and early intervention, and functional reintegration of the treatment of mental and substance use disorders.*

**Conclusions:** *A new wave of reform and major financial investment in the treatment of mental and substance use disorders is overdue. This can be best achieved by combining the evidence-based health care (EBHC) paradigm with a direct appeal to the self-interest of members of the general community. A National Institute of Mental Health and Addiction should be a key element of such reform, which must be a continuing process with substantially increased federal and State funding.*

**Key words:** *advocacy, mental health reform, reinstitutionalization, stigma.*

*There is enough money around to help those with mental illness and their families but it is not available because of the attitude of most decision makers and a large part of the general public towards mental illness and all that surrounds it. . .*

*. . . All other efforts that are undertaken to treat mental illness and rehabilitate people impaired by it are likely to be of little use if we do not make people think differently about it.*

*We should be active and loud advocates of the mentally ill and be in the forefront of their battle to realize their rights. This might require that we relinquish some of our professional role and add some political activism to our daily chores. Norman Sartorius<sup>1</sup>*

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*Mental illness is not a personal failure. It doesn't happen only to other people. In more ways than one we make this simple point: we have the means and the scientific knowledge to help people with mental and brain disorders. Governments have been remiss, as has been the public health community. By accident or design, we are all responsible for this situation. As the world's leading public health agency, WHO has one, and only one option – to ensure that ours will be the last generation that allows shame and stigma to rule over science and reason.* Gro Harlem Brundtland<sup>2</sup>

**M**ental health and mental illness are the major public health issue in Australia. Mental health problems and mental illness affect everyone both directly and indirectly. Just reflect for a moment. Have you ever been depressed? Have you ever needed help with a relationship breakdown, a bereavement or some other crisis in your life? Have you ever had a period of drinking too much? What about a psychotic episode? What about your children, your parents, your siblings, friends and colleagues? How many of you can truly say that you have survived so far in life without confronting these mental health issues. This readership may be a biased sample but even for many of you there is probably a failure to come out and fully acknowledge the personal impact and ubiquity of the problem. Just as we do not expect to live through even a 12 month period without the need to visit the doctor for some kind of physical health problem, it seems quite unrealistic for most people to expect to remain mentally healthy for long periods. Yet this is what we have all expected. So we do not recognize our mental health problems when they surface, and if we do, we don't tell anyone, and we usually don't seek appropriate help until we are forced to do so. When we seek help we don't know where to go, who to trust, and whether to engage in the treatment offered. Quality of care is highly variable and well below what is achievable for a nation such as Australia. There is a massive efficacy-effectiveness gap (EEG), that is the real-world outcomes of intervention are much worse than can be achieved under optimal conditions. This EEG is a much more serious problem for mental disorders than physical illnesses.

A decade after the Burdekin inquiry<sup>3</sup> and the First National Mental Health Strategy,<sup>4</sup> why have we made such little progress? It is not because many dedicated people have not tried. Nor because we do not have better and better treatments, innovative models and an increasingly strong evidence base. It is because we have not tackled the fundamental barriers successfully and particularly because we have not got through to the community in a way they can understand. The title of this paper is borrowed from a song by the band 'Placebo' ('placebo' is particularly apt, given the national state of mental health care). We need to reach every Australian to help them see that they and their families are all at significant risk, not only of mental illness itself, but of poor quality mental health care. Altruism, logic, sound evidence and even economic arguments have failed to produce growth, investment and sustained reform. Per-

**Table 1: Why should we be concerned about mental illness? (Patel<sup>7</sup>)**

- Because they affect us all
- Because they are a major health burden
- Because they can be very disabling
- Because mental health services are very inadequate<sup>8</sup>
- Because our societies are rapidly changing
- Because mental illness leads to stigma
- Because mental illness can be treated with simple, relatively inexpensive methods

haps the missing ingredient has been self-interest. As with the major physical illnesses, notably cancers and cardiovascular disease, a substantial proportion of the death and damage caused by mental disorders is already avertable with existing knowledge.<sup>5</sup> It is not being used. It is not available to most people who need it. Even individual wealth cannot buy it. The rich and powerful might be able to buy new organs but chances are they cannot buy quality mental health care or better outcomes. On average, what is available is something akin to the well characterized placebo effect, which has been described as 'a useful but fickle boon as it is difficult to predict when it will occur'.<sup>6</sup> Often the result is not even this good, thanks to a healthy dose of iatrogenic harm through crude management of emergencies and acute episodes, and non-evidence-based use of medications. We can do a lot better than this. The present paper aims to describe the current landscape, some of the current obstacles to progress, project an achievable dream and show how we can turn the dream into reality. I have tried not to focus on blame. This is a serious issue, and frequently a matter of life and death. The mental health arena contains an inherent reservoir of negative emotion constrained by silence. We need to build positive energy and momentum, and form an alliance for a new generation of sustained progress (Table 1).

## BEYOND THE GLOBAL BURDEN OF DISEASE

### The global burden of disease and mental disorders: shameful neglect

A vast amount has been written about the global burden of disease since 1996.<sup>9</sup> The contribution of mental disorders to this burden surprised many. This paradigm has been carefully applied to the Australian context and I will highlight some aspects from the Victorian Burden of Disease Study conducted for the Department of Human Services (DHS) by Vos and Begg.<sup>10</sup> Cancer, cardiovascular disease and mental disorders are the top three contributors. Cancer and cardiovascular disease produce most of the mortality, mostly in older people, while mental disorders produce most of the non-fatal disability, mostly beginning in younger people. A total of 40% of the

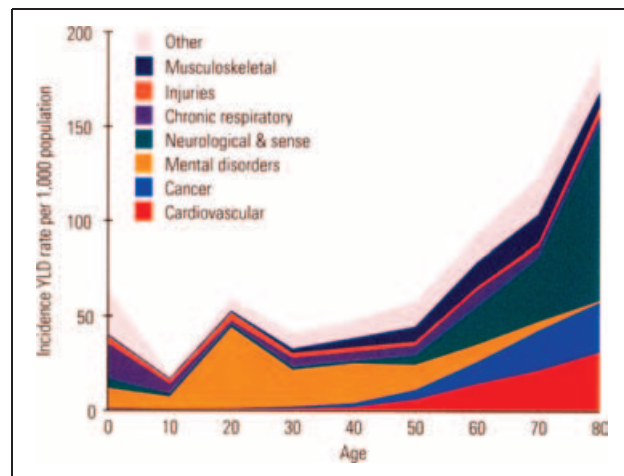
non-fatal burden of disease in Victoria in men and nearly 50% in women is caused by mental disorders. Nine of the top 20 causes of disability burden are mental disorders.

