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# Human Rights & Mental Illness

Report of the National Inquiry  
into the Human Rights  
of People with Mental Illness

## **Part III**

# **People with Particular Vulnerabilities**

# Chapter 17

## ELDERLY PEOPLE

### Introduction

Psychiatric disorder is at least as prevalent among the aged as among the young, but elderly people also have special needs. Old age can bring economic, social, physical health and accommodation problems which make coping with a mental illness doubly difficult. Compounding these factors, evidence to the Inquiry clearly established that the elderly are often victims of discrimination in health services, either through abuse or neglect. The worst images associated with the old mental institutions — for example patients being physically restrained or sedated — are still the reality for many confused and sick elderly people. Their mental illness frequently goes unrecognised and untreated, or inappropriately treated. All these problems are becoming more urgent as the proportion of older people in our population rapidly increases.

The most serious mental illnesses, such as schizophrenia and manic depression, are found among the elderly. But two disorders afflict them particularly frequently: dementia and depression.

### Dementia

'Dementia' means a loss or impairment of mental powers. The term is used to refer to a group of conditions (including Alzheimer's disease) where the most prominent symptoms are memory loss and confusion. It is the most common mental health problem among people over 80. Among the younger elderly (65-80) other disorders are more common (especially depression), but dementia is probably still the most troublesome.

It has been called the living death. And this is really what happens. The person in later stages is there in body but their personality has gone. It is not the same person.<sup>1</sup>

Most dementia (about 70 percent of cases) is due to Alzheimer's disease, and the term 'Alzheimer's' is often used (inappropriately) to refer to dementia generally. The precise cause of Alzheimer's disease is unknown. The second major cause of dementia is stroke, which damages patches of the brain and produces 'multi-infarct' dementia. Dementia can also result from diseases such as AIDS, Huntington's Chorea or Parkinson's disease, or from alcohol-induced brain damage.

Whatever its origin, the prominent manifestations of dementia are usually the same: confusion and loss of memory (especially short-term memory), often accompanied by delusions or depression. It is usually progressive and irreversible.

There is some disagreement about whether dementia is a mental illness or simply a physical disease affecting the brain. NSW is the only State which has a detailed operational definition of mental illness incorporated in legislation,<sup>2</sup> and that definition does not include dementia. So for certain important **legal** purposes (such as involuntary admission to a psychiatric hospital) dementia is not classed as a mental illness in our most populous State. But expert witnesses to the Inquiry were virtually unanimous that for medical purposes — and in terms of social impacts — it should be treated as a mental illness.<sup>3</sup>

### **Incidence: the Ageing Population**

The number of older people in the world is increasing rapidly. The **proportion** of the population which is elderly is also rising in industrialised countries, due to lower birth rates and greater longevity.

In Australia, the number of people over 80 years old is expected to grow from 260,000 in 1981 to 560,000 in 2001 and 790,000 in 2021. The number over 65 will be 2.26 million, or 12 percent of the population, by 2001; and 3.48 million, or nearly 16 percent of the population, by 2021. Some European countries already have more than 16 percent of their population over 65.

The rise in the elderly population will bring a corresponding increase in the mental disorders of the aged. In most industrialised countries dementia currently affects about 5 percent of people over 65. However, the incidence rises sharply as age increases: 20 percent of those over 80 are afflicted.<sup>4</sup> At present, 100-140,000 Australians have moderate to severe dementia — but this number is expected to exceed 200,000 within 10 years.<sup>5</sup>

Dementia is not restricted to the elderly: 10 percent of sufferers are under 65. However, there are no services designed specifically for these thousands of younger sufferers.<sup>6</sup>

### **Where are the Dementia Sufferers?**

Approximately half of Australia's dementia sufferers live at home, alone or with relatives. A substantial number live in residential facilities (hostels and nursing homes).<sup>7</sup> Many, however, are homeless or live in boarding houses or refuges, where they frequently receive no formal treatment for their mental

illness. They also miss out on support from family and friends which is vital to so many dementia sufferers living in the community.<sup>8</sup> Expert witnesses told the Inquiry that 60-80 percent of nursing home residents have dementia, and 30 percent suffer from depression.<sup>9</sup> But some are in residential care primarily because they are physically ill or frail. If they were physically well, a significant number could live at home.<sup>10</sup>

About 3000 dementia sufferers are patients in psychiatric hospitals.<sup>11</sup> Some are there primarily because they have another mental illness, and some because their dementia produces severely disruptive behaviour. However, a number are still so confined because our society has provided no alternative.

## **Depression**

According to expert opinion, depression among the elderly often goes undiagnosed — but it may be twice as common as dementia.<sup>12</sup> About 50 percent of elderly people have at least one symptom of depression.<sup>13</sup> Estimates vary, but one Australian study found major depression in 10.2 percent of those over 65.<sup>14</sup> (Even on a conservative estimate, this would mean over 100,000 older Australians suffer this painful condition.)

One measure of depression is the suicide rate, which is higher among people over 65 than in any other age group.<sup>15</sup> The rate for men 70-79 is the highest for all males.<sup>16</sup>

Depression frequently accompanies other health problems. It often occurs alongside dementia, and the symptoms of the two conditions are sometimes confused.<sup>17</sup> It is associated with chronic physical illness, which is itself more prevalent as people get older. Depressive symptoms are also a common side effect of prescription medications, including hypertension drugs — and the elderly take far more medications than the young.

Ironically, depression is one of the most curable mental illnesses. However, the evidence indicated that among the elderly, it is often — unnecessarily — left completely untreated. All too often it is not even diagnosed.

## **Treatment of the Elderly Mentally Ill**

Evidence to the Inquiry established that our health system often ignores elderly people who are mentally ill, or assigns them the lowest priority. The elderly are more likely to get drugs, less likely to receive psychotherapy, and less likely to use outpatient services than younger patients.<sup>18</sup> They may also miss out on

the medical care they need, for example an operation or physiotherapy which could improve the quality of their lives.<sup>19</sup>

People are often denied treatment or assessment because they are old and because they are dementing. Why operate on an old person's painful joint — they haven't got long to go. Or a person with dementia doesn't get treatment for their peptic ulcer because, after all, what do they know?<sup>20</sup>

Neglecting the physical health needs of old people is a form of elder abuse. It is also self-perpetuating: elderly people in poor health are three to four times more likely to become victims of abuse than those in good health.<sup>21</sup>

Inappropriate treatment is not only unhelpful; it can also distract attention from other health problems needing attention. For example, the Inquiry heard evidence concerning an elderly woman in Queensland who was given ECT as a treatment for disturbed behaviour which was assumed to be caused by a mental illness. In fact the behaviour was due to an undiagnosed bowel irritation which, in a younger patient, might not have escaped detection for so long.<sup>22</sup>

When an elderly person's mental illness requires hospitalisation or residential care, it is hard to find a bed available. And if one is found, it is quite likely to be inappropriate. If elderly people with mental illness remain in the community, the services they need are often not provided.

In the competition for scarce mental health resources, the elderly take low priority. For example, in hospital redevelopment, the elderly are at the bottom of the list:

The acute care wards are being rebuilt first and the drug and alcohol wards, and then eventually they plan to rebuild the psychiatric wards for the elderly. That may be seven years down the track, it may be ten years. But it is going to be last, there is no doubt of that, and of course, by then I expect the money will have run out.<sup>23</sup>

Some witnesses told the Inquiry of a shortage of psychogeriatric beds in hospitals; others said the problem is not so much an overall shortage as an inappropriate distribution of beds between hospitals and other residential facilities.<sup>24</sup> When places are available, they are not always appropriate. Little attention is paid to the need to separate the demented elderly from the psychiatrically disturbed but non-demented elderly, from psychiatrically disturbed younger people and (in nursing homes and hostels) from patients whose disability is solely physical.<sup>25</sup>

## Treatment of Dementia

We may still not know what causes the major dementing illnesses and we have no cure, but we do know how to treat them. I should say that we know how to treat the people who suffer from them because there is a difference between treating the disease and treating the sufferer... Let the researchers carry on their work. We all hope that science will provide the answer and that one day there will be a prevention and a cure. But in the meantime we must spread the word that dementia is manageable, that people with dementia need to be treated because of the illness.<sup>26</sup>

Managing dementia essentially consists of providing safe living arrangements where sufferers can maintain their remaining mental and social skills and be protected, as far as possible, from events that make them anxious, confused, angry or frustrated. 'Such feelings go badly with dementia because the sufferer is unable to deal with the reason and can only respond to the feeling itself. This means that, at least in the later stages of dementia, treatment is closely linked with accommodation. In the early stages it is more dependent on support services in the community.'<sup>28</sup>

Evidence to the Inquiry consistently indicated that people with dementia in institutional care should be separated from people who are not cognitively impaired. For people without dementia, it can be very distressing to be around someone who

doesn't know what day it is, where she is, who you are, what you just said, what happened 30 seconds ago, what is happening now and what will happen to her in the next 30 seconds.<sup>29</sup>

The evidence also clearly indicated that one important distinction frequently overlooked by health planners is between dementia sufferers who are bedbound and those who are ambulant, ie physically well and inclined to wander. The behavioural changes that come with dementia can be extremely disruptive to other patients. For example, the right to personal privacy is recognised in Federal law and the Federal Government's *Charter of Nursing Home Rights and Responsibilities*,<sup>30</sup> but it is extremely difficult to enforce against a wandering co-resident with dementia:

In a nursing home situation someone with dementia can go in and rummage in somebody else's locker or dressing table. They can get into the wrong bed. And the normal aged get very upset by this sort of behaviour and lack understanding, because that bed and that dressing table is their only private space left in that time of their life. And so they need to be kept contented and happy as well as the person with dementia, who does not deserve to be yelled at for going into the wrong room or rummaging. Rummaging and wandering is a symptom of Alzheimer's disease.<sup>31</sup>

People with dementia are also a continual disconcerting reminder to other residents of what may await them as they grow older. (And since the majority of our elderly will not develop dementia, this fear is often needlessly induced.)

The needs of dementia sufferers themselves are also very different to those of many other elderly people:

They do not need stimulation, they do not need occupational therapy. They need a quiet environment where they can do duties or participate in activities they are familiar with. Simple things like light housework, raking the garden. And they need to be in small groups. Large groups can confuse them more. It would be like going into a room and not recognising anybody there. And every time they go into a gathering that is how it feels to them because their short-term memory is very, very short.<sup>32</sup>

Contrary to the approach advocated by many witnesses to the Inquiry, the Federal Government's current policy on institutional care for dementia sufferers is to integrate them in ordinary hostels and nursing homes.<sup>33</sup> Recently it modified its hostel funding formula — apparently to allow a higher subsidy for residents suffering from dementia. But it has shown little support for the idea of dedicated dementia hostels or nursing homes.<sup>34</sup>

## **Residential Treatment**

### **Hospitals**

The psychogeriatric wards of public hospitals were criticised by a number of witnesses to the Inquiry. The large institutional setting is intimidating and depressing for patients and their families, lacking in privacy and expensive to run. For example in Sydney:

I would emphasise the very inappropriate nature of the long-term ward...it is a barn. It is very institutional, quite inappropriate for long-term care, for people to live in for the rest of their lives... And you should see the toilets and the bathing facilities. It is horrible.<sup>35</sup>

And in Newcastle:

Some examples I find unsatisfactory are the persistence of dormitory style accommodation for elderly patients, the absence of facilities in many wards for visitors' rooms and also the isolation of wards in which such patients are kept. For instance at Morisset Hospital, which is the site of most of our long stay beds, there is no public transport access. The railway station is some miles away and the taxi services there charge a country rate, which means that the relatives have to pay there and back for a trip. In general the standard of accommodation is very old and requires much renovation.<sup>36</sup>



Similarly in Tasmania, the major psychiatric institution is 40km outside Hobart and public transport access is described as 'terrible'. Not surprisingly, patients there rarely receive visitors (one-tenth the number received by patients in a smaller facility in town).<sup>37</sup> The isolation this imposes is cruel — and especially difficult for elderly people and their spouses to overcome.

A particular problem for elderly people in psychiatric hospitals is that their physical health needs tend not to be adequately met. The elderly have far more health problems than younger patients, but psychiatric facilities are not equipped to deal with chronic physical ailments. This means elderly psychiatric patients do not receive the level of care they should be getting from medical specialists, physiotherapists and other health professionals.<sup>38</sup>

There was a general consensus in the expert evidence presented that people with dementia should only be hospitalised as a last resort. But some 3000 dementia sufferers live in mental hospitals,<sup>39</sup> usually because there are no vacancies at smaller facilities. Some are people who were admitted years ago with schizophrenia or another mental illness, who have grown old and developed dementia in hospital. Others have been admitted more recently, specifically for disruptive behaviour caused by dementia.

Some people currently in hospital with dementia would be unable to cope with life anywhere else. But many patients admitted to specialist psychiatric facilities improve over time, to the point where they could very well be placed in purpose designed dementia facilities (of which there are still very few), nursing homes or hostels, making room in the psychiatric facility for more disturbed people. The Inquiry was told, for example, that Hobart's Royal Derwent Hospital has some 70 patients in this category. Unfortunately, the waiting list for a place in a nursing home in southern Tasmania is 100-120 names long; and as vacancies arise, they go first to people still in the community rather than those who are already in institutions. No new dementia patients are being admitted to Royal Derwent, but those already there remain in hospital because 'there is nowhere else to go.'<sup>40</sup> As one expert said:

I have always been convinced that this is almost a crime to send elderly people to such a situation. It is always counter-productive, always makes for more disturbance, and the only possible way that the mental hospital can cope with this is either to drug them down, tie them down, or lock them in and let them pace around.<sup>41</sup>

Discriminatory funding arrangements have also been a significant problem. Before the Inquiry commenced, Federal Government rules denied admission to a nursing home to anyone who had been a patient in a psychiatric hospital for 12 months.<sup>42</sup> The reason for the rule appeared to be cost-saving for the

Commonwealth (which funds nursing homes), by keeping patients in the hospitals (which are funded by the States).<sup>43</sup>

Discrimination by nursing homes against the mentally ill also prevents transfers out of hospital. An elderly person known to have schizophrenia would very likely be rejected, even if the condition were well controlled with medication.<sup>44</sup> A psychogeriatrician at the Selby Lodge psychiatric unit in Western Australia told the Inquiry:

We have had the situation where relatives have approached a prominent nursing home, told them that their relative was in Selby Lodge, and have been told: we do not accept patients from Selby Lodge. That same nursing home, on the other hand, will ask us for help when they have difficult patients.<sup>45</sup>

### **Nursing Homes and Hostels**

For many elderly people, involuntary admission to an aged institution can be the ultimate denial of human rights. The level of dependency and corresponding loss of power experienced is often without parallel. Lives have to be adjusted to accommodate a set of routines imposed by a hierarchical structure in which the patient is at the bottom of the heap. The loss of freedom and corresponding quality of life is devastating for many elderly people.<sup>46</sup>

Nursing homes and aged hostels are an important form of accommodation for elderly people who can no longer manage living at home. The two categories overlap, but generally hostels are for those who are physically well and without significant behavioural disorders, but who need some help with eating, bathing and dressing. They have fewer staff than nursing homes, and usually no nursing or medical staff.

Nursing homes generally cater for people who need substantial daily assistance and continuing nursing care. These facilities are often associated with hospitals, and most patients are seen regularly by their general practitioners. However, most nursing homes have little or no contact with psychiatric services.<sup>47</sup>

Most nursing homes and hostels are run by charities or private operators. They are funded by a Federal Government subsidy and by the residents, who pay 85-90 percent of their pensions to live there. In some cases State governments also contribute top-up funding.

Apart from these 'Commonwealth-funded' homes, there are a number of State nursing homes (run by State governments and funded from State health budgets) and some completely private facilities.

Nursing homes and hostels are intended to serve different clienteles, but they share common problems of long waiting lists and, at least from the perspective of dementia sufferers, poor design.<sup>48</sup>

Waiting lists for admission to both hostels and nursing homes are long — partly because of a shortage of places, but more because the shortage of support services in the community causes families to see residential care as their only option. Family carers often go to a great deal of trouble to research the best place for their demented relative to go, only to find that in reality they have very little choice. If a vacancy comes up they are forced to take it, regardless of whether they consider it appropriate.

The design of nursing homes and hostels poses a major problem for managing ambulant dementia. About 10,000 dementia sufferers in Australia who live in nursing homes have serious behavioural disorders.<sup>49</sup> Nursing homes, like other old age services, are usually designed to cater for frail elderly people who are often bedbound or at least chairbound. These homes often face onto main roads, and fire regulations require that the doors be kept open. But ambulant dementia patients tend to stray from the premises, or disrupt other residents if forced to remain inside. Staff cannot be expected to chase after them constantly, so instead:

they get zonked out with medication or tied to their chairs. Not the nursing home's fault, except they shouldn't have admitted them there in the first place. They admit them there because there is nowhere else for them to go.<sup>50</sup>

Poor architectural design has been exacerbated in the past by the Federal Government's formula for funding staff in nursing homes and hostels. The formula is based on a Resident Classification Instrument (RCI) (or in hostels the Personal Care Assessment Instrument), which measures the needs of every person admitted to a nursing home. The RCI weights physical disability far more heavily than mental disturbance. Someone with dementia who is physically well rates much lower for funding than a bedbound stroke victim. This means ambulant dementia sufferers are seriously underfunded — given the staff time they actually require. As one expert witness told the Inquiry:

A 70-year-old, fit as a Mallee bull, strong ex-farmer, say, who is wandering around trying to get out, potentially aggressive if he is frustrated, doubly incontinent, gets very significantly less nursing staff than somebody who is immobilised in bed...it is incongruous and grossly iniquitous.<sup>51</sup>

Since the cost of caring for people with ambulant dementia is so high, some nursing homes refuse to take them. More disturbingly, according to one expert:

every nursing home around the country that is trying to put in a special care unit for ambulant people with behavioural disturbance with dementia is going broke.<sup>52</sup>

After the Inquiry had heard the evidence referred to above, the Federal Government (on 1 April 1992) introduced a revised RCI which gives more weight to behavioural disturbance as a factor in funding nursing home and hostel residents.<sup>53</sup> However, it is not clear that this formula will significantly address the chronic problem of underfunding for dementia.<sup>54</sup>

## **Standards of Care and the Charter of Rights**

The Commonwealth has set care standards for its nursing homes and hostels which constitute conditions for funding.<sup>55</sup> In 1990 it also introduced a Charter of Rights and Responsibilities for nursing homes and a similar one for hostels.<sup>56</sup> Whereas the standards are basically regulatory, the Charter informs consumers of their rights. The rights prescribed reflect international human rights instruments; they include the right to quality care, to full information, to personal privacy, to move freely without undue restriction, to maintain control over one's personal and financial affairs, 'to be treated with dignity and respect, and to live without exploitation, abuse or neglect'.