When mortality is included, the contribution of mental disorders to disease burden goes down to approximately 14%. This is an underestimate, partly because suicide, in 90% of cases a consequence of mental disorder, is counted under 'injuries', and because the excess of premature deaths from cardiovascular disease and cancer in people with mental disorders is attributed completely to the physical illness. Furthermore, mortality in mental disorders may be much more preventable. When we move beyond the basic concept of mortality (years of life lost: YLL) to avoidable deaths, the situation is clear. Mental health problems contribute 8.1% of all avoidable life years lost, compared for example with 9% for respiratory diseases, 5.8% for all forms of cancer, and 4.4% for heart disease. In the year 2000, World Health Organization (WHO) estimated that around 1 million people died from suicide in the world.<sup>8</sup> Twenty million people attempted suicide. Suicide rates have increased by 60% over the past 45 years. The extent of avoidable death from suicide is similar to the road toll in Australia. However, it is not taken anywhere near as seriously in terms of preventive strategies and government expenditure, and the close link with mental disorders has been minimized.

Work impairment is one of the major adverse consequences of mental disorder, costing more than the costs of successful treatment.<sup>11</sup> Thomas and Morris estimated that in the UK the cost of this lost productivity, due to mental illness, was 23-fold the cost to the health service of treating mental illness.<sup>12</sup> In addition to 'days out of role', even when depressed people are at work, their performance is reduced, and this 'work cutback' or 'presentism' contributes further to the hidden disability of mental disorders. Productivity gains following effective depression treatment far exceed direct treatment costs. Similarly, there is a massive indirect effect on productivity from unpaid caring, when family members take days out of role to care for family members who are unwell. The magnitude of unpaid caring is enormous.<sup>11</sup>

Among a series of similar studies internationally, the crucial Duty to Care study from Western Australia showed that people with serious mental disorders, especially schizophrenia, had considerably elevated death rates from all main causes of death, with heart disease topping the list of causes ahead of suicide.<sup>13</sup> Not only is the prevalence of these disorders increased, but they are diagnosed late and treated inadequately. This pattern of premature death and substandard medical care is characteristic of marginalized and disadvantaged sections of the community and demands urgent action.

The final standout finding from the Burden of Disease data is the pattern of disease across the lifespan (Figure 1). The most obvious feature to note is that the level of disease burden increases steadily across the

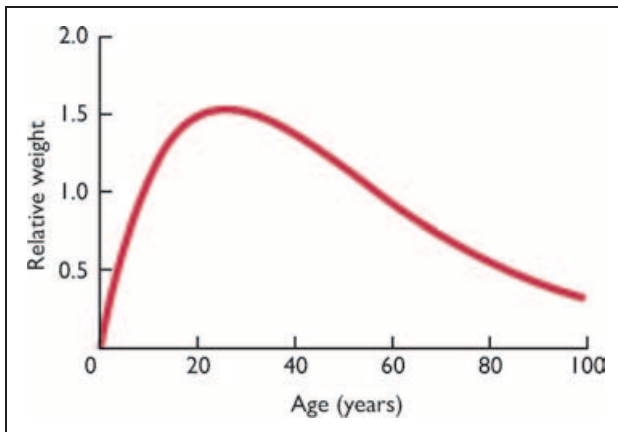


**Figure 1: Incident years lived with disability (YLD) rates per 1000 population by age and broad disease grouping, Victoria 1996. Reproduced with permission from the Health Surveillance and Evaluation Unit, Rural and Regional Health and Aged Care Services Division, Department of Human Services Victoria, Australia.**

lifespan. Mental disorders are the most important single group of disorders in late adolescence–early adulthood, after which the relative contribution from these disorders decreases at older ages. Mental disorders are also less common before adolescence, although much of the preventable risk for later illness is probably generated during this period of life. Obviously, cancer and cardiovascular disease take over as the main contributors during the second half of life as the overall burden increases with age, and mental disorders in fact contribute less. As such, cancer and cardiovascular disease inevitably overshadow the emergence of new types of morbidity from mental disorders in mid-life and old age, apart from dementia. These patterns across the lifespan raise the issue of cost-effectiveness, a key basis for carrying out burden of disease studies in the first place, and consequently the greater potential value of interventions earlier in life. Indeed, Murray and Lopez addressed this issue and placed the maximum weighting for the unit of disease burden, the disability-adjusted life year (DALY), around the age of 22 (Figure 2). Despite this greater capacity to benefit, the early adult period is the weakest link in our whole health system for detection and treatment of mental disorders in both primary and specialist care.

## BURDEN OF DISEASE PARADIGM: WHY HAS IT HAD SO LITTLE IMPACT ON MENTAL HEALTH?

All these facts are pretty compelling and they have been served up to policy makers ad nauseum by mental health leaders over the past decade. The former develop a glazed look when this kind of data are presented because they



**Figure 2: Relative value of a year of life lived at different ages, as incorporated into disability-adjusted life years (DALYs).**

have seen them so many times. Why has this information had so little impact on patterns of care and resource levels? Initially, this seems very puzzling. I suspect that there are two reasons. First, the public and decision-makers alike have a very weak knowledge base concerning mental disorders and their evidence-based treatment.<sup>14</sup> Second, as a result, policy makers and the public have little confidence that these illnesses can be effectively treated or that the burden can be reduced with current knowledge. This myth has been selectively perpetuated within Australia through secondary modelling exercises which have reinforced a sense of helplessness,<sup>15</sup> especially in schizophrenia. However, the problem goes much deeper than this. Deep pessimism and therapeutic nihilism has sapped the will to tackle all forms of mental disorder. Why invest if you cannot improve the situation? This is the mindset of key politicians and decision-makers. This is not only a myth but it has been a dangerous, frequently lethal one for many many people.

Contrast this with the sexing up of the latest, often trivial breakthroughs in mainstream health care, which derive from and paradoxically build an innate confidence that demands financial and policy support. The media devour such stories as they also do crises in the health system. The latter build support for better physical health care yet conversely undermine confidence in mental health care. Some have said that the shroud-waving approach to resource allocation should be replaced by logical allocation according to parameters of burden and cost-effectiveness of interventions. For mental health, that would be fine. However, such cost-effectiveness modelling must be done through processes fully independent of government influence because, like pharmaceutical companies, governments have an inherent agenda. But until other fields of medicine put away their shrouds, we will need to not only get ours out of cold storage, but also learn to wave them strategically and in a coordinated way, so that the responsibility is cor-

rectly targeted and the solutions are clearly stated. We must also show just how preventable so much of our disability and so many of our tragic deaths really are, even without a single new breakthrough. This is not hard to do.

## PREVALENCE OF MENTAL DISORDERS: EVERY ME AND EVERY YOU?

The Australian National Survey of Mental Health and Well-being shows that within a 12 month period approximately one in five people will meet criteria for a mental or substance use disorder.<sup>16</sup> The peak lies in the 18–24 age range, where 27% of young people meet criteria. Seventy-five per cent of mental disorders begin before age 25 and two-thirds of the health burden in the 15–24 age range is due to mental disorders.<sup>10,17</sup> Cumulative study designs show much higher prevalence rates. Costello *et al.* showed that by age 16, 36.7% of adolescents had met criteria for a disorder.<sup>18</sup> The National Comorbidity Study in the USA, and its replication, shows that rates of lifetime prevalence-to-date top 50% (Kessler *et al.* pers. comm., 2004).<sup>17</sup> Lifetime risk of any disorder will be substantially higher than 50% because obviously few participants in a cross-sectional survey have passed through the full period of risk. Cohort effects are also present and reveal increasing rates. So the ‘one in five’ slogan bandied around for years to emphasize the commonness of mental disorders is a substantial underestimate if we are talking about lifetime risk. One in two is much more like it and when we include the family and friends, we reach ‘every me and every you’ with ease.

These figures may seem staggering, almost unbelievable. This has led some to argue that not all of what is being measured here is disorder or illness that requires treatment. There may indeed be measurement error in some of the survey estimates. Also, some of the cases that are above the diagnostic threshold may not have a need for care. However, we do not really know this. The categorical definition of caseness, mainly required to define need for care, is unsatisfactory and despite the efforts of psychiatric epidemiologists, still lacks consensus support. Moreover, even subthreshold cases according to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) and *International Classification of Diseases* (ICD) diagnostic systems can be associated with significant distress and disability.<sup>19</sup> Those who are conscious of the practical and economic challenges in providing care to more than half the population at some point and up to one-quarter within a 12 month period, have argued that a diagnosis should be associated with substantial functional disability before treatment should be funded and accessed.<sup>20,21</sup> This is superficially attractive. However, it means that people are required to become functionally disabled by their symptoms before they can be offered help. Such disability is usually hard to reverse even when treatment is effective: for example psychiatric disorders with onset during high school or college

were shown to severely and permanently truncate educational attainment in 7.2 million young Americans.<sup>22</sup> Restricting access in this way is antithetical to preventive and early intervention approaches and would be completely unacceptable in general medical care where people with mild disorders, such as a viral illness, can gain ready access. It may also prevent the most cost-effective phase of serious illness from being treated, so capacity to benefit is a key consideration. Mild disorders should be able to access treatment for all these reasons.<sup>23</sup> In Australia, the requirement for entrenched disability or life-threatening risk operates at a high threshold at the entry points to specialist care. Primary care access is theoretically better, but practically it is still a problem. Generally, treatment for milder disorders and earlier phases of disorder is provided through little better than a lottery system in which affluence and local factors are key influences. Such people are often derided as the 'worried well' even within psychiatry. They may not need years of treatment but they do have a right of access to appropriate treatment. Why not acknowledge that ready access to mental health care of some kind, much of it relatively simple, even informal and self-care, is as necessary as access to general medical care? This should not be controversial.

## WHAT ARE WE DOING ABOUT IT?

*While Australian mental health policy is often depicted as world-leading, for some time both those using and those providing services have claimed that the system is characterized by restricted access, variable quality, poor continuity of care, lack of support for recovery from illness and overt and covert human rights abuses. . . . The more that people who have never thought about mental health recognize these challenges, the more likely we are to reduce the stigma and the additional burden it places on consumers and their families.*  
Keith Wilson,<sup>24</sup> Chairperson, Mental Health Council of Australia

### Half-hearted reform, a mental health system in disarray

In this section it is important to acknowledge the efforts that have been made by very many people, particularly clinicians, administrators and advocacy groups, to tackle the issues raised in the present paper, especially over the past decade or so. However, there is no doubt that there is a vast gap between the policy rhetoric and the reality for patients and their families. There was a brief period catalysed by the First National Mental Health Policy in which substantial reforms began and great innovation occurred. In Victoria, it built a new foundation for a 21st century model of care. Sadly, the cranes were dismantled with even the foundations incomplete. What's more, the maintenance staff were sent home. Unfortunately, the crowd turned up in greater numbers than ever because they could now find the stadium and wanted to be part of the action. Governments, however, thought the game was over.

In the recent *Out of hospital Out of Mind* report produced by the Mental Health Council of Australia,<sup>24</sup> I wrote in my foreword:

*Despite its demonstrated capacity for innovation, Australia has not translated recent advances into better mental health care. This report demonstrates that this is primarily due to a lack of political will and totally inadequate funding. The expertise and effective models of care are readily available but are not systematically supported. Australia is still trying to deliver mental health services on the cheap. In the more visible postinstitutional era, this is now having serious consequences for our community as a whole. Only the cosy bi-partisan neglect of mental health by both sides of politics and the lack of effective mobilization of the population enables this to persist.*  
McGorry<sup>25</sup>

The MHCA survey of mental health care across the nation, documents five key problem areas. These are as follows.