While witnesses expressed strong support for the Charter, evidence to the Inquiry indicated that for many nursing home residents these rights are not translating into reality:

[People] with dementia [aren't] fed, even though they can't feed themselves — the food is plonked down in front of them and they're left. Or the lack of dignity — they pull the clothes off themselves, and they're left naked. Or the lack of appreciation of personal values, so that an elderly man always had his shower in the evening, and he's forced to have it at five in the morning because that's the way the institution is structured. And of course he doesn't want the young female nurse showering him, because it degrades him, it humiliates him. And he lashes out and becomes angry when they try to do that, and so he is restrained or he is sedated.<sup>57</sup>

Even in the best nursing homes, people with dementia are frequently unable to understand or exercise their rights — for example the right to information about their treatment or the right to control their own affairs. In such cases it is up to family members or guardians to understand the Charter and protect these rights. The Charter does not mention dementia, but the Alzheimer's Association has asked the Government to consider the role of family carers in relation to the Charter, to strengthen and legitimise their involvement.<sup>58</sup>

The Charter also specifies responsibilities, including that of respecting the rights and needs of other residents in nursing homes or hostels. As previously mentioned, the presence of a person with ambulant dementia can seriously

infringe the rights of other residents who have their mental faculties intact. This places staff in the invidious position of having to decide whether to curtail the rights of one resident (eg by sedation) to preserve the rights of others (eg to privacy).<sup>59</sup> This is not a deficiency in the Charter, but rather a result of current nursing home design and the established — but quite inappropriate — policy of forcing many mentally ill elderly to live with the mentally well.

The Charter has the significant limitation that it applies only to Commonwealth facilities, and not to State government homes. Nor does it apply to psychiatric hospitals, boarding houses or private nursing homes which do not receive federal funding.<sup>60</sup> Since, according to the evidence, most people admitted to residential care have little choice and less knowledge of the type of funding arrangements applying to the facility they are going into, it is basically happenstance whether or not they get the benefits of the Charter:

We do not think, whether a service is State-run with the mental health system or Commonwealth funded in the nursing home or hostel, that people should have different rights. [In either type of institution] the needs of the person with dementia...are exactly the same.<sup>61</sup>

The Charter may not be delivering all that it promises, but the effects of excluding non-Commonwealth homes from its operation are substantial. The Charter is reinforced by a standards monitoring scheme which provides some level of control, through the potential threat to withdraw funding if standards are not met.<sup>62</sup> Residents of private or State government institutions are denied not only their rights being clearly defined, but also the protection that this monitoring affords.<sup>63</sup>

The States have their own regulations setting conditions for **licensing** of nursing homes, but evidence from several States (Queensland and Western Australia in particular) highlighted some disturbing practices in State nursing homes. Queensland has a regulation requiring the Director-General of Health to be notified if any resident has had to be coerced or restrained for long periods. The Inquiry heard evidence that this has been contravened by State nursing homes.<sup>64</sup> Some nursing homes make their own judgment on whether a person with dementia has a mental illness or an intellectual disability, and then 'process' the patient according to what is most convenient. Outright violent abuse also occurs: for example, in June 1992 a coroner in Victoria found that an elderly woman who died in a private nursing home in 1989 had been beaten by a nurse the night before.<sup>65</sup>

Denial of basic medical care is a more common form of elder abuse:

The daughter of an elderly lady in a nursing home...complained to the Senior Medical Officer of the facility that her mother's prescribed pain relief was not being administered by nursing staff...the SMO retorted: 'demented people don't feel pain.'<sup>66</sup>

Evidence to the Inquiry also suggests the general standard of living in some State nursing homes requires investigation:

For instance, six people live in a room and the food that is presented bears no resemblance to the menus on the walls.<sup>67</sup>

### **Overmedication**

Elderly people with a mental illness are more likely to be given drugs than younger patients — and less likely to be offered alternative forms of treatment such as psychotherapy.<sup>68</sup>

In the case of people with dementia, the tendency to administer drugs frequently turns into overmedication. Dementia sufferers are often alert and active at night, especially if they have not been fully occupied all day. To cope with the inconvenience this creates, staff in nursing homes often resort to the 'chemical straitjacket' of sedatives. For example, the Inquiry was told 60-70 percent of elderly patients in Tasmanian nursing homes are routinely prescribed night-time sedatives. Whether the drugs are actually administered depends merely on whether staff are available to supervise wakeful patients.<sup>69</sup>

Overmedication was also referred to by witnesses in other States,<sup>70</sup> and there is no reason to assume that Tasmania is worse than other jurisdictions in this respect.

Apart from being medically unnecessary, the sleeping tablets used are mostly benzodiazepines — drugs such as Valium, Mogadon and Serepax which are dependency-forming. The effects were described by an expert witness to the Inquiry in the following exchange:

Chairman: Is there any adverse effect that occurs from people taking sleeping tablets when they do not need them, or is it just completely neutral?

Dr Mathew: Definitely...if you sedate them they will be sleepy during the daytime and [have] hangovers and also they will get used to it and they will not be able to sleep without them. They will get habituated, most of these drugs do.

Chairman: Sorry, did you say they become habituated?

Dr Mathew: Habituated.

Chairman: So is there an element of addiction or habituation?

Dr Mathew: There is, yes.<sup>71</sup>

To make matters worse, psychiatric drugs can have effects which actually resemble the symptoms of mental illness, especially of depression. This can confuse the diagnosis and treatment, so that patients end up taking more drugs to 'cure' them of the effects of the drugs themselves.

## **Solutions: Special Dementia Care Facilities**

Many of the behavioural problems associated with dementia can be ameliorated by designing residential facilities specifically for dementia sufferers. Special dementia hostels are similar to standard hostels or nursing homes, but with a secure environment and with staff who have received training in dementia care.<sup>72</sup> These two factors virtually do away with the need for sedation as a 'management' (rather than a medical) practice.<sup>73</sup> From a practical point of view, one major design requirement is simply a garden for patients to walk in, with a secure fence around it to prevent them wandering away. The design should also minimise confusion for people who are apt to forget where they are.

In spite of the large and growing number of elderly people affected, Australia has only a handful of purpose-built dementia facilities. One which impressed the Inquiry is the **Flagstaff Gully** nursing home, opened recently in Hobart after an 8-year planning process. Operated by the Alzheimer's Association, it provides a series of small 'home-like' units in a secure environment,

but it does not appear or feel or look like a locked environment. There is enough outside wandering area and enough doors leading to other wandering places, so that they do not feel that they are in a locked environment. And neither do the staff or family who visit. And that is a very important part.<sup>74</sup>

Flagstaff Gully accommodates 32 people with ambulant dementia and significant additional problems — for example, double incontinence and behavioural disturbances like aggression or 'trying-to-get-out sort of behaviours'.<sup>75</sup> A research project is under way to compare its effectiveness with that of a normal mental hospital ward. The research to date is encouraging:

They are all so happy and relaxed... When you go there you will see people who you will say: these people are not behaviourally disturbed, they should not be here. I can assure you they were very behaviourally disturbed when they went there, and it is the environment and the staffing that has improved the situation.<sup>76</sup>

Flagstaff Gully's designers hope to demonstrate that their model is more cost-effective than a hospital ward, being cheaper to build and using staff more efficiently. They estimate staff time savings will pay for the building costs in two years.<sup>77</sup>

Another special dementia facility visited by the Inquiry is the **Lefroy Hostel** run by Anglican Homes in Perth. This hostel is also secure, with extensive grounds where the 36 patients can wander safely. The building itself is designed to allow residents to walk around without encountering long corridors or dead ends, and to end up back where they started.

Rooms at Lefroy Hostel are furnished with the residents' own familiar possessions to give them a sense of belonging, of ownership and self esteem. The dining areas are small, so that

even though they may not recognise people's names, they can recognise and retain the feeling and emotions and also retain some recognition of faces, so they can form friendships.<sup>78</sup>

Apart from the design of physical facilities, the success of residential dementia care depends critically on the quality of staff:

Good staff can partially retrieve a poor environment. The most marvellous environment cannot retrieve the situation produced by poor or untrained staff.<sup>79</sup>

The staff at Lefroy Hostel have had specific dementia training but they are not nurses. They are chosen 'more [for their] attitude to elderly people than qualifications'.<sup>80</sup> The hostel tries to keep its residents active, emphasising activities that they find rewarding and which maintain their skills as long as possible.

The operators of the Lefroy Hostel have estimated the relative cost of maintaining dementia sufferers in a standard hostel, an ordinary nursing home or a special dementia hostel like theirs:

	standard hostel	special hostel	nursing home (Cth)
cost per resident (\$/year)	17,000	<b>26,400</b>	34,000
subsidy from Commonwealth	5,400	<b>10,900</b>	24,000



The cost of running a dementia hostel is more than a standard hostel, but substantially less than a nursing home. The subsidy from the Federal Government is also lower — so low, in fact, that Lefroy Hostel loses \$250,000 per year. The Western Australian Government has been contributing approximately \$150,000 per year to make up part of the shortfall, but Anglican Homes told the Inquiry it cannot continue to operate at such a low level of Commonwealth funding. It has asked for the subsidy to be lifted to \$15,000 per year per resident. This subsidy would make Lefroy and future special dementia hostels viable, and allow a significant number of dementia sufferers currently in nursing homes to be cared for more humanely — and more cheaply.<sup>81</sup>

The NSW version of special dementia accommodation is the **CADE** unit (the acronym stands for Confused and Disturbed Elderly). There are 6 of these 16-bed units, all outside Sydney. They are purpose-built facilities designed on similar principles to Flagstaff Gully and Lefroy: a secure environment with a locked garden, catering for small numbers of ambulant residents, with behavioural disturbance, but who are not in need of nursing care. The bedrooms in CADE units are grouped around the kitchen and residents are encouraged to take part in cooking and other normal activities as much as possible. Witnesses who have observed CADE units praised them as excellent dementia accommodation, while lamenting the fact that there are so few (a total of 96 units for a State with at least 35,000 dementia sufferers).<sup>82</sup>

On the evidence presented to the Inquiry it is quite clear that the few special dementia facilities operating in Australia are far more successful than conventional methods of dealing with dementia — despite the financial and bureaucratic obstacles they face.

The demand for places in special dementia hostels is difficult to measure, because the paucity of special facilities means geriatricians and social workers generally do not consider them an option. However, one study of people with dementia found 77 percent of those admitted to nursing homes would have been appropriately placed in a special dementia hostel if one was available; only 23 percent actually needed the nursing care provided in nursing homes.<sup>83</sup> As special facilities are also much cheaper to operate, it is obvious that they are a far more economical and humane investment for dementia care than nursing homes.

Ironically, Federal Government policy is to keep down the number of nursing homes and expand the hostel sector: between 1981 and 1985 the hostel bed ratio per 1000 people over 65 has increased from 14.0 to 21.9.<sup>84</sup> But under the policy of integration, it is only standard hostels which are being encouraged.<sup>85</sup> Since standard hostels cannot cope with severely demented, behaviour-

ally disturbed people, they end up being placed in nursing homes — the very option the Government is trying to discourage.

According to one group of aged care agencies, the National Anglican Caring Organisations Network (NACON), the Government's refusal to support special dementia hostels is adversely affecting four groups of people: dementia sufferers in nursing homes (who are unnecessarily sedated or restrained); mentally well residents (who are subjected to the disturbing behaviour of their dementing neighbours); staff (who must constantly be policing dementia sufferers); and relatives (who can see that their loved ones are inappropriately placed). NACON believes this policy could constitute a breach of the Government's own standards and the Charter of Rights.<sup>86</sup>

## Community Care

A large number of dementia sufferers live at home, on their own or with relatives.<sup>87</sup> This is partly because it is so difficult to get into a nursing home or hostel; but it is also because many elderly people and their carers would prefer to 'keep the family together'— at least for as long as this is possible.

Dementia sufferers who live at home are said to be living in the community, or receiving community care. In fact 'community care' is a misnomer which obscures the reality of who is doing the 'caring'. It does not mean care by the community or even by the family, but most frequently by wives, daughters and daughters-in-law. Seventy three percent of dementia carers are female. The increasing participation of women in the paid workforce may well mean that the pool of women available for this unpaid work will shrink.<sup>88</sup>

Another effect of the ageing population is that carers are also getting older. Whether they are the wives, husbands or daughters of dementia sufferers, they are frequently elderly themselves.<sup>89</sup>

The whole demographic situation in Australia is changing, as in other Western societies. Because people had children later it means the carers are now getting older themselves and... If you're 60 years old looking after an 84-year-old mother and you've got bad arthritis, it might be difficult for you to lift her out of bed and shower her and things like that.<sup>90</sup>

As with other mental illnesses, the Federal Government's policy on dementia now aims to encourage community care instead of residential care. This policy reflects clinical opinion that residential care should be the last resort. In principle, dementia sufferers should be able to live in the community unless they are physically unwell or have serious behavioural problems such as a

tendency to run away.<sup>91</sup> Evidence presented to the Inquiry clearly indicates that providing such services would still cost the government significantly less than residential care.<sup>92</sup> But this policy can only respect the rights of the mentally ill if carers have the support services they need.

### **Burden on Carers**

Dementia places a great burden on family carers. Caring for a dementia sufferer is itself a psychological and physical health hazard.<sup>93</sup> Carers have high rates of depression, anxiety and other psychiatric problems.

The best way to support a person with dementia is to support his or her carer — because a dementia sufferer's quality of life is linked directly to the carer's ability to cope. The single most significant cause of institutionalisation is family carer breakdown.<sup>94</sup> One witness accurately reflected a great deal of evidence presented to the Inquiry:

I wanted to care for her at home, but in the end her mental state meant that I became so distressed and finally found it too difficult to cope with her. It was 24-hour care for the whole family.<sup>95</sup>

At its worst, inadequate support for carers can lead to elder abuse or 'granny bashing'. The United States has witnessed the emergence of a practice known as 'granny dumping', in which relatives unable to cope with the expense and strain of caring for their dementing elders simply abandon them in a public place.<sup>96</sup> Elder abuse ranges from neglect and manipulation to violence or exploitation:

It mostly occurs in families...because the families are under such stress that they don't know how to cope, and they lash out in frustration.<sup>97</sup>

### **Economics for Carers**

Caring for a person with dementia can be a full-time job. Apart from the economic sacrifice carers make by dedicating themselves to this task, they also save the community the cost of institutional care and accommodation. The cost of keeping someone in a nursing home is over \$500 per week.<sup>98</sup> As an incentive for home care, the Federal Government offers carers the Domiciliary Nursing Care Benefit (DNCB). The 1992 Budget raised this benefit to a very modest \$52 per fortnight — indexed annually. For the previous 11 years it had remained at \$42 per fortnight.<sup>99</sup>

Many carers told the Inquiry that the DNCB eligibility criteria discriminate against dementia sufferers. The criteria are extremely narrow. They require that

the carer live full-time with the patient, and that the patient be specifically in need of **nursing** care. Dementia sufferers need many hours of care and supervision which is not strictly nursing — so they frequently fail to qualify. This is another facet of the problem which has traditionally undermined funding for dementia sufferers in nursing homes.

Our taxation system discriminates against dementia sufferers who have paid carers living with them:

There is no allowance within the taxation [legislation] for payments made to a live-in carer. However, a person who looks after someone who is blind or confined to a wheelchair — that is, someone who has a physical disability — the person who is paying for that live-in carer can claim those expenses as a taxation deduction.<sup>100</sup>

The system also discriminates between dementia sufferers at home and those in residential care:

If someone with dementia is living in a nursing home, fees paid over \$1000 are claimable as a taxation deduction, versus no fees allowable if that person is still living at home. Indeed, that actually encourages people to move their family member into an institution.<sup>101</sup>

## **Services for People with Dementia and Their Carers**

Community care for people with dementia should start from the premise that

there is an invisible army of health workers out there who are doing most of this anyway. There are families, friends, neighbours who are doing a lot of this, and there is no way our country could afford to replace all that — nor should we try to. What we should try to do is harness it and fill in the gaps.<sup>102</sup>

The support carers ask for is hardly extravagant — indeed, in the Inquiry's view it is extremely modest:

Most carers of dementia sufferers agree that they can cope as long as they can get a good night's sleep, and some daily respite.<sup>103</sup>

The services that exist for dementia sufferers and their carers were described to the Inquiry by several expert witnesses as 'a hotch-potch, without any thought of a strategy',<sup>104</sup> 'a bureaucratic nightmare'.<sup>105</sup> This is largely because, historically, our aged services were developed with the physically frail in mind and dementia services were grafted on, often inappropriately. The most successful services overseas (eg in the UK) are based on integrated dementia teams comprising doctors, social workers and psychiatric nurses. The teams have contact with the hospitals, visit people in hostels and nursing homes, and

also support carers in the community.<sup>106</sup> Such an integrated approach is rare in Australia for any mental illness — including dementia.

As with other mental health services, dementia services, such as they are, are concentrated in the major cities. This creates serious inequities for elderly people and their carers in regional centres and rural areas, where services are often non-existent.<sup>107</sup> (See also Chapter 22 — People in Rural and Isolated Areas.)

The community mental health services that do exist are under strain due to lack of resources. This can be potentially dangerous. For example, a HACC worker in Tasmania told the Inquiry of an elderly immigrant man who was visited by a community nurse every day:

[The nurse] prepared a box of medicine for him — several pills three times a day. He would take the box in one go, unsupervised at home.<sup>108</sup>

Practical support services are important in enabling family carers to look after their elderly relatives, yet still maintain their own lives. For dementia sufferers who live on their own, these services are all that allows them to remain in the community. The services range from counselling and medical treatment to temporary residential care. They may also include assistance with housework or gardening, daycare to give the carer occasional time off, or technical solutions like changing all the locks over to one key to minimise confusion.