### Grossly unmet need for mental health services

- 62% of people with mental disorders do not use any form of mental health service.
- 38% do access care but this is largely provided through general practitioners (GPs). Access to this is declining through the decline in bulkbilling. GPs report that they are poorly supported by specialist mental health services and there is evidence of major deficits in the quality of mental health care provided by GPs.
- 2454 people died from suicide in 2001 (10.5% of YLL).

### Grossly inadequate growth in expenditure on basic services

- Australia spends 7% (\$2.56bn per annum) of its health budget (8.5% of gross domestic product, GDP) on mental health. State-funded services represent 61%, Commonwealth, 31% and private health insurance-funded private hospital services, 8%. Yet mental health accounts for 13% of the total disease burden and nearly 30% of the non-fatal disease burden. Other comparable countries spend up to 15%, although no developed countries have truly addressed the unmet needs. Because most people remain untreated, the cost of providing services is not a good measure of the cost of mental disorder to the community.<sup>11</sup>
- Although total expenditure on mental health has increased over the past decade by \$778m, this has been falsely represented by governments as a real increase. In fact, the proportion devoted to mental health has remained constant within the health budget, indicating that the increase has merely kept pace with inflation.

- State governments have progressively contributed less in proportion. The largest states of NSW and Victoria are surprisingly not the highest spenders. Victoria (\$86 per annum), once way ahead, has been overtaken by Western Australia (\$96 per annum) and has nearly been caught by NSW (\$77 per annum) in per capita spending.
- While the Commonwealth contribution has increased in real terms, this has flowed to support the cost of new drugs (a nevertheless welcome development), rather than service systems or non-pharmacological interventions.

### **Restricted access to existing services**

- The experience of current consumers is of severely limited access to primary, emergency, specialist and rehabilitation care services.<sup>26</sup>
- Care systems are perceived to be chaotic, under-resourced, and overly focused on providing brief periods of medicalized care within acute care settings. They have become progressively reinstitutionalized, with increasingly staff-centred work practices.
- Private psychiatric services are grossly maldistributed and involve large out-of-pocket costs. Health insurance does not accord parity to psychiatric care. Access to private psychology and allied health services is heavily restricted by lack of government and insurance support.

### **Ongoing human rights abuses and neglect**

- People with mental illness report abuse within emergency and acute settings within general hospitals. Emergency departments typically manage psychiatric presentations in an unacceptable manner.
- Despite the locus of care being in the community, there is no system of care to ensure that people can live productively within the wider community. Only 20% of those with the most disabling forms of mental illness have any access to rehabilitation programmes.<sup>27</sup>
- Discrimination in the key areas of employment and insurance continues.

### **Increasing demand for mental health care**

- Increasing levels of distress and mental illness, as well as the effects of social change and population growth, is documented.
- Expectations have been raised for better access and quality.
- New medications, new services, prevention and mental health promotion programmes are increasingly sought after.

Other independent reports agree with this analysis: SANE's mental health report states that 'mental health services are in disarray around the country and operating in crisis mode. . . . Effective treatments are not routinely available. . . . Untreated mental illness is a leading contributor to Australia's suicide rate'.<sup>28</sup> The Chair of the NSW Select Committee on Mental Health stated that 'Mental Health Services in NSW need revolutionary improvement. Deinstitutionalization without adequate community care has resulted in a new form of institutionalization: homelessness and imprisonment'.<sup>29</sup>

In Victoria, the Auditor General's report on mental health services for people in crisis highlighted serious access problems even for people in acute life-threatening crises and stated:

*It is clear that the service system is under significant stress, due to demand pressure, workforce shortages and the increasing complexity of mental disorder in our society.<sup>[26]</sup>*

### **HAVE WE DONE ANYTHING RIGHT?**

This sounds like a chronicle of gloom and doom. Many of us may feel that it is not that bad. Some even resent the chorus of justified complaint and advocacy for further reform and growth. We can certainly point to the positive effects of the reforms, especially in Victoria. The pattern of care has improved and the model is essentially sound. We do have mobile community treatment teams and new inpatient facilities, the Dickensian 'bins' have gone and their culture should not be missed for a moment. The Victorian government has endeavoured, especially since its re-election, to tackle some of the fundamental issues such as extending specialized early psychosis services into new areas, tackling comorbid mental and substance use disorders, and attempting to enhance the interface between primary care and specialist mental health. Some of these initiatives have reached 'proof of concept' stage but urgently need to move to versions 2, 3 and 4 etc. Innovation is often seen as a threat rather than a boon, and not appropriately supported. There is a dedicated workforce, public sector leadership and a mental health bureaucracy who strive valiantly to hold things together and address the issues from an increasingly embattled position. Yet the momentum for reform has evaporated. It is all too little too late, and frequently in the wrong places too. Federally we have drifted into some kind of surreal comfort zone, while at the State level a barely established system is seriously eroding and becoming reinstitutionalized. Consumers and family members' experience of access and quality confirms this.<sup>25-28</sup>

The previous State hospital model treated acute episodes of severe illnesses and provided institutionalized rehabilitation services, while the general hospital and private psychiatry system focused on people with high-prevalence disorders. The reforms of the 1990s largely closed the stand-alone psychiatric hospitals and created a blend of State-funded community-based services and

new general hospital inpatient units, now with a different clientele, the former users of the asylum system. State-funded public sector resources for non-psychotic disorders shrank dramatically. The new system still concentrated on acute care but in a different way with less reliance on long inpatient stays and more home-based care. At first, this model worked much better with the mobile community teams working in flexible outreach mode. However, more recently major problems have emerged. The new inpatient units are under severe pressure. They have to manage those acute patients who cannot be treated intensively in the community and such patients uniformly need highly intensive care. This work is highly challenging, yet receives insufficient recognition and resources. The clinical leadership, morale, nursing numbers and skill levels, and the specific environmental conditions required for this challenge have fallen well short. Smaller units of 8–12 beds as found in Scandinavia, seen here as uneconomic, are urgently required, together with much greater capacity for 1:1 nursing. This can be achieved by subdividing wards into functional subunits, although few have been designed this way. The intensive care units were designed for small numbers and can function only if these numbers are kept low. In practice, they are overcrowded, highly stimulating and consequently characterized by restraint and over-medication.<sup>30</sup> There are serious iatrogenic effects here. Inpatient teams with confidence, special personal qualities and inspired leadership are crucial but remain in short supply.

For a variety of reasons, as the Victorian Auditor General's report shows, the Crisis Assessment and Treatment Teams (CATT) have become increasingly embattled and are all too often reluctant to assess and treat people comprehensively in their home and community environments. Poor work practices and policies reflect a process of staff-centred reinstitutionalization, which contrasts with the early period of reform. There has been an excessive reliance by CATT teams on police in crisis situations. With the establishment of the eCATT model in Victoria, which saw psychiatric assessment resources located in many emergency departments, there has been an increasing tendency to direct new assessments into these stressed environments, even during normal hours. This is a perverse and unwanted effect of the scheme; the opposite is required: a diversionary strategy.

Due to the lack of continuing reform momentum, the new model has become steadily institutionalized, with patchy leadership and poor morale, and consequently non-consumer-focused work practices. The capacity for State-funded continuing care and rehabilitation is woefully inadequate as shown in the findings of the low-prevalence survey.<sup>16</sup> Only a fraction, even of the most seriously mentally ill, can gain secure tenure in this system. So even with a system heavily targeted to chronic schizophrenia, only a minority even of these cases gain appropriate coverage. The rest are referred back to unsupported GPs after the latest patch-up job otherwise called 'episode of care'. In many services the feet of most early

psychosis and non-psychotic cases do not even touch the ground. The adult system remains predominantly an acute care model for people with chronic psychotic illness, translocated from the 'bins' to the general hospital system. A hidden expectation of mainstreaming is that outside of acute care the same arrangements as for other medical disorders should apply, namely GP follow up. There is no research evidence whatsoever for the effectiveness of this model in psychiatry; hence it is a default model and in no way evidence-based. However, the funding split between hospital and community care is essentially a State/Federal one and it has proved difficult to grow the State-funded community-continuing care sector outside of acute phase care. Hence the repeated call for more beds (more clearly a State responsibility) rather than more community care, which is actually the main deficiency. Finally, the modus operandi of most continuing care teams is office-based rather than the mobile assertive outreach, which is evidence-based. This is a further weakness in the model, which inflates the apparent need for beds.

The attempts to shore up the interfaces between GPs and specialist care are appropriate. However, most of their work is with so-called high-prevalence or non-psychotic disorders, and sadly there is no longer expertise in the specialist system to help them manage the more challenging of these disorders. In fact, a team approach rather than a solo GP or even a solo private psychiatrist is needed for many of these cases. At Orygen Youth Health, we do have the capacity to treat around 600 new 15–25-year-olds with non-psychotic disorder each year. However, we still have to refer out large numbers of patients (1200 referrals per annum), most of whom really need a specialist approach (as one index of this, 25% of those we are unable to accept have attempted suicide recently and are clearly significantly impaired). Moreover, we have no consultation–liaison team to work with GPs or counsellors to manage these and other cases. We are deeply worried about this scenario. Substance use and mental disorders overlap more than ever before, yet in Australia we have managed to separate the systems of care intended to respond to them, so that now we have evolved two underfunded parallel systems with poorly compatible models and territorial attitudes. Embryonic programmes have been developed to bridge this gap but the solution requires much more radical surgery and regeneration.

## WHAT COULD WE DO ABOUT IT?

In an earlier Beattie Smith lecture, Professor Sidney Bloch chose the title 'Psychiatry: an impossible profession'. Although he concluded that it was not impossible, one of the barriers we face is the widespread belief that our task is all too hard and that our interventions do not work. The general public, most politicians, many doctors, and even many psychiatrists lack faith in the efficacy of psychiatric treatments. This perception is reinforced by the wide gap between efficacy (the effect of treatment under

optimal conditions) and effectiveness (the effect under current real-world conditions). People continually see the many shortcomings of poorly funded and poorly led services. However, there are several key monographs and systematic reviews documenting treatments that work,<sup>30</sup> as well as numerous sets of clinical practice guidelines,<sup>31,32</sup> which summarize the best available evidence in support of interventions. It is clear that psychiatric treatment has never had greater efficacy and tolerability and that it compares favourably with the spectrum of medical treatments. However, the gap between efficacy and effectiveness, or EEG (a matter of quality), and the low coverage of those affected are huge obstacles. Andrews has attempted to calculate how much of the burden associated with psychiatric disorders is avertable with modern evidence-based treatments.<sup>5</sup> Although he has underestimated this for schizophrenia,<sup>33,34</sup> his general conclusions are that much of this burden, up to 40% on average across a range of disorders, is potentially avertable. If evidence-based treatment was made available and coverage was increased, we could avert nearly 30% of the burden in contrast to the present 13%. Andrews had originally argued that greater efficiency should be the priority so as to allow greater coverage, but now concedes that it would be more feasible for greater efficiency (i.e. a narrowing of the EEG) to be pursued in parallel with greater coverage, which will inevitably require an increase in resources. It actually costs more money to reduce the EEG as well as to provide services to more people. Squeezing an already fragile and pressured system harder to try to achieve these goals is already proving counter-productive.

Our expectations should be high. A central theme of the US president's 'New Freedom Commission on Mental Health' states: 'recovery – too often thwarted today by a fragmented system – should become a defining expectation of future mental health care'.<sup>35</sup> Rosalynn Carter, the former US first lady, has commented: 'Today we know that recovery is possible for every person with a mental illness'.