The services required will vary with individual dementia sufferers and individual carers. They will also change as the dementia progresses. So a primary requirement for dementia services is flexibility.

### **Daycare**

Some communities have daycare centres where severely demented, behaviourally disturbed patients are looked after by nursing staff. Daycare helps maintain the dementia sufferers' social abilities.<sup>109</sup> But more importantly, it gives family carers the occasional respite they need to continue to do the job of caring. One such centre in Hobart is estimated to keep 30-35 people in the community and off the waiting list for residential facilities.<sup>110</sup> The Inquiry was told more dementia-specific daycare centres are 'desperately needed'.<sup>111</sup>

Dementia daycare should be programmed around clients — rather than around standard tasks or bureaucratic requirements. That means being flexible, allowing people with dementia to choose whether to be involved in group activities or not, acknowledging individuality and encouraging independence.

Successful daycare is culturally appropriate. This may mean furnishing facilities in an old-fashioned style that makes elderly people feel at ease, or in a centre with Italian-speaking clients, providing an interpreter and Italian shortbread at morning tea.<sup>112</sup>

The limited daycare available does not in itself substantially alleviate the pressure on home carers. Scarce resources only allow individual dementia sufferers a few hours of daycare each week, still leaving family carers to bear the overwhelming responsibility. One witness pointed out that dementia daycare does not even approach the service that is generally expected of childcare, ie 8.30-5.30 on weekdays.<sup>113</sup> Another suggested that daycare centres should ideally function as night-care centres as well, because people with Alzheimer's disease commonly have interrupted sleep patterns and are often especially alert and active at night.<sup>114</sup>

### **Respite Care at Home**

One of the most valued support services is respite care in the home. Various organisations and departments provide services such as Meals on Wheels, home help and domiciliary nursing. Home services are usually funded through the Home and Community Care Program (HACC). Some use volunteer labour; others have paid staff. These mainstream services offer valuable assistance to aged people and their carers. However, most are designed for clients who are physically infirm but mentally competent. People with dementia have special needs. They need services which are flexible enough to accommodate their erratic life patterns, with staff specifically trained to cope with confused behaviour.

#### *The Alzheimer's Association (WA) respite service*

One apparently successful respite service is run by the Alzheimer's Association in Western Australia. It has 30 paid carers and 22 volunteers who provide help to about 100 people each week. In its three years of operation it has helped over 500 dementia sufferers, including 165 'hard cases' who were referred on by other agencies because they did not fit their criteria.

Clients can be referred to the service by any source: relatives, a GP or another health worker or agency. The only criterion for acceptance is a diagnosis of irreversible dementia. Staff assess the elderly person 'in the most unthreatening way possible': obtaining details from a family member over the telephone and then visiting the family at home. The service then matches the family with a carer who is judged most appropriate for that client. Carers are matched on the

basis of personality and past experience, rather than on an arbitrary basis such as living in the same locality.

The scheme's strong point is that it is tailored to meet the individual needs of each person. This contrasts with most mainstream programs, which require their clients to fit into fixed schedules. Clients in the respite scheme receive six hours of care a week, which can be during the week or weekend, during the daytime or at night. If the family carer wants to go out, the respite carer stays with the demented person at home. If the family carer needs some quiet time at home, the respite carer takes the client out for the day.

Each client is assigned to his or her respite carer for as long as the service is needed. This minimises the confusion that could result from having to develop more than one new relationship. Carers receive intensive training initially and then continuing training, support and weekly debriefings. This is essential because the work is stressful:

I have sat with a sufferer for six hours...it is a long time when you are with somebody who is forgetful, who repeats the same story over and over again, and does not let you out of their sight.<sup>115</sup>

The success of the training is demonstrated by the low staff turnover of 13 percent. This compares with a turnover rate of 60 percent in respite care services run by other organisations.<sup>116</sup>

The Association believes six hours a week is not enough respite care for a person with dementia. However, their resources are stretched to the limit and:

Unfortunately, at the moment, because of funding we have a waiting list of 30 families needing help. And these people are in desperate situations. Every one of them is a deserving case but they cannot be helped at this stage.<sup>117</sup>

### **Respite Care Away from Home**

People with dementia who are living in the community also need access to occasional respite care away from home. In the event of a family crisis or the family carer becoming ill, dementia sufferers often have nowhere to go except a hospital acute ward. This, the Inquiry was told, is

absolutely inappropriate. Staff in public hospitals and acute hospitals do not know how to handle somebody with dementia and because the behaviour is so paradoxical they often think the person with dementia is just being difficult.<sup>118</sup>

Lack of flexibility in the services available can have serious consequences for dementia sufferers. For example, a family carer who had to go away for several months was placed in a very difficult situation: with no temporary respite care available, her only option was to commit her mother permanently to a nursing home or hostel.<sup>119</sup>

Country people are especially disadvantaged in this regard — as in so many areas of mental health.<sup>120</sup>

## **Information for Carers**

Family carers also need information and education:

That's information about the diagnosis and likely process of the disease, so they can understand what's going on and know what to expect. They need to handle difficult behaviours, [and to know] how to communicate with a confused person, how to prevent or defuse difficult situations, how to organise respite care, how to make necessary legal arrangements, how to use the system which is a very confusing thing — ultimately how to find appropriate residential care when the need arises.<sup>121</sup>

Information about support services, like the services themselves, is generally inadequate, and in many areas non-existent and poorly coordinated. There is usually no central point of contact and carers must fight their way through a maze trying to find out what services are available and how to use them:

Knowledge is usually restricted to the knowledge of the person you go to, so if they are a Federal government employee they will know about Federal services and they will not necessarily tell you about State services or local services and vice versa.<sup>122</sup>

One solution recently developed is a brokerage model, a one-stop shop for information, referrals and services.<sup>123</sup> Brokerage offices, funded by HACC, purchase and coordinate whatever services are needed to prevent individual dementia sufferers from having to be institutionalised for as long as possible.

[The service] needs to be accessible... It needs to be user-friendly so that people don't feel intimidated from getting help. It needs to be flexible so that for one person the critical point about keeping them in their own home is if they can get meals. [In another case a person might need] someone to do some maintenance on their home so they can get up and down the steps.<sup>124</sup>

## **Alzheimer's Association**

The Alzheimer's Association is the main support group representing carers and families of people with dementia. It has a national office and state branches which provide public education programs, library resources, information and



counselling for sufferers. It runs support groups for carers and in one State, Western Australia, provides an in-home respite service. The Queensland Branch provides respite by operating two daycare centres. The Tasmanian Branch operates the Flagstaff Gully nursing home. (The Association also organises events such as national conferences on Alzheimer's disease.)

One of the Association's main functions is as an advocacy and lobby group on behalf of families of dementia sufferers. Because of the effects of the illness, the vast majority of people with dementia cannot be their own advocates; but their families are so exhausted by caring for them that they rarely have time or energy left over to perform this role.<sup>125</sup>

The Association claims an expertise in dementia management which is rare even in government health and aged services departments. This means the Association makes an extremely important contribution by helping to develop policies on dementia.<sup>126</sup>

Like other mental illness support groups, the Association relies on volunteers, but in most States it also receives government funding toward the cost of administration and provision of direct services. Like other groups, it faces a heavy demand for its services. Unlike other groups, however, the Association's clientele is growing rapidly, because the ageing of the population means the incidence of dementia is increasing much more rapidly than most other mental illnesses.

Ironically, just when demand for its services is surging, the Alzheimer's Association may lose part of its already modest funding. The Association's national office received \$300,000 as a four-year seeding grant under the Federal Government's Community Organisations Support Program. However, the Inquiry was told that grant would cease in mid 1993, and the Government had decided not to provide ongoing funding after that date. Unless an alternative source of funding is found, this will mean the end of the Association as an effective national voice on behalf of many people with dementia and their carers.<sup>127</sup>

## **Policy Issues Emerging from the Evidence**

### **Inconsistent and Contradictory Provisions**

The lack of uniform mental health legislation (see Chapters 3,4 and 29) or of portable services between the States is especially relevant for dementia sufferers because elderly people frequently live interstate from their relatives. Provisions for guardianship, power of attorney, testamentary capacity and even the

definitions of mental illness vary from state to state. Relatives trying to cope with this face enormous difficulty, frustration and expense.

The former Department of Health, Housing, and Community Services recently conducted the second stage of its Mid Term Review of the Aged Care Reform Strategy. This stage aims to develop 'integrated approaches to dementia care'.<sup>128</sup> Under this strategy, a five-year National Action Plan for Dementia Care was announced in 1992.<sup>129</sup> This Plan aims to make all aged care services more responsive to the needs of dementia sufferers and their carers. It should bring about improvements in terms of broad policy and planning. However, the Alzheimer's Association believes that implementing changes at a practical level requires an independent, well-resourced national task force on dementia, analogous to the National Task Force on AIDS.<sup>130</sup> Proponents of the task force point out that dementia is an incurable disease affecting numerically far more people than AIDS. An independent task force might prove more amenable to the proposition that dementia sufferers in residential care should be separated from non-dementing elderly people. Such a task force would also be less likely to overlook the 10 percent of dementia sufferers who are not elderly.<sup>131</sup>

People who are elderly and also mentally ill are particularly vulnerable. As is common — but inexcusable — for people with dual 'disabilities', they tend to fall between government departments: in this case between health (usually State) and aged care (Federal). One psychogeriatrician working in a State psychiatric hospital and attempting to get a community care program off the ground told the Inquiry:

The State really would like us to perhaps be entirely Federally funded, and Federal funded departments do not want to know us either: they say we are State, so which side do we go to?... HACC simply do not want to know us because we are seen as a State government department even though our particular projects...are entirely community based.<sup>132</sup>

Dividing responsibility for aged health services between the Commonwealth and the States has led to excessively rigid and complex guidelines and arbitrary distinctions. For example, whether a dementia sufferer ends up in a State or Commonwealth nursing home is purely a matter of luck. Yet their rights and the standard of care they receive may be quite different, because Commonwealth protections do not apply to State facilities.<sup>133</sup>

The conceptual and formal division between health and aged services also creates difficulties in the admission process for nursing homes. The gatekeeper to Commonwealth nursing homes in most areas is the Geriatric Assessment Team (GAT) from the Department of Health, Housing, Local Government and

Community Services. One problem, already noted, has been the policy of refusing nursing home admission to former psychiatric patients; this has recently changed. Another problem is that psychogeriatricians are not allowed to authorise the transfer of their own patients from hospital into a nursing home without approval from a GAT or a geriatrician.<sup>134</sup> To get this approval, psychogeriatricians often feel compelled to overemphasise their patients' physical problems, since GATs, like the Resident Classification Instrument, tend not to attach enough weight to dementia as a criterion for admission to residential care.<sup>135</sup>

Witnesses to the Inquiry suggested that placing psychogeriatrics and all other aged services under one budget would allow more comprehensive and equitable services.<sup>136</sup> At the very least, coordination between services would be improved!

Confusion about definitions can result in services being denied to the people who need them most. In one part of Sydney, nurses funded by HACC were assigned to provide services for the confused and disturbed elderly, but told they were not to see anyone with a mental illness, eg depression or paranoid states. Since many people with dementia also suffer from those other conditions, the nurses were in a quandary as to whether they were allowed to assist or even see these elderly people.<sup>137</sup>

Policy-making in the field of mental illness is frequently characterised by a failure to consult and inform interested groups and individuals when changes are proposed. In this respect, dementia appears to have recently fared better than other areas of mental illness. The Federal Government has consulted psychogeriatricians and the Alzheimer's Association on recent initiatives in aged care, such as the Mid Term Aged Care Review and the nursing home *Charter of Rights and Responsibilities*.<sup>138</sup> However, at a State level it appears that lack of consultation is still a major problem. In Western Australia, for example, there is no mechanism for the State's two psychogeriatricians to put their views to anyone involved with policy or service planning.<sup>139</sup> In NSW extensive consultation preceded the decision to place dementia sufferers under the *Guardianship Act* rather than the *Mental Health Act*. Even so, this has resulted in some perceived shortcomings:

We find, for example, people who are dementing and aggressive may be harmful to their family and...they're not a mentally ill person as defined by the act. So that if they haven't got a single hallucination or delusion the *Mental Health Act* can't be used.<sup>140</sup>

## **Funding**

In the competition for scarce mental health resources, the elderly mentally ill take low priority. There is an acute shortage of services for treatment, accommodation and support for family carers. Unless we rapidly develop effective planning to take account of the ageing population, the shortage will become much worse.

Throughout the mental health system, resources are overwhelmingly concentrated in institutions instead of in the community. As noted elsewhere in this report, 80 percent of mental health monies are still tied up in hospitals and other institutions, even though 95 percent of the mentally ill now live in the community.<sup>141</sup> The distribution of the aged care budget similarly focusses on institutions. Yet at least half of all dementia sufferers live at home, and more would if the support services were there to allow it.<sup>142</sup>

The Federal Government spent \$1.5 billion in 1990-91 on nursing homes, where (according to expert evidence cited earlier) at least 60 percent of residents have some degree of dementia. This represents \$21,400 per resident. Expenditure on aged hostels was \$351 million. About 25 percent of residents in these hostels have dementia, which represents \$7,970 per capita.<sup>143</sup>

Expenditure on HACC programs, which allow people to continue living in the community, was only \$279 million. The number of people using HACC was about 200,000, of whom an unknown proportion have dementia. The per capita expenditure for people living at home and using those services was therefore only \$1394.<sup>144</sup>

Evidence to the Inquiry strongly suggests that many dementia sufferers are having to make do without any assistance from government services at all. Roughly four out of five personal services to the elderly are provided by family or others in the community without cash exchange — in the private economy which is not reflected in the national accounts.<sup>145</sup> In South Australia, for example, there are an estimated 11-12,000 people with dementia. Some 4000 are in residential facilities; but of the 8000 who are not, only 2000 are on the records as using dementia services. What is happening to the other 6000, apparently no one knows.<sup>146</sup>

Providing more resources for dementia sufferers in the community cannot come about merely by redistribution. The nursing homes and hostels do not appear to have funds to spare; in fact, some of the practices which are most unacceptable from a human rights perspective stem directly from insufficient funds. So the total funding for dementia and other mental illnesses in the elderly must be

increased. At present there is some disagreement on how much money is actually spent on dementia care: the Federal Government cites a figure of \$1.045 billion in 1990-91,<sup>147</sup> but one expert witness called this 'outrageous sleight of hand':

They have used the figure of 60 percent of residents having dementia...to say that 60 percent of the total nursing home budget is therefore being applied to dementia services. And they have done the same for hostels. The fact that most of these residents were admitted for reasons other than dementia...appears to be irrelevant. The Department can say that \$1.045 billion is being allocated to dementia services whereas in fact the bulk of this sum is spent on the treatment and management of physical conditions.<sup>148</sup>

### **Home and Community Care (HACC) Funds**

Dementia services, like other aged care services, are mainly funded by the Federal Government — through nursing homes and hostel subsidies and through the HACC program. The Alzheimer's Association expressed concern to the Inquiry about two aspects of HACC: the distribution of funds through State governments, and the possibility of HACC devolving entirely to State control in the future.

HACC provides funds to match contributions from each State on a dollar-for-dollar basis. This means federally-funded services for the elderly are only provided if a State government is prepared to allocate an equal amount. Depending on the priorities of different governments, this produces gaps, duplications and inequities between States.<sup>149</sup> The Alzheimer's Association maintains that aged services are a Commonwealth responsibility which should be funded directly by the Commonwealth to ensure, as far as possible, that all elderly Australians receive the standard of service to which they are entitled.<sup>150</sup>

The possibility of HACC being handed over entirely to the States is viewed with similar misgiving by dementia support groups, which believe that the uneven record of State governments in using HACC funds casts doubt on their commitment to adequate dementia services in the future. If HACC is devolved to the States, state legislation will be needed to safeguard the rights of those affected by dementia.<sup>151</sup>

### **The Need for Specific Aged Psychiatric Services**

Australia has very few designated psychogeriatric services. Elderly people with mental illness are dealt with by the general adult psychiatry services, which sometimes do not adequately understand that problems can present differently

in the elderly. This can result in treatable conditions like depression remaining undiagnosed and untreated due to ignorance.

The Inquiry was told that elderly people of non-English speaking backgrounds are particularly at risk of their mental illness going undiagnosed. This means no attempt is made to manage their condition until it reaches crisis point. A community worker from the Migrant Resource Centre in Hobart gave this example of a 74-year-old man of Eastern European background:

I was contacted by [his] landlord... I tried to go and find the gentleman; we could not find him. The landlord let me inside so I [found out] his name and nationality, contacted the ethnic group, all possible services. The gentleman was found seven days later in a local park, probably [had been] there for the last seven days. He was totally unable to find his way home, [after] not eating for definitely several days... These examples are happening too often. It is very difficult for me to believe that nobody could recognise [the problem] earlier. I do not know how often examples like this happen in the Australian community, but they are happening much too often in [the] non-English speaking one. It is just that nobody is prepared to sit and spend enough time to recognise how deeply disturbed these people are.<sup>152</sup>

Staff may also find younger patients more interesting to work with:

they would much prefer a person with a personality disorder or an acute schizophrenia to some elderly person who may be frail and have physical problems who also is acutely depressed or anxious.<sup>153</sup>

Many elderly people have physical problems which make it difficult for them to visit doctors, outpatient clinics or community health centres. They need home visits, which they often do not get — either because of staff shortages or because their GPs do not recognise the problem.<sup>154</sup>

These problems all highlight the need for special psychogeriatric services. Witnesses to the Inquiry favoured a model based on integrated multidisciplinary teams working in the community and also with patients in hospitals, nursing homes and hostels. The teams should link in with aged medical services, including geriatric services but especially GPs, who are the main providers of health care to the elderly. One community team would be needed to cater for each 20-25,000 aged people in a particular area. The team would coordinate a range of facilities including outpatient services, acute, rehabilitation and long-stay hospital beds, as well as assessment and care in patients' homes.<sup>155</sup> A few integrated psychogeriatric services have recently been established in capital cities: on Sydney's North Shore and in St George in the south; in Melbourne and in Adelaide. But the Inquiry was told they are 'very embryonic and resisted by a lot of people'.<sup>156</sup>

## **Research, Training and Staffing for Mental Illness in the Elderly**

Considering the magnitude of the challenge posed by dementia, Australia is disastrously deficient in training and research to meet it.<sup>157</sup> For a disease which has the potential to cripple the health budget, the funding for research on preventing dementia is woefully inadequate: in 1991-2 the total expended by the National Health & Medical Research Council for research on dementia was less than \$600,000. This compares with \$10 million spent on cardiovascular disease, \$10 million on AIDS and \$11.8 million on cancer research.<sup>158</sup> One leading dementia researcher in 1989 said he spent one-third of his time trying to raise money instead of working on his research.<sup>159</sup>

One limitation on research and also on the development of special psychogeriatric services is a shortage of health professionals trained in psychogeriatric care. Expert evidence to the Inquiry indicated that the entire country has fewer than a dozen practising psychogeriatricians, whereas Britain, for example, has about 200.<sup>160</sup> At its Tasmanian hearings the Inquiry was told that State had only one psychogeriatrician, whose responsibilities covered the southern part of the State. There is not one psychogeriatrician in Queensland.<sup>161</sup> Western Australia has only two — the same number it had in 1980.<sup>162</sup>

Psychogeriatrics is not a particularly attractive area for doctors, being

one of the most personally demanding and difficult areas of medical practice. It is low tech, depending on the good nature and skills of dozens of workers, and hence does not attract the headlines and photo opportunities of other areas of clinical practice.<sup>163</sup>

For most old people their only contact with the health system is the local GP. But doctors receive virtually no training in psychogeriatrics. Many doctors simply do not know how to detect mental disorders in the elderly, much less how to treat them.<sup>164</sup>

This evidence from experts was reinforced by a 1990 study of general practitioners' ability to detect dementia and depression in elderly patients.<sup>165</sup> The doctors correctly diagnosed dementia in the majority of patients affected, but only managed to detect 20 percent of patients affected by depression. This failure is extremely important. Depression is almost always treatable — but only if it is recognised.