This resonates well with the very first guideline in the NICE clinical practice guidelines from the UK: 'Health professionals should work in partnership with service users and carers offering help treatment and care in an atmosphere of hope and optimism'.<sup>36</sup>

## WHY AREN'T WE DOING THIS? THE BARRIERS AND THE INHERENT DEGREE OF DIFFICULTY

### Stigma, mental health literacy, help-seeking and access

Sartorius argues that stigma and prejudice are the very first obstacles that must be tackled if the quality of life and of care is to improve for people with mental illness.<sup>1</sup> Whether people with mental disorders get appropriate help is the end result of a series of processes. These start in the mind of the affected person. First, there is the

issue of awareness of the problem and whether it is recognized as illness, or even as a problem. In Australia, Jorm *et al.* have made significant contributions to understanding this phenomenon of mental health literacy. To summarize, the general public had relatively poor levels of recognition of depression, which was even worse for schizophrenia.<sup>37</sup> They had little confidence in many evidence-based psychiatric treatments, and their understanding of interventions likely to be of benefit diverges strongly from that of professionals. Similar gaps occur in young people. On the canvas of this background level of knowledge and prejudice, the person with emerging subjective or behavioural change and distress and/or disability may or may not recognize that they have a problem. This is confusing for young people, especially young men. If they do so, what is their response? What would you feel, what have you felt when you have been depressed? It is common to feel shame, weakness, helplessness and an urge to withdraw from others, not only due to stigma, but also through the distorting effects of the change in mental state, the illness itself, on self-esteem, cognition, energy, judgement and, crucially, on social relationships. What is difficult in this process is how to share distress and personal problems with strangers, such as the local GP that governments insist must be the first port of call. It requires a high level of trust, a leap of faith. This leap is frequently not taken without encouragement and 'brokerage'. This is seen clearly with refugees and with young people. However, it may be equally important in other subgroups, such as middle-aged men struggling with a potentially lethal midlife crisis. Shame mixed with desperation permeates the frequent, often furtive, telephone calls I have received from mature, often successful and normally assertive people trying to obtain help for someone, a relative or friend they know is unwell or for themselves. This brokerage and advocacy is a crucial element especially when the illness itself has impaired awareness of the need for care or immobilized the person involved. What is lacking is the next step where prominent or ordinary citizens will talk openly among their friends and colleagues about the illnesses they have encountered or experienced, just as they do when someone has had an asthma attack or developed diabetes.

While an unknown number fall by the wayside, it is incredible that so many people get over these obstacles and do seek help. However, they frequently get lost along the way or take the long way round. This is because the next barrier surfaces, namely the failure of the professional they have sought out to recognize the problem or to respond effectively. Depending on the nature, severity and urgency of the problem, other barriers may then come into play, such as 'closed books', waiting lists, reluctance of specialist services to get involved (a mix of work practice and funding barriers) or the frightening and uninviting nature of clinical environments. This means that people typically present late in their illness course, and may be much less personally accessible and responsive to treatment. Treatment often gets off on the



wrong foot and there is much collateral damage to repair. The degree of difficulty is greatly increased and the prospects for a full recovery reduced by such delays and complications. The illness in question may also be biologically less responsive to treatment.<sup>38</sup>

Another key issue is the fact that many of the people we want and need to treat do not want our help or struggle to accept it. This is a major challenge for clinical staff in services for both mental and substance use disorders. In the latter, the typical stance is that people with a substance use disorder must seek help and have at least some motivation for change. Despite the seriousness of these disorders, there is no philosophical or legal framework supporting a more assertive or early intervention approach, nor the funding capacity to support such a model. Indeed, such an endeavour is still impeded by a tenacious moral dimension in conceptualizing these disorders. The clinical focus is typically on advanced phases of disorder (even in young people) where treatment can no longer be withheld, yet where it may be much less effective and the capacity to benefit reduced. Drug and alcohol services also operate on the basis of 'evidence' that these severe, persistent and life-threatening illnesses will respond to brief, almost trivial (such as 'advice') interventions just as well as longer-term ones. One suspects that neither type of intervention is having much impact on the untreated or natural course, and that little of the burden of disease associated with drug and alcohol problems is avertable with current knowledge.<sup>15</sup>

Mental health services face similar problems, especially with the treatment of psychoses and severe mood disorders. However, the philosophical and legal framework includes a stronger element of duty of care, and augmented by the growing early intervention paradigm has spawned a more proactive attitude that at least tries to overcome treatment reluctance, including assertive outreach and, where necessary as a last resort, involuntary admission. The interpersonal clinical skills, commitment and resilience required on the part of clinicians in mental health and substance use disorders is of a different magnitude to most other areas of health care. It is ironic that similar qualities in teachers and nurses attract high levels of respect and affection from the community, even translating into support for their industrial campaigns. Not so in mental health. We are more likely to be tarred with the same stigma-dipped brush used for our patients. We have to change that. A related point is the level of negative emotion that clinicians are exposed to on a daily basis. Once again, this contrasts greatly with other health-care settings. The patients can in no way be blamed for this, but the erosive effects of this on morale have been underestimated. This is partly responsible for the perceived endemic lack of warmth and flexibility frequently highlighted by consumers and their families in clinical settings. Many staff become detached and burned out. This is not their fault and indeed these effects are by no means inevitable.

## **Inequalities in mental health care**

A further barrier relates to the severe inequalities in the distribution of the already limited mental health resources.<sup>39</sup> In Australian psychiatry we have never acknowledged the effects of a very nasty trifecta. First, the incidence and prevalence of all forms of mental disorder are substantially higher in disadvantaged areas. Even for schizophrenia, the incidence as well as the prevalence is much higher in disadvantaged urban environments.<sup>40</sup> Second, in Australia, and notably in Victoria, the distribution of public mental health services, private psychiatrists and high levels of quality primary care is almost the direct inverse of the need for care. The affluent inner metropolitan areas have high levels of services of all kinds, while the growing or deprived outer suburban and rural regions have minimal resources with inevitable consequences. The funding model was never valid and is now obsolete as well. Third, while this 'law' may be true to an extent in general health care, in psychiatry it is even more discriminatory than is realized. This is because mental health services are tightly catchment. So you cannot 'shop around' either for acute care or for aftercare in the public sector. In effect you can be marooned in your own underresourced outer metropolitan or rural area, where there are few if any private sector options. It is possible for people to move beyond these catchments for private psychiatric care, for example by visiting a private psychiatrist in another part of the city. However, apart from the geographical barriers, there are large cost barriers for disadvantaged people, because most private psychiatrists, like all specialists, now charge well above the scheduled fee and rarely bulk-bill. As a result, rates of treatment for high-prevalence disorders are almost certainly much lower in disadvantaged areas.<sup>41</sup> This scenario, which pertains across most regions of Australia, has not been honestly acknowledged by health planners.

## **Further endemic obstacles**

Another set of obstacles that undermines our best efforts are somewhat endemic, but maybe by identifying them we can minimize them. The first is powerlessness. Typically, we think of the patients and their families as the powerless ones, but many mental health professionals, administrators and advocates also feel this way. It is hard not to be struck by the low expectations, the resignation, and fatalism in colleagues, even those who are perceived as 'powerful' in the mental health system. Many well-motivated people seem stuck in a gridlock not of their own making. Across the nation, disempowered mental health bureaucracies operate within a 'yes minister' culture, collude with a containment strategy in which rhetoric glosses over reality and inhibits dissent. This bureaucratic containment strategy misguidedly seeks to protect incumbent ministers and governments, even when they are sympathetic to mental health! Its architects have sought to gain legitimacy through what I have called 'assumption-based medicine'

(ABM), where selected elements of the evidence base are fed into new and poorly validated forms of modelling, the interpretation of which goes way beyond what can be deduced from such exercises. The assumptions are often more like leaps of faith. Even when conceded, they seem not to temper the conclusions. This degree of spin invites a parallel with pharmaceutical industry-commissioned studies of drug efficacy, where a perception of bias at least is widespread, particularly if the interpretation of the research seems questionable. We need to seriously scrutinize government commissioned studies of need for care and cost-effectiveness, especially when they have been directly funded as an initiative of senior bureaucrats outside of normal scientific grant schemes.<sup>42</sup> We need a fully transparent process for guiding evidence-based mental health care. I also believe that the process we have been following of trying to persuade key politicians of the value of growth and reform is not necessarily going to work on its own. What if a Minister for Health, although highly supportive, also felt powerless to change things because of a lack of cabinet support or the 'yes minister' factor? Such a minister might benefit from broader level of support and popular momentum.

Other endemic forces include austerity. Reform needs new money. Budgetary stasis, and even progressive budget cuts, such as we have seen in inpatient settings over the past 10 years, are unlikely to be associated with improvements for patients, especially given the massive new challenges faced by such units. Criticism refers to the culture of blame, usually devolved downwards, which persecutes those at the sharp end of the problem for inevitable errors or for whistleblowing and advocacy. Enmity involves the lack of collegial support and factionalism, which is often seen across services, between disciplines and even between the components within a so-called integrated mental health service. This has been augmented by the disaggregation of the public mental health system when mainstreaming occurred. We need to find ways to become a more cohesive system of care.

## THE ACHIEVABLE DREAM

*I got help early, and when I needed it, and so did my family.*

*Our insurance paid for the help we received.*

*We were able to see doctors and others who were smart, well trained, and knowledgeable about where, when, and how to make referrals.*

*We saw people who (liked and) respected us and who taught us. We saw people who liked their jobs and felt respected and valued in them.*

*I had a place to get away and regroup and hide out that was quiet, safe, gentle, and like a home away from home. People respected my privacy.*

*I never had to go before a judge, or a magistrate, and no one in my family had to act in a punitive way to get help for me*

*or themselves. No one ever locked me up or made me take medications against my will.*

*The people in my family understand that it's not all my fault, and not all their fault. They understand that everyone has a part in our lives and my troubles – and theirs. They understand that there are no simple answers and they don't see me as a disease.*

*I got to go to school, live in a decent place, get money, have my pets – have a life without giving up everything else, like my dignity and my hopes for a future I'd want to be in.*

*No-one hassled me about how sick I was or whether I deserved to get help. I just got it.*

*And when I talked, people listened. What I said, felt, and wanted made a difference. I didn't always get what I wanted when I wanted it. But people listened – no b.s.; honesty is what I got.*

*I know this all sounds too good to be true. It is. That's the only tragedy here. Estroff<sup>43</sup>*

Moving past the impossible to the achievable: what could things look like in another 5–10 years? Here is one scenario circa 2010.

## beyondeverything

beyondblue has evolved into beyondeverything and in a joint venture with health promotion agencies and the Federal Department of Health has funded a \$50m per annum continuous national campaign to promote mental health, ensure high levels of mental health literacy and actively guide help-seeking. Ordinary people talk much more freely about their own emotional problems, provide immediate support when someone they know is struggling or unwell, and can offer mental health 'first aid'.<sup>44</sup> Countless prominent community leaders and media and sporting celebrities have 'come out' and not only spoken about mental illness in their families and their own lives, but have devoted time and energy to supporting mental health services and psychiatric research. AFL and NRL clubs now include visits to psychiatric units in their community service programmes. As a result, children's and cancer hospitals have become 'celebrity-poor' hospitals. FM radio and music TV constantly features mental health issues and the whole topic has become quite 'cool'. People can recognize when they or someone close to them is developing a mental health problem, are able to provide initial support, and know exactly where to go in their area for a respectful and expert initial assessment. Emergency presentations have reduced dramatically and most assessments of these take place in the person's home or local environment.