Doctors themselves say they feel frustrated when faced with dementia — given their lack of training. Many are concerned about the difficulty of making a clear diagnosis or of managing a progressively deteriorating condition. Equally

difficult is knowing how to help families cope with a dementing relative. GPs need training in all these areas.<sup>166</sup>

Ignorance among government policy-makers helps perpetuate the poor state of knowledge among GPs:

Recently there was a paper put out by the National Health and Medical Research Council titled *General Guidelines for Medical Practitioners on Providing Information to Patients*. We noted that there was not one reference in those guidelines as to how to deal with someone with dementia. Again, [in] a recent publication — admittedly it is only at draft stage — which is titled *Patients' Rights and Responsibilities*, which is something being undertaken by the WA Government, there was also no mention in the document as to how people with dementia could be dealt with. In other words, there was no provision for people who need advocates.<sup>167</sup>

Similarly, the Federal Government's guidelines for nursing homes (published in 1987) contain not one express reference to dementia.<sup>168</sup> This is extraordinary, given the numbers affected. The more recent guidelines on standards for aged care hostels do mention dementia.<sup>169</sup>

According to the Royal Australian and New Zealand College of Psychiatrists<sup>170</sup> more psychiatric nurses skilled in dealing with the elderly are urgently required. Education about mental illness in the elderly is also needed for other workers, especially staff of nursing homes, hostels, daycare centres and also boarding houses and retirement villages. Thousands of people, including many volunteers, provide direct care in those facilities with very little education or information about dementia or the other conditions affecting their clients. Aged care work is poorly paid, highly stressful, physically taxing and accorded little prestige.<sup>171</sup> Not surprisingly, the people who do it have a high burn-out and attrition rate caused by overwork, low morale, frustration, anxiety, anger and guilt.<sup>172</sup> Maltreatment of nursing homes patients may be at least partly attributable to the high stress on staff.<sup>173</sup> Financial remuneration is one factor, but in the absence of resources to raise salaries, administrators should recognise staff contributions, and meet their needs for training, information, counselling and adequate staff levels.<sup>174</sup>

## Human Rights

Apart from ignorance, there is another reason why the mental health needs of the elderly are constantly neglected. It is prejudice — the idea that old people are disposable items, no longer useful and not worth spending money or energy on. It is the attitude that old people are not entitled to quality of life, because getting sick, feeling depressed and losing one's memory are just natural parts



of getting old which must be expected; because they are old and going to die anyway; or because they are not assertive enough to complain.<sup>175</sup>

Visiting one day I found her in a wheelchair being pushed along a long draughty corridor, her hospital gown hitched above the pubic area and the blanket which was meant to cover her flung in a haphazard manner around her neck... Another time I arrived to find my mother tied in a chair, alone in a large room, again uncovered and she was hallucinating. I thought she was dying and tried to get help but nobody took any notice... She was treated like this because she was a person of no account.<sup>176</sup>

In contrast, the same person was later cared for by staff who respect their elderly patients:

Eventually I found an excellent nursing home... She was well cared for without any sedation, managed with kindness and firmness and a lot of attention and care. The example of an excellent matron who was active in supervising and helping and a small team of experienced senior sisters who liked old people and had been there many years, seemed to influence all the other members of the staff.<sup>177</sup>

The successful Lefroy Hostel for dementia sufferers in Perth maintains that attitudes are more important than formal qualifications in selecting the right staff.<sup>178</sup>

Older people are generally vulnerable to neglect and abuse, whether physical, psychological or economic. Australian and overseas studies indicate that 3-5 percent of the elderly become victims of abuse.<sup>179</sup>

The elderly mentally ill are entitled to the same human rights as other people who are vulnerable and in need of protection. Those who come from Aboriginal or non-English speaking backgrounds are especially disadvantaged.<sup>180</sup> (See Chapters 23 and 24 respectively for evidence relating specifically to the needs of Aboriginal and Torres Strait Islander people and of people from non-English speaking backgrounds.)

Recognising the particular vulnerability of elderly people in residential care, Australia has at least addressed their basic rights in standards and the nursing home Charter. However, evidence to the Inquiry clearly established that for many elderly mentally ill people, especially those with dementia and depression, those rights are being consistently violated.

Many elderly people rely on family members to be their advocates, but these carers already have their hands full trying to meet all the immediate needs — partly because the support services are so inadequate. Concern for the human rights of the elderly mentally ill must also, therefore, extend to the basic rights of their carers — if protection of their rights is to be effective.

The Inquiry has deliberately sought to identify the most positive models of caring for people with dementia, either in residential facilities or living at home. Those models show that dementia, like other mental illnesses, can be managed successfully without compromising protection of human rights. Facilities such as those we have identified in this chapter are encouraging — but pathetically few in number.<sup>181</sup> They must be replicated, with adaptations where necessary, so that all dementia sufferers can be treated with the respect our older Australians deserve.

1. Roberta Gripton, Alzheimers Association (Western Australia). Oral evidence, Perth 12.2.92, p347.
2. See Chapter 3 — Definitions and Conceptions of Mental Illness.
3. Prof Henry Brodaty, psychogeriatrician and Alzheimers Association Federal President. Oral evidence, Sydney 19.6.91, p263.
4. *ibid*, p262.
5. Dr Jacob Mathew, psychogeriatrician. Oral evidence, Hobart 13.11.91, p266.
6. Brodaty, *op cit*, p264. Also Lynette Chester, President, Alzheimer's Association (Western Australia). Oral evidence, Perth 12.2.92, p346.
7. Brodaty, *op cit*, p263.
8. Raphael Chapman, Community Accommodation Support Service (Adelaide). Submission, *Fritz and White Bread*, Appendix 3, p4.
9. Prof John Snowdon, psychogeriatrician. Oral evidence, Sydney 20.6.91, p511. Also Dr Stephen Tycehurst, psychogeriatrician. Oral evidence, Newcastle 9.7.91, p831.
10. Dr John Tooth, psychiatrist and President, Alzheimers Association (Tasmania). Oral evidence, Hobart 11.11.91, p41.
11. Brodaty, *op cit*, p263.
12. J Snowdon, 'Psychiatric services for the elderly,' *Australian and New Zealand Journal of Psychiatry* v21, 1987, p132.
13. H Brodaty, 'Psychiatric co-morbidity in Alzheimer's Disease', *Proceedings of the Second National Conference, Alzheimer's Association Australia*, Adelaide 1992, pp11-13, at p13.
14. Snowdon, *op cit* (ANZJP), p132.
15. A S Henderson and S J Rosenman, 'Psychogeriatrics (Part 1: Psychiatric illness in late life)', in P Beumont and R Hampshire (eds), *Textbook of Psychiatry*, Blackwell Scientific Publications, Melbourne 1989, p222.
16. Snowdon, *op cit* (oral evidence), p511.
17. Henderson and Rosenman, *op cit*.
18. Brodaty, *op cit* (oral evidence), p264.
19. *id*.
20. *ibid*, p265.
21. M Pinkerton-James, *The Elderly as Victims of Crime, Abuse and Neglect* (Trends & Issues No37), Australian Institute of Criminology, Canberra 1992, p4. Pinkerton-James cites K Pillemer and D Finkelhor, 'The prevalence of elder abuse: A random sample survey,' *The Gerontologist*, v28 No1, pp51-57.
22. Advocacy for the Aged, Queensland. Evidence provided to the Inquiry.
23. Snowdon, *op cit*, p516.
24. Brodaty, *op cit*, p276; Snowdon, *op cit*, p514.
25. Mathew, *op cit* (oral evidence), p264.
26. B Price, 'Education for caring — no longer a privilege', *Proceedings of the Second National Conference, Alzheimer's Association Australia*, Adelaide 1992, p6.
27. *id*.
28. An innovative, much more active approach has been taken by a group in Christchurch, New Zealand, where a mutual support group for people in the early stages of Alzheimer's disease has operated for two years. The group meets to talk about the difficulties faced by

- dementia sufferers, including problems they feel unable to discuss with their family members. They share ideas for coping with failing memories, and encourage each other to accept help or even make the transition into residential care. The group cannot arrest the progress of the disease, but it has been successful in enhancing the members' self esteem and ability to cope with their condition. E Peach and G Duff, 'Mutual support groups: A response to the early and often forgotten stage of dementia', *Proceedings of the Second National Conference, Alzheimer's Association Australia*, Adelaide 1992, pp61-62.
29. Price, op cit, p7.
  30. Department of Community Services and Health, *Charter of Residents' Rights and Responsibilities in Approved Nursing Homes*, AGPS, Canberra 1991.
  31. Gripton, op cit, p352.
  32. ibid, p349.
  33. R Lefroy, 'The special hostel for care of people with dementia', *Medical Journal of Australia*, v55 No3, 5 Aug 1991, p141. See also J Callum, 'Quality of survival in an ageing society', *Proceedings of the Second National Conference, Alzheimer's Association Australia*, 1992, p16. The Commonwealth Government's policy of integrating the demented elderly with the cognitively well is not explicitly stated; rather the issue of separating these two groups of patients is consistently not addressed. See for example Department of Health, Housing and Community Services, *Aged and Community Care Budget Initiative IA*, 1991; or the Department's *Aged Care Reform Strategy, Mid Term Review 1990-91*, AGPS, Canberra 1991, p177.
  34. Paul Wilmot, Anglican Homes (Western Australia), Presentation to the then Minister for Aged, Family and Health Services, 24 May 1991.
  35. Snowdon, op cit, p517, referring to Rozelle Hospital.
  36. Tycehurst, op cit, p819.
  37. Mathew, op cit, p266.
  38. Prof John Snowdon. Evidence to the Inquiry subsequent to the formal hearings.
  39. Brodaty, op cit, p263.
  40. Mathew, op cit, p265.
  41. Tooth, op cit, p42.
  42. Tycehurst, op cit, p819.
  43. Mathew, op cit, p265.
  44. ibid, p271.
  45. Dr Neville Hills, psychogeriatrician. Oral evidence, Perth 12.2.92, p367.
  46. Pinkerton-James, op cit, p4.
  47. Snowdon, op cit, p511.
  48. Mathew, op cit, p272.
  49. Tooth, op cit, p45.
  50. Snowdon, op cit, p511.
  51. Tooth, op cit, pp42,48.
  52. id; and Mathew, op cit, p267.
  53. The old RCI provided 12 criteria for measuring the level of nursing assistance needed by a patient, and only one of the 12 referred to 'behaviour'. In the new instrument, three of

the 14 criteria refer to behavioural difficulties: physical aggression, verbal aggression and other behavioural problems.

54. The owner of one nursing home that meets all the Commonwealth's outcome standards has been quoted in the press saying the funding formula means he cannot afford to take dementing or psychogeriatric patients. J Chandler, 'Standards high, but income of home isn't,' *The Age* 1 June 1992, p15.
55. The nursing home standards, introduced in 1987, are contained in the *National Health Act*, s45D. They are interpreted in a longer document used by monitoring officers as a reference: *Living in a nursing home - Outcome standards for Australian nursing homes*, AGPS, Canberra 1987. Hostel standards, formulated in 1990 under s10F(1) of the *Aged or Disabled Persons Homes Act*, are set out in *Keeping the Quality in Hostel Life*, AGPS, Canberra 1990.
56. Department of Community Services and Health, *Charter of Residents' Rights and Responsibilities in Approved Nursing Homes*, and *Charter of Residents' Rights and Responsibilities in Approved Hostels*.
57. Brodaty, op cit, p266.
58. Pat Jones, Alzheimer's Association. Oral evidence, Sydney 19.6.91, p268.
59. Lefroy, op cit, p141.
60. Brodaty, op cit, p265.
61. Jones, op cit, p269.
62. The monitoring scheme appears to be successful in compelling homes to raise their standards. Dr John Braithwaite and his colleagues at the Australian National University have been studying the effectiveness of Commonwealth regulation of nursing homes for five years. Their interim report says facilities identified as poor performers in a 1987 survey have since mainly improved their service. Braithwaite et al, *The Contribution of the Standards Monitoring Process to the Quality of Nursing home Life: A Preliminary Report*, Department of Community Services and Health, Canberra 1990. According to press reports, the Commonwealth has threatened 22 Victorian nursing homes with funding cuts over the past two years as a result of monitoring teams observing sub-standard conditions. J Chandler and D Wilson, 'Threats improve nursing home care,' *The Age* 1 June 1992, p1.
63. Chester, op cit, p350.
64. Advocacy for the Aged, Queensland. Submission, p1.
65. 'Beating "was part of cause of death"', *Canberra Times*, 3 June 1992.
66. Advocacy for the Aged, op cit, p2.
67. Chester, op cit, p350.
68. Brodaty, op cit, p264.
69. Mathew, op cit, p269.
70. For example Snowdon, op cit, p511.
71. Mathew, op cit, p269.
72. R Lefroy et al, 'The care of people with dementia: Is there a need for a special hostel?', *Australian Journal on Ageing*, v9 No4, 1990, p26.
73. Dr John Tooth. Evidence submitted to the Inquiry after the close of formal hearings.
74. Anne Kelly, Flagstaff Gully nursing home. Oral evidence, Hobart 12.11.91, p226.
75. Tooth, op cit (oral evidence), p46.

76. *ibid*, pp43,46.
77. *id*.
78. Peter McHale, Lefroy Hostel. Oral evidence, Perth 12.2.92, p360.
79. J Tooth, 'Design for residential care', *Proceedings of the Second National Conference, Alzheimer's Association Australia*, Adelaide 1992, p23.
80. McHale, *op cit*, p269.
81. Paul Wilmot, Anglican Homes. Letter, 16 April 1992.
82. Tycehurst, *op cit*, p828; Snowdon, *op cit*, p511. Formal evaluation of CADE's operations also shows the system significantly improves elderly residents' health and quality of life: R Fleming and J Bowles, 'Successful ageing in long-term care for the dementing,' *Proceedings of the 25th Annual Conference of the Australian Association of Gerontology*, Canberra 1990, pp81-84.
83. Lefroy et al, *op cit*, p28.
84. Department of Community Services, *Nursing Homes and Hostels Review*, AGPS, Canberra 1986. Cited in J Snowdon and S Mackintosh, 'Depression and dementia in three Sydney hostels', *Australian Journal on Ageing* v8 No4, 1989, p24.
85. Lefroy et al, *op cit*, p28.
86. National Anglican Caring Organisations Network, 'Resolution of Concern'. Submitted to HREOC 8 May 1992.
87. Brodaty, *op cit*, p263, and in evidence to the Inquiry subsequent to the formal hearings.
88. Dr Anthony Jorm, Social Psychiatry Research Unit, Australian National University. Oral evidence, Canberra 18.3.92, p18.
89. *id*.
90. Brodaty, *op cit*, p276.
91. Tooth, *op cit* (oral evidence), p41.
92. The Alzheimers Association in WA estimates the cost of providing a home care service to one dementia sufferer one day per week at \$5000 per year. Ideally each sufferer should receive two or three services per week, which would cost \$10-15,000 per year. The cost of ordinary nursing home care is \$27,000 per year; and even in special dementia hostels it is \$23,000 per year. A very large number of dementia sufferers use no services at all, which keeps the present overall cost of services to people living at home low. The Alzheimers Association says this non-use is unmet need: the Government is keeping costs down by failing to provide the services people need. Similarly, the cost of an intensive domiciliary service provided to dementia sufferers in Adelaide was estimated in 1989 at \$115 per week, or just under \$6000 per year. L J Mykyta and G Lovell, 'Community care for dementia sufferers', *Australian Journal on Ageing* v8 No3, 1989, p19.
93. Jorm, *op cit*, p14.
94. Brodaty, *op cit*, p267.
95. Lorraine Beard, carer (NSW). Letter, 8 July 1991.
96. T Egan, 'Dad got old, so they dumped him,' *Sydney Morning Herald* 27 March 1992, p4. Egan quotes an American estimate of up to 70,000 elderly parents abandoned in 1991.
97. Brodaty, *op cit*, p265. This is also supported by Pinkerton-James, *op cit*, p4.
98. Brodaty, *op cit*, p282; Lynette Chester, letter, 15 April 1992; Paul Wilmot, letter, 16 April 1992.
99. Jones, *op cit*, p267.

100. Chester, op cit, p345.
101. id.
102. Brodaty, op cit, p279.
103. M Hueke, 'A model for the management of people with diagnosed dementia in country areas', *Australian Journal on Ageing* v9 No4, 1990, p34.
104. Tooth, op cit, p39.
105. Brodaty, op cit, p277.
106. Tooth, op cit, p40.
107. Even the provision of nursing home and hostel beds is problematic — for example, the New England Health Region of NSW has a nursing home and hostel deficit of 277 places, based on the Commonwealth's recommended ratios of 40 nursing home and 60 hostel beds per 1000 people over age 70. Hueke, op cit, p34.
108. Zophia Pakulski, Migrant Resource Centre. Oral evidence, Hobart 13.11.91, p285.
109. F Jordan et al, 'Quality care and best practice for people with dementia', *Proceedings of the Second National Conference, Alzheimer's Association Australia*, Adelaide 1992, p3.
110. Mathew, op cit, p273.
111. id; and Gripton, op cit, p349.
112. Jordan et al, op cit, p5.
113. Jorm, op cit, p18.
114. Gripton, op cit, p350.
115. *ibid*, p353.
116. P O'Connor and E Kingsley, 'When all else fails: In home respite may be the answer', *Proceedings of the Second National Conference, Alzheimer's Association Australia*, Adelaide 1992, pp31-33.
117. Gripton, op cit, p348.
118. *ibid*, p349.
119. *ibid*, p355.
120. Chester, op cit, pp346,350.
121. Brodaty, op cit, p267.
122. Jones, op cit, p269.
123. id.
124. Brodaty, op cit, p278.
125. *ibid*, p264.
126. Dr John Tooth. Letter to the Chairman of the Inquiry, 5 March 1992.
127. Chester, op cit, p350; Franceska Jordan, letter, 13 February 1992.
128. Department of Health, Housing and Community Services, *Mid-Term Review of the Aged Care Reform Strategy - Stage 2, 1991-92*. Background Paper, 30 Sept 1991.
129. *Health Care for All Australians: 1992-93 Reforms* (Budget Related Paper No8), p29.
130. Brodaty, op cit, p264.
131. Prof Henry Brodaty for the Alzheimer's Association. Submission, p2.
132. Hills, op cit, pp377-378.
133. Brodaty. Oral evidence, Sydney 19.6.91, p265; Jones, op cit, p269; Chester, op cit, p350.

134. Hills, op cit, p366.
135. Prof Henry Brodaty. Evidence to the Inquiry subsequent to the formal hearings.
136. Snowdon, op cit, p516.
137. *ibid*, p515.
138. Brodaty, op cit, p274.
139. Hills, op cit, p372.
140. Brodaty, op cit, p274.
141. Dr John Hoult, psychiatrist. Oral evidence, Sydney 20.6.91, p408. Magdi El Hag, Victorian Community Managed Mental Health Services. Oral evidence, Melbourne 8.4.91, p125. Lisa Brophy, Association of Mental Health Workers. Oral evidence, Melbourne 9.4.91, p227.
142. Brodaty, op cit, p263; Jones, op cit, pp266-267.
143. Wilmot, op cit. This is roughly consistent with figures provided by Dr John McCallum at the National Centre for Epidemiology (Australian National University): he estimates that HACC accounts for 12.4c in each long-term aged care dollar, while residential care takes 69c. J McCallum, 'Quality of survival in an ageing society', *Proceedings of the Second National Conference, Alzheimer's Association Australia*, Adelaide 1992, p16.
144. Wilmot, op cit.
145. McCallum, op cit, p15.
146. Alzheimer's Association (SA). Evidence to the Inquiry subsequent to the formal hearings.
147. A Howe, 'Putting the pieces together — towards a National Action Plan for dementia care', *Proceedings of the Second National Conference, Alzheimer's Association Australia*, Adelaide 1992, p18.
148. Tooth, op cit (letter to Chairman of the Inquiry, 5 March 1992).
149. Alzheimers Association (South Australia). Evidence to the Inquiry after the close of formal hearings.
150. Brodaty, op cit, p277.
151. Jones, op cit, p269.
152. Pakulski, op cit, p285.
153. Snowdon, op cit, p510.
154. *id*.
155. *ibid*, p511.
156. *id*.
157. 'Alzheimer's cure key to reducing nursing home patients,' *Hospital and Healthcare Australia* v21 No7, July 1990, pp14-15.
158. Franceska Jordan, Alzheimer's Association. Submission.
159. Dr John Currie, Mental Health Research Institute of Victoria, quoted in Alan Attwood, 'Scourge of the aged,' *Time Australia*, 25 September 1989, p67.
160. Snowdon, op cit, p509. The number of geriatricians in Australia is half the recommended level of the British Geriatric Society, with only ten geriatricians in training around the country in 1990: 'Alzheimer's cure key to reducing nursing home patients', op cit, p14.
161. Mathew, op cit, pp264,275.



162. Hills, op cit, p367. In November 1992 the Western Australian Government announced it will fund a Chair in Psychiatry for the Elderly at the University of WA.
163. ibid, p368.
164. Brodaty, op cit, p263; RANZCP, *Position Statement on Psychiatric Services for the Elderly*, p2.
165. J Bower, A Jorm, S Henderson and P Harris, 'General practitioners' detection of depression and dementia in elderly patients', *Medical Journal of Australia* v153, 20 Aug 1990, pp192-196.
166. Brodaty et al, 'Dementia, doctors and carers', *Proceedings of the Second National Conference, Alzheimer's Association Australia*, Adelaide 1992, p67.
167. Chester, op cit, p345.
168. Department of Community Services and Health, *Living in a Nursing Home - Outcome Standards for Australian Nursing Homes*, AGPS, Canberra 1987. The document does refer to 'managing aggressive behaviour': 'The cause of the behaviour should be identified, steps taken to alleviate the problem, and the situation reviewed.' However, if the problem is dementia, an ordinary nursing home will have difficulty alleviating the problem. Similarly, the document mentions the use of restraint on residents' movements: 'Before use, all types of restraint, including chemical restraint, must be carefully considered and authorised by the resident's medical practitioner... When residents with diminished intellectual competence are restrained it is particularly important to involve their [family] representative in the decision.' Evidence to the Inquiry suggests the reality in many nursing homes falls far short of this considered approach to restraint of elderly patients.
169. Department of Community Services and Health, *Keeping the Quality in Hostel Life*, AGPS, Canberra 1990.
170. RANZCP, op cit, p3.
171. Pinkerton-James, op cit, p5.
172. Dr Michael Duke, RANZCP. Oral evidence, Melbourne 10.4.91, p347. Also see Bob Price, op cit, p6.
173. Pinkerton-James, op cit, p5.
174. Jordan et al, 'Quality Care and Best Practice for People with Dementia,' *Proceedings of the Second National Conference, Alzheimer's Association Australia*, Adelaide 1992, p4.
175. Brodaty, op cit, p263.
176. Thea Waddell, carer. Oral evidence, Sydney 19.6.91, p270.
177. ibid, p271.
178. McHale, op cit, p361.
179. Brodaty, op cit, p265. See also Pinkerton-James, op cit, p4. She cites J McCallum, S Matiasz, and A Graycar, *Abuse of the Elderly at Home: The Range of the Problem*, National Centre for Epidemiology and Population Health, Canberra, 1990; also NSW Task Force on Abuse of Older People, *Abuse of Older People in their Homes*, Office on Ageing, Sydney 1992.
180. Brodaty, op cit, p277.
181. Apart from Flagstaff Gully and Lefroy facilities the Chairman of the Inquiry was also impressed by a specially designed home for dementia sufferers recently opened by the Salvation Army near Geelong — Kardinia Lodge.

# Chapter 18

## HOMELESS PEOPLE

Mental illness can happen to anyone...all those shuffling lost souls...were once somebody's bright-eyed son or daughter.<sup>1</sup>

### Definitions

Homelessness among the mentally ill is a very visible and growing problem.<sup>2</sup> Formal definitions of homelessness vary, but the National Inquiry into Homeless Children defined it as a lack of shelter that is permanent, adequate and secure, together with the vulnerability that lack of shelter brings.<sup>3</sup> The US Federal Task Force on Homelessness and Severe Mental Illness defined a homeless person as someone lacking a fixed, regular and adequate night-time residence, or someone whose primary night-time residence is a temporary shelter or a place not designed for people to sleep.<sup>4</sup>

Some witnesses to the Inquiry considered homelessness to describe not only those who sleep the night outside, in refuges, night shelters and empty buildings or squats; but also the many thousands now living in sub-standard boarding houses and other inadequate, low-cost accommodation.<sup>5</sup>

Many of the problems confronting the homeless are certainly faced by larger numbers of people who are variously described as 'disaffiliated', or lacking social roots in a community. These people may live in cheap single rooms or other marginal accommodation.<sup>6</sup>

### Who and How Many Are They?

The size of the homeless population in Australia is difficult to estimate accurately.<sup>7</sup> This is partly because definitions of homelessness vary, but also because the erratic lifestyle typical of many homeless people defies attempts at measurement. However, in 1985 the Federal Department of Housing and Construction estimated that 40,000 Australians slept outdoors, and 60,000 were housed inadequately without security of tenure or income.<sup>8</sup>

The homeless are not one homogeneous group.<sup>9</sup> They include the elderly, the young, individual women and men and families. Some may be relatively stable, staying for years in a refuge or shelter; others lead very transient lives.<sup>10</sup>

However, they have one thing in common: they live in poverty, with little or no social support.

Homeless people suffer a high rate of physical and mental health problems.<sup>11</sup> In a 1991 survey in Melbourne, 90 percent of agencies working with homeless adults reported psychiatric illness as a significant problem. Other major disabilities included drug and alcohol abuse and dependence, poor nutrition, dual disabilities and intellectual disabilities.<sup>12</sup>

A recent profile of the homeless mentally ill indicates that 80 percent have been unemployed for over 10 years, and most would be regarded as unemployable. They are isolated: one-third report no living relatives, and half report no close friends. Over half have never married.<sup>13</sup>

All receive some form of social security — be it one or a combination of sickness, invalid, age or unemployment benefits. However, which pension or benefit they receive appears to be unrelated to the severity of their illness.<sup>14</sup>

Homeless people with mental illness tend to concentrate in the inner cities, but many come from the country or from outlying suburbs — where accommodation and services are even more scarce.<sup>15</sup> Some 15 percent left school before age 12, and 75 percent left by the time they were 16.<sup>16</sup>

About 90 percent of the homeless mentally ill are smokers.<sup>17</sup> Homeless people not only have much higher rates of disease than the rest of the population, they have much higher rates of mortality as well.<sup>18</sup> A witness from a St Vincent de Paul hostel for the homeless told the Inquiry:

Personal hygiene is a constant concern... Just to encourage them to bathe regularly, to change their clothes and to wash their clothes always seems a problem. They are not able to cook and eat proper food, and hence why they come to us, I believe, [is] just for nutrition.<sup>19</sup>

Most homeless mentally ill people fall into two broad groups.<sup>20</sup> One group is the ageing, destitute, long-term mentally ill. The other comprises younger people who are transient — constantly shuttling between hostels, refuges and hospitals.

Over the last 20 years the age profile among the homeless has shifted markedly toward the young.<sup>21</sup> The Inquiry was told these younger people are more likely to be aggressive, less amenable to the rules of agencies or organisations, more likely to 'cause trouble' and provoke hostility, and to kill themselves: 'they are the most distressing group to deal with.'<sup>22</sup>

It is in the evenings when you go to these centres that these young people come in. They have been out in the day wandering around and in many ways nobody can get a handle on them. They move up and down the coast of Australia between Sydney, Melbourne and Brisbane.<sup>23</sup>

## **Alienation, Isolation, Victimization and Violence**

Apart from the direct effects on the homeless sufferer, mental illness alienates other people. One worker from a Melbourne homeless agency told the Inquiry:

Just the nature of psychiatric disability is that it is feared by many people. We, as workers, find it difficult to come to grips with; people in the community also have trouble trying to do that. What that means is that they are ostracised, they are alienated, they are isolated, and they are put back into other suburbs, for instance, like St Kilda...where, in fact, there's lots of other people there that are also vulnerable.<sup>24</sup>

Suburbs like St Kilda<sup>25</sup> (or Darlinghurst in Sydney or Fortitude Valley in Brisbane) thus become 'a big stewpot of all sorts of different people with all sorts of different vulnerabilities'.<sup>26</sup> This phenomenon increases the pressures on each mentally ill person in the area — because it is not only the 'normal' community which shuns them: homeless people generally (ie those who are not mentally ill) do not understand psychiatric disability and are afraid of it:

What that means is that the people react in two ways: they either use [the homeless mentally ill] as scapegoats, and heighten and feed into what a psychiatric disability sufferer is going through; or they actually shun them and turn away and they then become isolated. So certainly...having a psychiatric disability in the homeless field or scene can be a very scary [experience], a very isolated one.<sup>27</sup>

One unfortunate consequence of this prejudice among the homeless population is that many mentally ill people prefer to stay on the streets rather than endure rejection in a refuge for the homeless.<sup>28</sup>

Homeless people's isolation is such that they can get into severe difficulties (for example, their welfare benefits being cut off) without anyone around them realising their plight.<sup>29</sup> Witnesses to the Inquiry emphasised the vulnerability of homeless people to violence and exploitation:

They can be preyed upon; some of the elderly people can be beaten up for their money; they are ostracised<sup>30</sup>... Many times they are robbed, assaulted, raped, you name it... They are systematically, almost continuously robbed.<sup>31</sup>

They are one of the most vulnerable groups in our society, open to being robbed, violently treated, sexually abused and especially mistreated in business affairs. They are easy prey for anybody, especially those wanting to 'borrow' money or cigarettes. And they usually oblige, for their own safety or they're too trusting of people, or simply the need for attention and affection... They are confused about their possessions, what they own and

where they've left them, or how much has been stolen from them or taken from them at one stage or another.<sup>32</sup>

## **Transience**

Homeless people, especially the mentally ill, typically lead very transient lives. Many are caught in a revolving cycle of hospital admissions and discharges.<sup>33</sup> They move between States, from shelter to shelter:

[They] wander the length and breadth of Australia without any consistent adequate support, virtually untouched by anyone (except maybe counter staff at CES, or Department of Family Services or Social Security), but [they] somehow have developed a link of homes, in inverted commas, throughout Australia...the Salvation Army hostels or St Vincent de Paul hostels, because they see them as the only place that really cares for them.<sup>34</sup>

Witnesses from the Catherine House women's shelter in Adelaide said their clients never stay more than two months in one place:<sup>35</sup>

[One] young woman...for a period of 2½ years she'd come back to us on 12 occasions...because she had nowhere else she could live... Another young woman of 25 who came to us was a transient and during five months she visited us seven times, and of the times she came to us on two occasions she'd been on the streets, another time living in a squat, another time she had come from the parks.<sup>36</sup>

The homeless mentally ill frequently rotate between welfare agencies:

I can remember when I started at Hanover...I went to visit another agency and standing outside was this gentleman who was - he had a psychiatric disability. He was very angry, he was yelling at a lamp post, playing with the cars. Everyone didn't know what to do. I mean, we were literally comatose. We couldn't communicate with this person and he certainly wasn't in a position to communicate with us.

I thought at that stage, oh well, I don't work here, so that is okay. Except two days later of course he turned up at Hanover Centre, so I had to deal with it.<sup>37</sup>

This restlessness (often caused by mental illness) is a convenient excuse not to provide services to homeless mentally ill people, since they are perceived as a problem from elsewhere.<sup>38</sup> At the same time, transience is virtually imposed on some mentally ill people by government services — which send them to another area as a way of passing on responsibility.<sup>39</sup>

## **Prevalence of Mental Illness**

If you ask any of the services dealing with homeless people about changes in the homeless population over the last ten years, they will talk about the growing numbers of homeless people with a psychiatric illness who arrive at their services without support or direction.<sup>40</sup>

The most common mental illness among the homeless is schizophrenia. This cruel disease is estimated to affect one in four residents in Sydney's inner city refuges for the homeless.<sup>41</sup> While this figure is high, it is consistent with studies of inner city shelters overseas, which have indicated a prevalence of schizophrenia up to 36 percent.<sup>42</sup>

In Brisbane the homeless shelters on any one night probably accommodate as many people with schizophrenia as do the psychiatric units of [the two main] hospitals. In Sydney, researchers have shown there are more people with schizophrenia using the shelters than are using the beds of the three inner city psychiatric units.<sup>43</sup>

Homelessness itself is increasing,<sup>44</sup> and mental illness is obviously increasing among the homeless. A study in Sydney in 1974 found 11 percent of homeless men had had at least four psychiatric hospital admissions<sup>45</sup> — today that figure would be considered extremely low. The National Health and Medical Research Council reports that in Australia, the US and Britain between a quarter and half of all homeless adults are 'suffering severe and perhaps chronic mental disorder'.<sup>46</sup>

According to evidence presented on behalf of the Royal Australian and New Zealand College of Psychiatrists, 50-75 percent of people in shelters for the homeless have histories of major mental illness.<sup>47</sup> A 1988 study of homeless people in Melbourne indicated over 70 percent had experienced some period of mental disorder, and almost half of those had current disorders.<sup>48</sup> This evidence is also consistent with studies overseas.<sup>49</sup>

At the Ozanam House shelter in Melbourne, which accommodates up to 180 men per night, a survey of long-term residents, who have been there five to ten years, found 25 percent have a current psychiatric illness.<sup>50</sup> At the Catherine House shelter for women in Adelaide, 32 percent of residents have a history of mental health problems. (Overall, 75 percent have drug or alcohol problems and/or intellectual or psychiatric disabilities.)<sup>51</sup>

At Matthew Talbot Hostel for homeless men in Sydney, the psychiatric illness rate is estimated at about 30 percent.<sup>52</sup> At St Vincent's Hostel in South Brisbane the rate is 15-30 percent.<sup>53</sup> The Salvation Army's Crossroads agency in Melbourne told the Inquiry that during 1990, one-third of the 24,000 people requesting help from Crossroads had a psychiatric illness or severe behavioural disorder.<sup>54</sup>

The magnitude of the problem has been well documented in the past and should not require further detailed surveys... Issues now revolve around the adequacy, effectiveness and coordination of services for people with a mental illness. These are questions of political will rather than of further demonstration of need.<sup>55</sup>

## Treatment

The right of these people to first rate treatment and rehabilitation is denied to them. I believe it is a disgrace which no caring community should tolerate, if not for compassionate reasons, then for selfish reasons.<sup>56</sup>

Homeless people need accommodation, but if they have a serious mental illness they also need treatment. Many mentally ill people have difficulty obtaining treatment, or even recognising that they need it — and the homeless are especially disadvantaged in this regard because they have no family or friends to give them support.<sup>57</sup> As a result:

These people tend to move in and out of crisis situations, often resulting in them either being picked up by the criminal justice system or remaining on the peripheries of society. They rely on homeless and crisis agencies to cope until events escalate into what could have been an avoidable acute admission.<sup>58</sup>

In theory, the policy of deinstitutionalisation means the homeless mentally ill should be receiving treatment through community mental health services, with hospital admissions for the occasional acute episode. (This approach to treatment is now the 'accepted norm', rather than prolonged institutionalisation in a psychiatric hospital.) However, as one submission to the Inquiry said:

Despite their failings, institutions did at least provide food and shelter.<sup>59</sup>

On the streets, the mentally ill find neither adequate food nor shelter. Nor are they likely to receive treatment for their mental illness.