## Youth of the nation

In 2010 the prototype early psychosis programmes established across Victoria and later across the rest of Australia based on Early Psychosis Prevention and Intervention Center (EPPIC) and its overseas cousins have provided the platform and confidence to move to a fully

fledged youth health model delivering expert early intervention in mental and substance use disorders within non-stigmatized settings. Young people aged 13–25 are able to access a broad range of primary and specialist services in community-based ‘youth precincts’ where their mental health, physical health and well-being needs can be addressed. These environments, which are jointly run by management structures that include young people, include vocational and educational services, sports and cultural facilities and workplaces. They are closely linked with networks of related services in local communities. When young people need inpatient care, they receive it in a purpose-built facility that allows them to be treated in culturally appropriate environments separate from older adult patients and from younger prepubertal children. Adolescent and adult psychiatrists, other former mental health and substance use professionals, GPs and primary care staff all receive a core specialized training in the major health issues affecting young people and also in proved clinical services within this new system. Young people at last have a functional health care system able to respond to their key health problems.

#### **The workers united . . .**

Mental health and substance use services are now delivered jointly under the same banner in the same environments with dual training for all workers. There are specialist subclinics for those who more clearly have a primary disorder in one or other realm, and those with heavily blended patterns of illness receive a more comprehensive service. Assertive and sustained intervention is now available for those with potentially serious alcohol and drug problems. Expert specialist medical care is freely available for complications of substance use without discrimination and many countries are emulating this highly effective and long overdue model.

#### **Recovery for all!**

Community mental health teams are much less office-bound and have caseloads that enable them to support people in many settings. Duration of care is no longer limited to brief post-hospital phases or restricted to the most disabled group. Vocational recovery programmes run in conjunction with employment services have appeared in all regions and are closely connected with networks of local businesses. It is now accepted that mental illness is not only associated with creativity but also productivity! The focus of mental health services is much more on care and much less on risk and containment. Bed occupancies are down and inpatient environments are smaller, modular, well-resourced, calmer and more therapeutic.

#### **Preventive psychiatry**

Firmly on the front foot now, not only are health promotion agencies infusing the community with universal messages promoting social connectedness and positive mental health, but we are proactively targeting the high

risk groups and life phases for onset of mental disorders. The population health people and the clinicians have finally come to see that their strategies are highly synergistic rather than conflicting. Targeted prevention has become especially prominent, supported by a strong evidence base, and focuses on the key life transitions, namely the period around birth and early childhood for parents and children, the lengthy transition to adulthood, the mid-life phase with its perils and the challenge of regeneration, and the retirement process. The other preventive focus has been on marginalized groups, notably young people in juvenile justice settings, recent migrants and refugees, unemployed people and the recently bereaved. Preventive psychiatry has moved beyond rhetoric to humane and cost-effective reality.

### **SOME IMMEDIATE TARGETS**

- 1) A National Mental Health and Addiction Summit should be held in 2005, opened by the Prime Minister and chaired by the new Federal Minister for Health, with all State Ministers of Health chairing specific sessions. Endorsement and participation should be sought from business, community leaders, service organizations such as Rotary, the philanthropic sector, the pharmaceutical industry, consumers, relatives, and professionals. A consensus statement should be produced and adopted, known as ‘The Canberra Declaration’.
- 2) A serious national mental health and addiction plan with progressive funding growth should be developed to supersede the abortive third plan, with specific programmes and significant new funding allocations to drive a new wave of reform over a 5 year period. This would involve direct grants tied to specific reform and growth schemes enhancing and blending mental health and substance abuse services within the State service systems and linking these to primary care. The plan should ensure that spending on mental health as a proportion of the health budget reflects the seriousness of its public health impact. It must grow at a higher rate than other health areas to catch up. An initial growth target of 10% per annum in real terms each year for 5 years should be agreed.
- 3) A National Institute for Mental Health and Addiction (NIMA) independent of the National Health and Medical Research Council (NHMRC) framework should be established with a substantial budget of \$200m per annum to fund research and innovation. National projects are designed and implemented to study risk factors for onset and persistence of mental and substance use disorders and support evidence-based medicine (EBM) in mental health. A network of centres of excellence should be created and supported, including a preventive psychiatry network.
- 4) beyondblue should be strongly endorsed by all States and federally, and be financially strengthened and

refocused with a full mandate across the full mental health spectrum, beyond depression. It should become the flagship and engine for attitudinal change across Australia. Its research role should be devolved to NIMA while its public awareness focus is enhanced and extended into prevention and early intervention campaigns. A key focus should be a new improved national suicide prevention strategy with similar quality and funding to the campaign to reduce the road toll.

- 5) A new stream of integrated care linking adolescent and young adult psychiatry resources with substance abuse services and primary care for young people should be engineered and mainstreamed with educational, vocational, sports and leisure programmes in key locations across all capital cities and regional centres.
- 6) A new system of vocational recovery programmes within public sector mental health/substance use services should be developed in conjunction with the Commonwealth and the business sector.

## DREAMS TO REALITY

We must engage and mobilize the general community. We have tried for a decade or more to appeal to sympathy and altruism. We have tentatively tried the shroud waving of our colleagues in general health, but because the effects are more complex in psychiatry, we have 'choked' on this. We have tried the hit and miss approach of influencing individual politicians and bureaucrats. Some of us have been too cautious and even colusive at times. Perhaps a more effective and sustainable approach will be to blend and temper the principles of EBM and evidence-based health care (EBHC) with social policy analysis,<sup>45</sup> projecting a solid confidence in our interventions and models, and overtly targeting the inherent self-interest of the average person. If we can convince them that they and their families are directly in the firing line, but that there are effective counter measures, we may make more rapid progress. Evidence rarely initiates or drives reform. It is best viewed as a form of insurance that confirms the direction of reform or guides the route, including the need for occasional U-turns.

This will require teamwork, a full-frontal advocacy approach, and ideally a consensus within the field particularly on reform plans based on, but not limited by, best available evidence. The proposed National Institute for Mental Health and Addiction could ultimately carry out this latter role. The coalition of defeatists, spin doctors and risk-averse bureaucrats who have held sway since the First National Mental Health Plan will have to counter the data and the arguments we marshal in a convincing way. The crucial ingredient, however, will be the engagement and support of the average Australian, and I believe that this can best be achieved by generating a direct appeal to self-interest as well as concern. This

is truly a battle for the hearts as well as the minds of Australia. It will be won only through 'people power'.

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