The most poverty-stricken group in our community, stricken and alone, lost, eke out their days in a monotonous way, often still tormented by the symptoms of florid mental illness.<sup>60</sup>

Witnesses representing homeless agencies and hostels repeatedly told the Inquiry of the difficulties they experience in attempting to obtain or sustain treatment for their clients who are mentally ill. One problem which arises frequently is that mentally ill residents in hostels or refuges refuse to take their prescribed medication. Staff with no mental health training are then forced to confront a person who is becoming psychotic. A worker at the Ainsley Village homeless shelter in Canberra described a common scenario:

They will lock themselves in...and when we go up there and they say, 'I do not want to see anybody' — in fact we have no powers. We would not force anyone to do anything they would not do. But it gets to the stage...where we need some sort of power to — here we go, we are talking about human rights here — but to try and force people to take their medication.<sup>61</sup>

Sometimes 'if it is a real crisis', staff from the shelter take the mentally ill person to a hospital, only to find the hospital refuses to accept the person as a patient. An appalling shuttling process ensues:

So what we are forced to do in many cases is to pin an eviction notice on their coat and leave them in the emergency centre. Well, this is very upsetting for us...to try and force the hospital to take these people. We have done that and they send them back. They have sent them back in a taxi. One chap collapsed on the floor; we had to put him in hospital, send him back again.<sup>62</sup>

In many cases, what I've had to do is put them in a taxi and send them up to hospital. Many times they've sent them back to me.<sup>63</sup>

Even when a hospital does accept a homeless mentally ill person,

they have short-term [treatment] and the door swings back and we get them back again. They go off their medication and we are pleading with the hospital to take them back again, and so it goes on.<sup>64</sup>

An experienced Melbourne psychiatrist described to the Inquiry the life pattern of the thousands of homeless Australians affected by mental illness:

Most, sadly, cycle backwards and forwards from shelter to hospital back to shelter again like some endless game of musical chairs, competing for the few beds available and leaving often prematurely from hospital, and often inappropriately, before any response to treatment.<sup>65</sup>

Despite the difficulty of obtaining treatment, however, many homeless people do end up in hospital — at least briefly. (A 1991 study in Western Australia found 10 percent of patients discharged from Graylands psychiatric hospital had been homeless before admission; 46 percent had been homeless at some point, and 14 percent said they were frequently homeless.<sup>66</sup>) The disparity between the rhetoric and the reality is not so much what happens in our hospitals — but the pathetic paucity of services available after discharge.

## **Medication**

Many mentally ill people have been prescribed medication to lessen the severity of their illness, but non-compliance in taking medication is common. Homelessness increases the chance of non-compliance, because transience makes it virtually impossible to maintain a routine. The homeless mentally ill are also likely to have difficulty obtaining medication, and they have nowhere to store it. Since they lack the support and continuity of family and friends, homeless mentally ill people rarely have anyone monitoring whether they are taking their medication, or even whether any has been prescribed for them. They may



wander from refuge to refuge without anyone knowing what treatment they are (or should be) receiving.<sup>67</sup>

## **Why Are They Homeless?**

Why some people become homeless and others do not is poorly understood. Many factors contribute to the genesis of homelessness, including mental and physical health, institutionalisation as a child, socioeconomic status, intelligence, education, personality, family and social support, and the prevailing economic and social policy climate.<sup>68</sup>

Witnesses to the Inquiry generally identified homelessness as the result of poverty,<sup>69</sup> alienation and the housing crisis, the loss of boarding houses and other low-cost accommodation,<sup>70</sup> and the inadequate provision and high cost of housing for those most in need.<sup>71</sup>

For example, in Sydney in 1987 some 28 boarding houses, which had long provided cheap accommodation in the inner city, were demolished and replaced with expensive units [to house] visitors to the Bicentenary. As far as we are aware, no provision was made for the occupants of the boarding houses.<sup>72</sup>

## **Does Mental Illness Cause Homelessness?**

A major American study of the health of homeless people found that homelessness and mental illness are causally related.<sup>73</sup> Mental illness can directly or indirectly lead to homelessness — either through deinstitutionalisation or simply because mentally ill people do not get the support they need to cope with normal life. Conversely, homelessness precipitates and exacerbates a wide range of health problems, including mental illness. Homelessness also makes treatment and management of mental illness more difficult, even if appropriate services are available.

The policy of deinstitutionalisation, which began in the 1960s in some States and later in others, is widely believed to be the major cause of homelessness among the mentally ill. But the homeless mentally ill did not become visible in large numbers until years after the peak of that policy. Clearly, therefore, deinstitutionalisation was not the only cause. The loss of low-cost rental housing since the 1970s is another important factor.<sup>74</sup>

It is our view that people with schizophrenia who once could afford a room or boarding house can no longer do so and must seek shelter in the refuges. In fact, it was only after 1981 when low cost accommodation became scarce in Sydney that 20 out of the 22 schizophrenic men [in the study] began to use the refuge on a regular basis.<sup>75</sup>

In an era of affordable accommodation, our psychiatric hospitals were emptied with little or no thought apparently given to where the former patients would live. (If thought was given, then clearly grossly inadequate resources were allocated to translate policy into reality.) In the 1990s analogous and equally irresponsible practices continue. Mentally ill people are admitted to hospital in an acute state, then discharged without health authorities having any idea what becomes of them.

Apart from the direct effects of deinstitutionalisation, evidence to the Inquiry clearly established that homelessness is a frequent consequence of mental illness. Expert witnesses referred to a 'social drift' of people with long-term disabilities down the socioeconomic scale, through unemployment and into homelessness.<sup>76</sup> It is especially true of people with schizophrenia and those with drug and alcohol abuse problems (which frequently accompany mental illness among the homeless)<sup>77</sup>, who end up 'disadvantaged and destitute'.<sup>78</sup>

The vulnerability of someone with a current disorder is considerable... As social and economic supports fall away, it becomes increasingly likely for a person to become homeless.<sup>79</sup>

### **Does Homelessness Cause Mental Illness?**

A person who is homeless is susceptible to stress and hardship that most of us cannot even begin to imagine. Such pressures are likely to bring about mental illness.<sup>80</sup>

For most homeless people with a mental disorder, the disorder occurs before homelessness.<sup>81</sup> However, on the evidence presented to the Inquiry, it is clear that homelessness may contribute to mental disorders, to associated problems such as substance abuse, and to impeding appropriate treatment or responses. As one expert witness explained:

It's certainly true that people become mentally disturbed [and] very depressed by their experience in this environment... You often see people talking to themselves or... sitting together talking and having what I call parallel conversations — so in other words nobody is listening. And I think that sense of isolation and lack of feedback does lead to mental disturbance, and certainly would contribute to pre-existing mental illness and...to drug-taking and alcohol abuse and, I think, would cause depression.<sup>82</sup>

This view is strongly supported by recent overseas research.<sup>83</sup>

Homelessness and poverty can also contribute to a perception of mental illness:

If that person was well off, had supports, they may be labelled eccentric. If they are poor, without accommodation, homeless, they are labelled mad. And I think that is a big distinction we need to be aware of.<sup>84</sup>

## Particularly Vulnerable Groups

The combination of homelessness and mental illness is a daunting burden. But among the homeless mentally ill there are groups with special needs who are even further disadvantaged.<sup>85</sup>

One group frequently identified by witnesses was homeless women.

Very little information is available on homeless women: most surveys of the homeless focus on single men.<sup>86</sup> Few services exist for homeless women, or for homeless families.<sup>87</sup> Boarding houses, being mixed accommodation, are often inappropriate for women who have been abused by men.<sup>88</sup> For women with a mental illness, sometimes compounded by drug or alcohol dependency, there is almost nowhere to go — especially if they have children. In Adelaide, for example, Catherine House is the only shelter prepared to take women with psychiatric or substance abuse problems.<sup>89</sup> But even that shelter cannot take children — so in Adelaide, as in a number of other cities, women with children who are homeless and mentally ill have no accommodation options at all.

Children and young people with mental illness are also at particular risk if they become homeless. The deprivation, violence and exploitation associated with youth homelessness has been described in the Commission's report *Our Homeless Children*; mental illness makes a homeless young person even more susceptible to those risks.<sup>90</sup>

People who live in rural communities are another group with special needs. Homelessness and mental illness are by no means confined to the cities:

Almost all the new services which have been established to accommodate and assist homeless people in the country areas report that they have many clients who have been discharged from hospitals or who are mentally ill.<sup>91</sup>

Smaller population centres also lack the cheap accommodation which transient people can often find in cities. In Port Lincoln the Inquiry was told:

There are no hostels, no boarding houses, there is no form of alternative accommodation in Port Lincoln, and I have known of young people sleeping on the oval because they suffer from schizophrenia and nobody wants to have them in their home.<sup>92</sup>

Mental health services generally are woefully lacking in country areas, and any support for the homeless mentally ill is spread very thin indeed.<sup>93</sup>

Dual and multiple disabilities are common among the homeless.<sup>94</sup> For example, many homeless people have a mental illness and an intellectual disability, or a mental illness and a substance abuse problem:

We observe that these people in fact abuse a variety of substances to cope with their illnesses and their subsequent rejection by existing [mental health care] systems. [They often use] prescription pills and alcohol rather than hard illicit drugs.<sup>95</sup>

People with dual disabilities have particular difficulty coping with daily life: they are possibly the most disadvantaged of all the mentally ill. Paradoxically — and inexcusably — they are often excluded from support services because they do not comply with formal guidelines designed for only one disability. For example:

The staff of one inner urban non-medical detox [centre] cannot supply people with medication for mental illness because it is a non-medical detox! This leaves the person unfortunate enough to be afflicted with a dual disability — alcohol dependence and mental illness — without access to treatment services. Similarly, many psychiatric services refuse to treat the mentally ill who have drug or alcohol related disorders.<sup>96</sup>

The resistance from government psychiatric services is based on the assessment of problem behaviour as being 'drug induced' and therefore not appropriate to a mental health facility.<sup>97</sup> The evidence from staff in one major Victorian agency typified reactions to this policy expressed by community groups:

We recognise that the distinction between psychiatric illness and substance abuse can be murky, however... It is our belief that the [Victorian] Office of Psychiatric Services has to accept the reality of this client group, that they are likely to abuse substances (as opposed to being addicted to them), and that this is another symptom of the individual not coping, rather than the cause.<sup>98</sup>

This process of exclusion 'borders on the systemic for homeless people with multiple disabilities'.<sup>99</sup>

## **Conditions in Shelters and Refuges**

Many who would have been in previous times housed in hospitals...are now housed in accommodation which would never be tolerated in hospital.<sup>100</sup>

A major form of accommodation for homeless people in cities is shelters or refuges. Many of these are run by religious charities, often with government support; others are funded directly by State governments. The biggest hostels, located in Sydney<sup>101</sup>, each provide a meal and a bed for up to 400 men per night.

With the enormous size of the hostel there is little quality or quantity of care for the individual... Care facilities need to be small to build up decision-making ability and a sense of worth.<sup>102</sup>

Three of the largest urban shelters for the homeless are run by the St Vincent de Paul Society. In a written submission to the Inquiry, the Society described these shelters as

a dumping ground for men with a behavioural or mental illness problem. Police, hospitals...ambulances etc just drop them off at the front door.<sup>103</sup>

Conditions in the refuges and shelters — even the most reputable — are clearly unsatisfactory:<sup>104</sup>

There is one psychiatric nurse available and most of his/her effort is taken up with dispensing medications. The men spend most of their time waiting for meals, a bed etc. There is a general feeling from the staff that we are letting men down — we offer food, shelter, but that's it. Loneliness and anonymity pervade the hostel.<sup>105</sup>

Crowding is a major problem, especially for the mentally ill:

People with schizophrenia and manic depression illness spend a great deal of time during the night walking. At present there is a lot of frustration experienced as some people are trying to sleep and others are in motion.<sup>106</sup>

They need to stomp around at night, and there's just no place for them to stomp between mattresses on floors.<sup>107</sup>

Residents are generally locked out of dormitories during the day,<sup>108</sup> and:

The lack of privacy is unbelievable, even your clothes are put in a wire basket, people can see all your everyday activity — it is a very public thing to happen to you.<sup>109</sup>

Refuge life can also be stressful and distressing:

During the day there [are] up to two or three hundred people on the premises. For anyone with a psychiatric disability that is quite frightening, to be in amongst people with psychiatric, intellectual, drug [addiction] and alcoholic dependency.<sup>110</sup>

Security is also a major concern. At Catherine House in Adelaide:

We have four staff...but because of the behavioural difficulties that we experience at times, we do need someone [on duty] 24 hours a day. We believe it is unsafe for the women generally and for individual women to be in that house without someone who can immediately get assistance... We have tertiary students sleeping over from midnight till 7.30 in the morning, and their job is to contact a staff member if there's a problem. But it is a cause of anxiety...because there's not someone right on the spot.<sup>111</sup>

Sometimes the difficulties caused by disturbed or sick people must be dealt with by calling the police:

There's often violence in the house at 3am...[or] during the night from 10 or 11. Sometimes the police are asked to come in.<sup>112</sup>

We can't always cope with the problems that arise and we do have to ask them to leave, and indeed at times we have to ask the police to assist us and move these women on.<sup>113</sup>

## **Women's Refuges**

I am finding more and more that women are choosing to return to unsafe situations because accommodation is not available.<sup>114</sup>

Homeless women and their children are frequently referred by welfare agencies to women's refuges, because no other alternatives are available. These refuges generally serve as a haven for women who have been victims of domestic violence. Bringing mentally ill women into a refuge, where they cannot receive any appropriate treatment, can have deleterious effects on others who are there attempting to recover from the experience of domestic violence.<sup>115</sup>

It's a burden to other residents already in the shelter who are experiencing crises themselves, and when a woman is inappropriately referred she either contributes to [the others'] crisis situation, or they will start to target her because they can't understand what's going on and they are frightened. And it also has issues for staff working in shelters, in terms of the amount of resources that you need to allocate to one person when there are several families experiencing distress.<sup>116</sup>

Conditions in women's refuges (such as the necessary high level of security) may also aggravate a mental illness or disorder. One of a number of examples cited to the Inquiry concerned a woman who had paranoid schizophrenia and was fleeing a violent home:

I referred her to one of the women's shelters and they were happy to assist her because she was on medication and it was controlling her situation. However, as soon as [we] got to the women's shelter she saw the security screens on the windows and doors, and that immediately escalated her mood and she became paranoid. Within five minutes it became apparent that it wasn't appropriate for her to stay in any shelter accommodation... [Eventually] the woman was quite frustrated with the limited options she had and chose to return to an abusive relationship, stating that at least there she knew what was happening and...what she was dealing with.<sup>117</sup>

It is inexcusable that women suffering a mental illness are forced to choose between homelessness and violent abuse.

## Homeless Service Agencies

It's a wonderful feat that the financial cost and some of the odium of caring for this group has been shifted from health services to someone else.<sup>118</sup>

The Inquiry heard evidence in every State from representatives of refuges, charities like St Vincent de Paul and the Salvation Army, and other agencies providing shelter or services to the homeless. Many of these witnesses believe they have shouldered responsibility for the homeless mentally ill as a result of deinstitutionalisation;<sup>119</sup> but that government bodies have failed to recognise or support them in that role.<sup>120</sup>

Professor Ian Webster, a doctor who cares for the homeless in Sydney, expressed the frustration of charitable organisations:

Does anybody ask these organisations are they prepared to pick up the tab or pick up the load when a government makes a decision not to do something?... Nobody has asked the people at Matthew Talbot hostel, or me or the nurses who work with me, is this something that you have expected to do in that environment?<sup>121</sup>

Many staff in non-government homeless agencies resent having to cope with people who were never intended to become their responsibility. The agencies work on the assumption that most homeless people are 'fairly ordinary people who will eventually be able to get back to a home or...return to a normal life.'<sup>122</sup> But increasingly, the homeless consist of people who are so disabled that they need permanent support of many kinds, not just emergency accommodation for the night. Government mental health policies — either deliberately or negligently — have forced these people onto the doorsteps of charities which have neither the resources nor the skills to help them:

No department will accept the responsibility so homeless persons agencies with open door policies become the only option.<sup>123</sup>

The growing problem of mental illness among the homeless has prompted some agencies to form special bodies dedicated to this issue. For example, the Society of St Vincent de Paul, which has worked with homeless people for many years, has formed State and National Committees in Support of People with Mental Illness.<sup>124</sup> However, no comparable response has come from governments to specifically address the needs of this very vulnerable and disadvantaged group.

Accommodation is not the only area where agencies feel compelled to do the job of governments. Homeless people are entitled to income support, health and other services, but the government departments which should be providing

those services are reluctant to deal with the homeless mentally ill. The burden of advocating and obtaining these services for them invariably falls on the shoulders of the agencies.

## **Access to Services**

Effective responses by psychiatric services to assist staff and people who are homeless with a mental disorder have been limited... Services have, in many cases, remained inflexible and inaccessible.<sup>125</sup>

Homeless people are affected by a pincer movement: they are caught between increasing poverty and decreasing capacity of the system to respond to people in need. This means the homeless mentally ill are routinely denied the services and benefits they need most, and which other people reasonably expect to have: housing, employment, social security, medical care and other services.<sup>126</sup>

## **Discrimination**

One reason for this deprivation is discrimination.

Homeless people find themselves excluded from generic services. They may be considered undesirable or too much trouble or inappropriate...or the way that services are delivered is inappropriate for someone who is unable to keep an appointment or who feels too uncomfortable to hang around for long periods in crowded waiting rooms, to be viewed at best with curiosity and more usually as an object of distrust and suspicion.<sup>127</sup>

The Inquiry was told government health services are reluctant to deal with the homeless, especially if they are mentally ill. For example, if a homeless person with mental illness needs medical treatment, even for major problems requiring an operation, staff of non-government agencies are forced to adopt 'extraordinary strategies' to get them accepted into a public hospital. And

even when they got them into hospitals, of course, they came out as quickly as lightning because [the hospitals] had great difficulty coping with them.<sup>128</sup>

## **Bureaucratic Barriers**

Another reason homeless people are denied access to the services they need is the rigid division of responsibilities among government departments:

Increasingly barriers are being set [up]...and people are saying 'this is not my problem but somebody else's problem. This doesn't belong to the mental health system, it belongs to the social welfare system; it doesn't belong to the social welfare system, it belongs to the judicial system,' as the case may be.<sup>129</sup>



Government departments tend to see their functions as meeting only certain specified needs. As one expert witness commented, they prefer only to deal with 'clean-skins', and not with people who have complex problems with every aspect of their lives.<sup>130</sup>

As already noted, people who have multiple disabilities — and thus do not fit neatly within the guidelines of any one service — often miss out altogether. A homeless person with a mental illness typically has many overlapping needs,

and whilst departments argue about [who should take] the responsibility for that person, no support is provided in the meantime by the statutory authorities.<sup>131</sup>

If no department accepts responsibility, the homeless agencies with open-door policies become the only source of assistance.<sup>132</sup> However, even some of the agencies prefer not to deal with mentally ill people, based on past difficulties with individual clients.<sup>133</sup>

### **Identification Requirements**

Another obstacle is the increasingly strict requirement for proof of identity and entitlement. When governments have, in the past, decided to tighten eligibility for people claiming health or welfare services, little consideration appears to have been accorded to the consequences for the homeless mentally ill — all of whom depend on the welfare system.<sup>134</sup>

The national health system has in many ways improved homeless people's access to health care, but

On the other hand, there is an incessant problem, particularly amongst those who are confused and disorientated, of losing their Medicare cards, not being able to prove who they are, and not being able to gain free medical treatment.<sup>135</sup>

Homeless people lose their Medicare cards not only because they are personally disorganised, but also because lack of secure shelter means their belongings are frequently stolen.

The same problem applies to the Pharmaceutical Benefits Scheme (PBS). As one experienced doctor said:

They cannot find their pension number and we have to go through all sorts of ruses to try and get just reasonable supplies of pharmaceuticals to treat their medical conditions.<sup>136</sup>

The Inquiry was told recent changes to the PBS have made it even more inaccessible to this destitute group of people. In response, some of the homeless

hostels in Sydney have entered into a complex arrangement with the Federal government, to fund a local pharmacist to provide the drugs needed by hostel residents.<sup>137</sup>

The Department of Social Security also has stringent requirements as a deterrent to fraud:

The onus is on the client to provide certain things such as identity, proof of residence, birth certificates and all that sort of thing. [For the homeless mentally ill], that is a monumental and totally unrealistic task. You have to remember that most of these people are at best very confused. Some of them don't know who they are, where they are, let alone...dealing with Social Security or the Ministry of Housing.<sup>138</sup>

Most homeless people do not know how to deal with the Department of Social Security.<sup>139</sup> People who lose their identification but who know they are entitled to benefits sometimes become infuriated at 'being given the runaround'. Social Security staff may feel threatened by this and be even less helpful, which only makes the homeless person more upset. According to one expert witness:

While Social Security might believe it is doing the right thing by checking up against fraud — and my personal view is that there is an absolute obsession with fraud — I think it operates against the interest of these people who have quite genuine need... And it leads to quite a lot of conflict and disharmony in Social Security offices as these people quite reasonably get agitated about what is happening to them.<sup>140</sup>

Even if homeless mentally ill people manage to get on Social Security benefits, they are often cut off because they do not understand the rules. This happens particularly when a person has been classified in the wrong category of benefits:

For example, someone who does have a slight disability which may have not been diagnosed by the system, may well be on unemployment benefit, on sickness benefit or on a benefit which requires that person to do certain things like putting in a medical certificate or fortnightly application for unemployment benefits; they do not do that (for whatever reason), and very soon the income security is gone because the benefit has been cut off.<sup>141</sup>

The Inquiry heard that some mentally ill individuals actually become homeless because their welfare benefits are cut off:

This has usually been because of their incapacity to negotiate the Social Security system effectively. It may be the result of frank psychosis, such as paranoid delusions, but more often it seems to be a simple matter such as failure to notify a change of address.<sup>142</sup>

In this situation it is once again the non-government agencies which assume responsibility for helping these people to obtain the benefits which are their

right. The agencies are less preoccupied with bureaucratic formalities than government departments are:

The great virtue of some of these organisations is there is no need to produce a ticket. You don't have to define who you are to get in.<sup>143</sup>

Sometimes homeless people are not aware that their benefits have been cut off, or they are reluctant to seek help. One Melbourne agency described a typical experience with one client:

We found that three months ago in fact his sickness benefits were cut off. He didn't tell anybody; he doesn't particularly like using the money from the government. It only came to our attention because the rooming house rang us up and said that his rent wasn't being paid. For this gentleman to be able to go and fill out a Social Security sickness benefits form again, which meant that he could then be put back onto sickness benefits, was an awesome ordeal. What we were able to do, because of the relationship that was there, was simply get him to sign a form; tell him that, yes, we will fill out the rest of the details and take it through to Social Security.<sup>144</sup>

Helping people to regain their welfare benefits is a daily task which is frustrating and 'very, very time-consuming' for agency staff.<sup>145</sup>

### **Inadequate or Inappropriate Services**

Most homeless mentally ill persons are willing to accept offers of help, but their perceptions of needs and service priorities often do not coincide with those of providers.<sup>146</sup>

When homeless people with a mental illness do gain access to mainstream services, they frequently find the services are inadequate for their needs. A mundane example is that there is no public provision of podiatry or physiotherapy, which are considered optional luxuries by our health system.<sup>147</sup> But for people who sleep rough, are frequently injured and wear ill-fitting shoes or none at all, those services can bring significant improvements in health.

As already indicated, health and welfare services generally define their ambit of operation in a limited and inflexible manner. But the homeless mentally ill have many interrelated problems:

People who are long-term mentally ill have a greater rate of physical health problems and unmet health needs. Conversely, the people with a long-term disability have a higher rate of mental illness.<sup>148</sup>

**In fact, medical treatment may be the least difficult need to meet:**

A lot of the time people's medical needs are looked after: you can get services for the medical side of psychiatric illnesses. [The problem] is the non-recognition that people with psychiatric illnesses are just like the rest of us. They have a personality before they got the psychiatric illness, they will have it afterwards and they will have it during it...

They have housing needs, they have personal needs, friendship needs, to be able to be understood, to be in a situation where they are not judged just because they have a psychiatric disability... [But] the concentration of psychiatric services on their medical illness often alienates the people from that service.<sup>149</sup>

**Mentally ill people have difficulty using hospital outpatient services:**

These people who go to outpatient clinics, they're waiting two and three hours in some places to be attended to... People who are kind of mentally unstable at that time, they don't have that kind of time to sit around because they're very agitated, and they're needing direct care now.<sup>150</sup>

**Not surprisingly, these obstacles are enough to dissuade many homeless mentally ill individuals from even attempting to obtain the help they need to survive. One witness cited the public housing waiting list as an example, but his comments apply equally to other services:**

Waiting time is of such a nature that most people don't even bother to apply; and that applies for homeless people in particular because they are very suspicious and wary of the way — of their experiences with authorities and...well, their perception that they have been given a raw deal, which most of the time is absolutely true.<sup>151</sup>

**The alarming result of all these factors is that thousands of homeless mentally ill Australians go without the treatment and support they need — not for any reason connected with their illness, but because the systems which are supposed to help them simply do not do so.**

### **Resistance to Services Being Established**

Evidence to the Inquiry demonstrated a general recognition that the services available for the homeless mentally ill are inadequate. Yet any efforts to establish more appropriate services must confront formidable obstacles: not only bureaucratic and financial limitations, but also community resistance from residents who object to seeing mentally ill people in their neighbourhoods.

For example, the St Vincent de Paul Society planned to open a hostel for the homeless mentally ill in the Sydney suburb of Lewisham; local opposition forced the agency to abandon the plan.<sup>152</sup> One objective of the Lewisham project was to allow careful consideration of the best housing models for the

homeless mentally ill. Very little is known on this subject, because so little has been attempted:

We need to pay more attention to what are appropriate kinds of accommodation for people with mental illness, in which environment they could be protected, at the same time be independent and yet gain access to services.<sup>153</sup>

The Inquiry heard extremely disturbing evidence of active discrimination, outright harassment and vandalism directed at a charity which attempted to set up a rural home for people recovering from mental illness on the South Coast of NSW. Local residents, allegedly with the support of the local council, obstructed the project's development, threatened its members and vandalised the property. Finally the project was abandoned:

The nervous and physical sufferings which we have received on this property as a result of this consistent harassment makes it impossible for our St Francis 'family' to continue there. The stress we have been under is amplified in one person, John Holt, who, because of the pervading anxiety decided he would 'prefer to go back to prison'.<sup>154</sup>

### **Primary Health Care**

Homeless people who are mentally ill have difficulty using the ordinary health services, for reasons already mentioned — including loss of Medicare cards, inability to keep appointments and discrimination. Some cities have free clinics for the homeless. In Sydney several were established after the Henderson Poverty Inquiry in 1974.<sup>155</sup> Apart from providing health care, these clinics must often act as mediators between this very disadvantaged group and the bureaucracies of the health, mental health, welfare and guardianship systems.

Evidence to the Inquiry clearly indicated that the concentration of mental health resources in large hospitals seriously disadvantages people who are transient and have little contact with the health system. This can be improved: training is improving for doctors and nurses, with more emphasis being placed on community medicine and community mental health;<sup>156</sup> additional responsibility appropriately conferred on local area health services can also contribute.<sup>157</sup>

One widely available but under-used 'mental health resource' identified by several expert witnesses is general practitioners. Although only a small proportion of the homeless mentally ill have any contact with formal mental health services, 95 percent have contact with a GP.<sup>158</sup> GPs thus 'offer a great potential as agents of care and support' for homeless people with a mental illness:

They accept [GPs] as a reasonable way of making contact with the care system. They in fact value that because this person is not a psychiatrist, not part of the formal mental health system and...they look towards that person as being on their side and reasonable.<sup>159</sup>

One expert witness pointed out a danger to the homeless mentally ill in the ethical debate over the allocation of health resources. The question being asked is: who deserves health care? If the answer is framed in terms of personal characteristics and behaviour patterns, it will be easy for the homeless mentally ill to be systematically excluded from levels of health care which other people receive as a matter of course:

For example...at public hospitals where people talk about how they would decide who should be admitted for heart transplantation... The criteria that people use...might include things such as smoking or some other attribute of that kind.

Now there may be reasonable reasons for using that as a point of discrimination, but taking this class of people [the homeless]...most of them are smokers. And that has been a product of not so much their wantonness or inclination to self-abuse...but it has been a part of the undervaluing that they have experienced in their life.<sup>160</sup>

## Agency Staff

The Inquiry repeatedly heard evidence that the homeless agencies are understaffed, and their workers are undertrained to deal with the range of problems they are required to confront. Homeless people with a mental illness need substantial and continuing support. But as one Melbourne worker said:

We are a team of three social workers, basically working with up to 250 people, we are stretched very thinly... Professionals, generally speaking, don't have the time to spend with these people because they are just too thinly spread.<sup>161</sup>

Working with homeless people is emotionally taxing for staff who see injustice being done on a daily basis:

It's very heart-breaking from a human point of view, it's very frustrating for workers.<sup>162</sup>

At some shelters (especially women's refuges) mentally ill people are often turned away in the interest of protecting the other residents. A worker at a South Australian women's refuge told the Inquiry:

As for myself and the staff at the shelter, this doesn't help our mental wellbeing at all, because we're there to help women and to work with them — and having to see women turned out on the streets mentally ill or disturbed, nowhere to go, at risk to themselves and to the community, doesn't help us at all.<sup>163</sup>

Because most agencies are intended to serve people who are homeless but not mentally ill, their staff rarely possess the expertise needed to help individuals affected by mental illness.

The hostel is becoming an extension of the psych hospital but without the expertise to provide a therapeutic environment.<sup>164</sup>

Training is needed in hostels and refuges, where staff are expected to dispense medication to people who are mentally ill.<sup>165</sup> One expert witness called for an integrated scheme of accommodation and medication, to take adequate account of the fact that many homeless people are mentally ill.<sup>166</sup>

Even the few experts working with agencies told the Inquiry there are big gaps in their understanding of mental illness and mentally ill people. One witness, referring to younger, transient homeless people with a mental illness, said:

There is so much uncertainty...in my mind about even getting a handle on what they are like. Perhaps the most I can say is...when you look at this group they are often dressed outlandishly, with tattoos or hair grown in particular ways, unusual garb on. And most citizens would be offended by them and yet they are very mentally ill young people who need help, and they are sometimes quite aggressive... What [we] need more than anything else is a way of identifying with them and being their advocate.<sup>167</sup>

One submission to the Inquiry suggested that governments should consider directly funding the employment within non-government agencies of mental health professionals:

Many of the staff in the agencies already have excellent skills through years of practical work with the mentally ill. However, specific professionals, such as psychiatric nurses, could help shoulder the burden and quickly teach other staff new skills.<sup>168</sup>

## **Relations Between the Health System and Agencies Assisting the Homeless**

The following statement summarised a great deal of evidence to the Inquiry presented by staff at homeless agencies:

Aside from finding appropriate accommodation [for their homeless clients] they will say that they are unable to access services to provide support and assistance to people with psychiatric disability, or to secure support for themselves as workers in situations which they are often not confident in dealing with.<sup>169</sup>

## Hospitals

Witnesses in all States repeatedly stressed the failure by psychiatric hospitals to communicate with agencies or anyone else when a homeless person is admitted or discharged. For example, on admission:

One woman was taken to hospital from a rooming house. She did need to go to hospital — there wasn't any question of that. I actually was visiting someone else in the hospital a week later, [and] saw her there...she had been there for one week in a hospital gown, fresh gowns daily; nobody in that hospital had contacted where she had come from (and she did have an address) to say could someone bring out her personal belongings.

So there she was without any underclothing in the hospital, just stuck there; and it just happened that I was passing and was able to go back and get it. But that is not the way things should work.<sup>170</sup>

Hospital monitoring of patients on release is also deficient. The Inquiry heard of a number of incidents such as the following:

[A] gentleman was brought in by two elderly people...he had walked from Ballarat to Melbourne. He had a...psychiatric history, he had been in institutions for most of his life. Unbeknownst to him we did ring the institute he had just left, the psych hospital that he had just come from. They did not realise he had left — he wasn't certified.<sup>171</sup>

Even when mentally ill people recognise that they need treatment, agency staff have great difficulty in obtaining assistance. A worker at the Ozanam House shelter in Melbourne recounted a typical incident:

A gentleman came into my office one day asking for protection, that he wanted to go to one of the major psych hospitals near us to be put in. I rang the hospital nearby asking could I send him over. Because of the red tape and the bureaucracy we had to go through, it took up quite a few hours of time... In the end I had to take the gentleman...to the doctors on the premises — who are not psychiatric trained — to get medication, and he ended up staying at Ozanam House.<sup>172</sup>

Agency and refuge staff are often confused by hospitals' refusal to take people who obviously need help, but who do not fit the definition of mental illness. For example, at the Crossroads crisis centre in Melbourne:

We constantly have problems with the medical system saying that these people don't fit the criteria for psychiatric hospitals for their care, and yet if you look at the DSM-III-R, which is the Americans' diagnostic manual for psychiatric illnesses, [the symptom] appears. So there seems to be some discrepancy there.<sup>173</sup>

The evidence presented to the Inquiry clearly established that while we have relegated large numbers of Australians who are severely disturbed or mentally



ill to an existence centred around shelters for the homeless, such refuges cannot provide effective access to our health care system.

Access to treatment services should not be premised on primary care givers in homeless services distinguishing between conditions such as alcohol-related brain injury, behavioural disorder, psychiatric illness, intellectual disability or drug-induced psychosis, particularly as they may all manifest in similar behaviour. In the past staff from shelters have been criticised for not making these distinctions when making referrals to mental health services.<sup>174</sup>

Indeed, the health care system throws up barriers to treatment for people in urgent need by relying on clinical distinctions which frustrate the efforts of those working in shelters and refuges.

Glenside and Hillcrest [psychiatric hospitals] are not prepared to offer accommodation to women who are classified as having either a behavioural disorder or personality disorder...[but only those] who have treatable illness. And a lot of the women I see are classified as having personality disorders<sup>175</sup>... It is confusing to a lot of women working in women's shelters exactly how they define a personality disorder and why that is not considered a mental illness<sup>176</sup>... Some of the behavioural traits that have been described to me for women suffering from personality disorders [include] talking to themselves, having hallucinations, having [a] fascination with knives...paranoia, lighting fires and isolating themselves from their supports and the women around them.<sup>177</sup>

(The problems created by the diagnosis of 'personality disorder' are discussed further in Chapter 25.)

Women escaping violent abuse may be

assessed as [having] a personality disorder simply because [hospital staff] have got the information about their social background — that background being that they have experienced several years of abuse. So therefore their mental problem is because of their social environment and not a medical issue.<sup>178</sup>

On the basis of all the evidence, one of the most serious problems is many hospitals simply 'passing the buck' to the shelters on discharge:

- ♦ Many are discharged from the psych services to Ozanam House as their home, as their permanent accommodation and with no follow-up or no services to those people — and also no phone call to Ozanam House to inform us that they are being placed there. We are not a special service and we are not funded for special services... We have no drug and alcohol service and we have no psychiatric service.<sup>179</sup>
- ♦ The patients from the hospital usually end up in the St Vincent de Paul hostel, Mt Isa.<sup>180</sup>

- I can't think of an example when we received follow-up phone calls from anyone at the hospital about how the person was going, or to offer us any suggestions about how we might manage that person.<sup>181</sup>

Hospitals justify the policy of discharging patients directly to homeless shelters on the basis that there is nowhere else for them to go. Since the agencies generally have no psychiatric skills, this policy not only puts a great strain on their resources — but it is also detrimental to the patients' recovery, perpetuating and in many cases exacerbating the downward social spiral associated with mental illness.<sup>182</sup> Shelters have all the disadvantages and none of the advantages of hospitals:

[A] crisis accommodation centre isn't a good place for someone to be sent straight from hospital. For one...it's still a semi-institutional sort of environment where the person doesn't have a lot of privacy and certainly is surrounded by other people who have their own difficulties. But...it also has the disadvantages of not having the structure that the hospital has, so they're being thrown into a fairly...chaotic situation which wouldn't seem to be the one that would help a person stabilise when they're just recently leaving hospital.<sup>183</sup>

While the evidence clearly established that this practice by hospitals is widespread, the Inquiry heard of at least one hospital which does co-operate with the shelters and agencies. Staff at Catherine House women's shelter told the Adelaide hearings:

We have a very good relationship with Glenside Mental Health Hospital. We ring and consult and they're always very helpful.<sup>184</sup>

If we get a referral from a hospital, if we have support from social workers and doctors we can manage. We have meetings with workers from Glenside to discuss how to handle [mentally ill residents], how to protect ourselves. But at the end of the day we get very stressed out.<sup>185</sup>

## Crisis and Outreach Services

Witnesses from homeless agencies told the Inquiry that even outreach or crisis services are difficult for them to use. Crisis teams are notoriously short-staffed and frequently non-existent. In St Kilda, which has the highest per capita psychiatric admission rate in Victoria, there is no after-hours psychiatric crisis service.<sup>186</sup> Even in the daytime, workers in the homeless agencies have an enormously difficult time getting assistance from the psychiatric hospitals. For example, staff at the Crossroads Centre in Melbourne recounted their efforts to get help for a man who was having a psychotic episode, and was dripping wet and screaming:

The [Crossroads] worker phoned St Kilda Community Health Centre, who were unable to attend and suggested calling Albert Park Clinic. They also were unable to attend and suggested calling Royal Park. Royal Park also said they were unable to attend and advised contacting Albert Park! Another call to Albert Park Clinic led to the Community Policing Squad being recommended. However, Prahran Community Policing Squad were not available at the time and were only able to attend after a new shift began.<sup>187</sup>

Where crisis teams do exist, the logic of their operation can be frustrating:

We've had several instances where [a] woman with, for example, a history of manic depression recognises that her symptoms are escalating and is asking for help, and shelters will ring for an outreach service from a psychiatric institution and they won't come — or they only come when there's a crisis. They actually say 'We'll come when there's a crisis.' And this woman is trying to manage her problem; and it seems to me that the respect [she deserves] to be accorded for trying to do that...is just not there.

Or what will happen is that they won't come out and you've actually got to get the police to take them into the institution. I mean, that must be enormously traumatic for the person on top of everything else that is happening to them.

We just don't know when the outreach service actually works. And I mean if we can't demystify when the service works ourselves, how could you expect somebody else to do it?<sup>188</sup>

## **Relations Between Government Departments and Agencies**

The Inquiry heard disturbing evidence about the lengths to which some government services and agencies will go in an attempt to pass on responsibility for the growing number of homeless people affected by mental illness.

One tactic is to refer the person on to an agency without mentioning to staff there that the person is mentally ill. For example, a women's refuge worker told the Inquiry:

It concerns me that the information we receive from other service providers is either deliberately misleading or they underplay behaviours so that you don't get the total picture... We had a Family and Community Services worker ring us with a referral for a woman and four children who was of a non-English-speaking background. And basically what this person said was that it was straight domestic violence and that the children were dirty — they had nits because of travelling. When we started to look at the issue a bit more, because we try to get as much information as we can about a particular family, this worker then acknowledged that they were long-term clients...that she has a very long record of mental illness. He would not have said anything unless we pressed... He recognised that this person was going to be difficult to place, so he would withhold information in order to improve her chances of being placed, without perhaps recognising the consequences of inappropriate referral.<sup>189</sup>

When a mentally ill person is placed inappropriately in a shelter, this can produce problems between agencies:

[I]t soon becomes apparent to staff at the shelter that this is not going to work. And then...what happens is that you become part of a co-abuse. You again have got to move that woman on, so you prolong her crisis situation, her distress — and...you are placed in the situation of: where are you going to move her on to? Because basically there isn't anywhere. And you are facing the questions that this FACS worker had to face when he was giving us information. How much are you going to actually share with someone about the person you are trying to refer?<sup>190</sup>

The end result is depressingly predictable:

Often, on the grapevine, we will hear that this woman has gone back to her partner or is out on the street where men who prey on such women will target them, and so that their abuse is perpetuated and that their transient lifestyle and their issues are never addressed by anyone.<sup>191</sup>

Another appalling practice revealed by evidence to the Inquiry is known as 'bus therapy'.<sup>192</sup> It consists of mental health or welfare agencies putting a homeless mentally ill person on a bus (or train) with a ticket to another town, in the hope that someone there will take responsibility. A psychiatrist in Orange, NSW explained:

Some [patients]...will even tell you that, you know, professionals will give them money out of their own pockets and say, 'Look, you are to go up to the bush, conditions are better up there.'<sup>193</sup>

In the new town the mentally ill person rings the police or FACS or a crisis line, if there is one, and the whole process begins again. A refuge worker in Cairns told the Inquiry:

The train ticket to the next stop occurs a lot in northern regions because of that enviable winter we have...to the point a few years ago that we were so swamped that we had to send out a form letter to other shelters and agencies nationwide to please be a bit more considerate because we simply could not cope. And also they were under quite a lot of assumptions about what was available up here and what the lifestyle was like.<sup>194</sup>

## Poverty and Trustees

The physical and psychological problems of the homeless mentally ill are generally compounded by extreme poverty.

In order to be able to pay for something you have to have money. Now most homeless people with a psychiatric illness do not work... Basically, 99 percent of the people are on benefits — if they are on benefits at all. Many of them do not have any income for the

same reason that they are not confident and skilled enough to deal with what is really a very complex and intimidating sort of a structure.<sup>195</sup>

Some people with a mental illness do have money which is administered by legally appointed trustees. However, it was clear from evidence to the Inquiry that there are serious problems in many relationships between trustees and beneficiaries. For example, the Inquiry was told trustees are frequently neglectful or obstructive toward the people whose money they are managing. In the case of a mentally ill person on the verge of homelessness, an unresponsive attitude by trustees, or even some unnecessary delay, can have serious consequences.

There was one fellow who had a long history of mental illness, finally got stable accommodation; his rent was to be paid by the State Trustees. The rent went up. Numerous letters had gone to the State Trustees; it was not taken note of. In the end, that man could have been evicted for rent arrears. It happened that the landlord was okay, so he wasn't — but how many cases does this happen, I think to myself, when you know of only one?<sup>196</sup>

Trustees' judgments about the best interests of a mentally ill person may be based on well-meaning but ignorant assumptions. For example, a homeless agency worker told the Melbourne hearing:

A woman who has accumulated \$900 worth of debts... She does have that amount of money with the State Trustees. I rang on her behalf asking could we negotiate some way of paying off her debts to free her from this, because - I was talking about the dignity of being able to pay your debts, which is something I know a bit about personally.

But the [State Trustees' officer] would not entertain it. She said [the homeless person] has to learn to budget — which I never have, and I am sure a lot of the people in [this] room never have learnt how to do. She must negotiate - all of the people on this woman's list had to write to the State Trustees to get their \$4 back, their \$80 back. The woman had no say in her money.<sup>197</sup>

Many people feel so intimidated and misunderstood by their trustees that they avoid dealing with them altogether. This forces them to live in even greater poverty — principally as a result of the trustees' attitude, or perceived inaccessibility.

For example, an agency worker told the Inquiry of a homeless mentally ill woman who needed a warm jacket as the Melbourne winter approached:

I said, how about getting one? And she said, 'Oh, I will go to the op shop.' I said, what about your money in the State Trustees? [She replied,] 'Oh no, I don't want to go in there and talk to them, I will go to the op shop.'<sup>198</sup>

For the homeless mentally ill, the poorest people in our society, this inaccessibility, insensitivity or even intimidation denies them access to their own money just as effectively as deliberate discrimination would. It is obviously a serious form of neglect, and should not be allowed to continue. The homeless mentally ill must be accorded their economic rights as far as is possible and reasonable.

They get the feeling that it is not their service. They have to feel that they can walk in and maybe [be] a pest sometimes and say, I want some of my money now. I mean, you have got to put checks and balances and things...[but] people have to feel the services are theirs, because it is their money.<sup>199</sup>

## What the Services Should be Like

The homeless mentally ill must be able to feel that it is their right rather than a privilege to obtain the services they need.

Witnesses to the Inquiry repeatedly emphasised that services — whether they are night shelters, community health centres or home care — must be designed for the people they are trying to help. This means a service should acknowledge and accommodate clients' mental illness — but it must also recognise they have other needs beyond their psychiatric disability.<sup>200</sup> Services should be multidisciplinary, and not dominated by psychiatrists.<sup>201</sup>

Continuity of relationships is one of the most important factors — yet it is precisely what is missing from government health services. When it is provided, it can contribute significantly to the mental health of a homeless person. For example, the man who four years ago was severely disturbed, yelling at lamp posts and playing in the traffic:

We couldn't communicate with this person and he certainly wasn't in a position to communicate with us... 4½ years down the track, this gentleman (although he doesn't comply with medication, [and] he does have alcohol and drug problems), I believe through...continuity of relationships with him he has a bigger and better insight into some of his own behaviour.<sup>202</sup>

He feels welcome when he comes to the day centre. The insights to his own behaviour about what is acceptable and what is not acceptable, I believe, through the channels of communication and friendship that he has found at the centre has meant that, for instance, he gets locked up by the police less than he did 4½ years ago; that he can come into the centre and he has got some idea...that if he is angry what he might be able to do is go for a walk around the block, or he can talk about it.<sup>203</sup>

Other important requirements are that services be more flexible and accessible. At present a homeless mentally ill person seeking support 'finds it a difficult and confusing process, because service provision and methods of service delivery can vary so much from area to area.'<sup>204</sup>

These features — continuity, flexibility, accessibility — can only be achieved if adequate resources are allocated:

As far as support goes, I believe it is the quality of support that is given to these people [that matters]. It is time-consuming to give good quality of support; I guess if it is time-consuming therefore it is costly.<sup>205</sup>

However, on the basis of evidence presented in every State and Territory, homeless people with mental illness are clearly among the most vulnerable and abused in our society. The cost of protecting their rights is not, therefore, an optional extra; it must be accorded an urgent and effective response.

1. Dr David Leonard, representing the Royal Australian and New Zealand College of Psychiatrists. Also Director of Clinical Services at Royal Park Hospital. Oral evidence, Melbourne 10.4.91, p346.
2. Rehabilitation Advisory Group (Western Australia), *Community Based Rehabilitation and Support Services for People with Long-term Mental Illness*, 1991, p8.
3. Human Rights and Equal Opportunity Commission, *Our Homeless Children*, AGPS, Canberra 1989, p43.
4. US Task Force on Homelessness and Severe Mental Illness, *Outcasts on Main Street*, Department of Health and Human Services, Washington DC 1992, p7.
5. These witnesses not only included advocacy groups, but also experts such as Dr N Buhrich, Acting Director of the Department of Psychiatry, St Vincents Hospital. Oral evidence, Sydney 18.6.91, p135.
6. H Hermann, P McGorry, P Bennett, R van Riel, D McKenzie and B Singh, 'Prevalence of severe mental disorders in disaffiliated and homeless people in inner Melbourne', *American Journal of Psychiatry* v146, 1989, p1179.
7. This is not a problem peculiar to Australia. In the US, where efforts to measure the homeless population have been going on for considerably longer, estimates vary between 200,000 and over two million. Even the US Government's own estimates vary by over 300 percent. National Institute of Medicine, *Homelessness, Health and Human Needs*, National Academy Press, Washington DC 1988, p3.
8. National Health and Medical Research Council (NHMRC), *Homelessness and Severe Mental Disorders* (Report of the Health Care Committee Expert Panel on Mental Health), AGPS, Canberra 1991, p4.
9. Netty Horton, Coordinator, Victorian Council of Homeless Persons. Oral evidence, Melbourne 10.4.91, p401.
10. id.
11. *Homelessness, Health and Human Needs*, op cit, pp39-75.
12. H Clough, *Somewhere That's Home... A Report on Adult Homelessness in the Inner East of Melbourne*, Compass Accommodation Support Service, 1991, p7.
13. Buhrich, op cit, p135.
14. id.
15. Prof Ian Webster, Professor of Public Health at the University of NSW and visiting medical practitioner at Matthew Talbot Hostel, Sydney. Oral evidence, Sydney 20.6.91, p459.
16. Buhrich, op cit, p137.
17. ibid, p135.
18. Webster, op cit, p450.
19. Sister Kay O'Neill, St Vincent de Paul. Oral evidence, Cairns 9.8.91, p1050.
20. Webster, op cit, p461.
21. NHMRC, op cit, p5; *Our Homeless Children*, op cit, p65.
22. Webster, op cit, p461.
23. id.
24. Megan Campbell, Health and Welfare Coordinator, Hanover Day Centre. Oral evidence, Melbourne 10.4.91, p403.



25. St Kilda has the highest psychiatric admission rate in Victoria: 76.4 admissions per 10,000 people per year. David Eldridge, Director of Crossroads Supported Housing Network. Oral evidence, Melbourne 8.4.91, p100.
26. Campbell, op cit, p403.
27. id.
28. id.
29. ibid, p405.
30. ibid, p403.
31. Ben Hagedorn, Hanover Access Centre. Oral evidence, Melbourne 10.4.91, p411.
32. O'Neill, op cit, p1050.
33. Webster, op cit, p451.
34. O'Neill, op cit, p1050.
35. Sister Anne Gregory, Catherine House shelter for homeless women. Oral evidence, Adelaide 22.10.91, p233.
36. Sister Margaret Tulley, Catherine House shelter for homeless women. Oral evidence, Adelaide 22.10.91, p236.
37. Campbell, op cit, p404.
38. Homeless Mentally Ill Advocacy Group, *No Fixed Abode. Homeless, Mentally Ill and Desolate - A Call for Action*, Brisbane 1992, p4.
39. Paul Fanning, Chief Executive Officer, Orange Health Service and Director of Psychiatric Services for the Central Western Health Region. Oral evidence, Orange 12.7.91, p904.
40. Horton, op cit, p400.
41. M Teesson and N Buhrich, 'Prevalence of schizophrenia in a refuge for homeless men: A five year follow-up', (Australian) *Psychiatric Bulletin* No14, 1990, pp597-600.
42. Buhrich, op cit, p136.
43. Homeless Mentally Ill Advocacy Group, op cit, p3.
44. 'The increasing trend towards homelessness is frightening. As unemployment rises and agencies report an alarming increase in new people coming on to the scene, the too hard fall even lower to the bottom of the ladder and there are more people to join them.' Horton, op cit, p402.
45. Webster, op cit, p449.
46. NHMRC, op cit, p4.
47. Leonard, op cit, p345.
48. H Hermann, P McGorry, P Bennett, Pamela, R van Riel, P Wellington, D McKenzie, and B Singh, *Homeless People with Severe Mental Disorders in Inner Melbourne*, Council of Homeless Persons, Melbourne 1988.
49. The US Task Force on Homelessness and Severe Mental Illness cited one in three as the rate of severe mental illness generally among the homeless (*Outcasts on Main Street*, p7). This figure is lower than might be expected, given that the rate of schizophrenia alone is up to 36 percent in shelters. But it reflects the relative weakness of the welfare safety net in America, which forces homelessness on many people who are poor but not mentally ill. In Australia those people are more likely to remain housed, however precariously.
50. Cathy Meese, assessments and referral team at Ozanam House. Oral evidence, Melbourne 10.4.91, p408.

51. Sister Anne Gregory, Catherine House shelter for homeless women. Oral evidence, Adelaide 22.10.91, p233.
52. St Vincent de Paul Society, NSW. Submission, p8.
53. *ibid*, p9.
54. Crossroads, Victoria. Submission, p4.
55. Ozanam Community. Submission, p4.
56. Leonard, *op cit*, p346.
57. John Quinn, mental health nurse, Brisbane. Submission, p2.
58. Crossroads, *op cit*, p5.
59. Quinn, *op cit*, p2.
60. Leonard, *op cit*, p345.
61. Bill Aldcroft, Ainslie Village. Oral evidence, Canberra 18.3.92, p117.
62. *id*.
63. Moira Shannon, Port Lincoln Women's Shelter. Oral evidence, Port Lincoln 18.10.91, p17.
64. *ibid*, p116.
65. Leonard, *op cit*, p345.
66. M Harries, L Jayasuriya, A Wearne, and J Dickinson, *Schizophrenia and Social Needs*, Department of Social Work, University of WA, 1991. Cited by the Rehabilitation Advisory Group (Western Australia), *op cit*, pp11-12.
67. David Eldridge, Director of Crossroads Supported Housing Network, Melbourne. Evidence given to the Inquiry subsequent to the formal hearings.
68. NHMRC, *op cit*, p8.
69. Chris Allison, Coordinator, George Street Outreach Project. Oral evidence, Melbourne 10.4.91, p406.
70. Webster, *op cit*, p451.
71. Horton, *op cit*, p400; Buhrich, *op cit*, p137.
72. *Our Homeless Children*, *op cit*, p207.
73. *Homelessness, Health and Human Needs*, *op cit*, pp39,50-51.
74. NHMRC, *op cit*, p9; Teesson and Buhrich, *op cit*, p597.
75. Teesson and Buhrich, *op cit*, p599. Other surveys of mentally ill people in homeless shelters indicate significant variations in the number that are former psychiatric patients, eg NHMRC, *op cit*, p9.
76. Buhrich, *op cit*, p137; Leonard, *op cit*, p345.
77. *Outcasts on Main Street*, *op cit*, p10.
78. Webster, *op cit*, p456.
79. Horton, *op cit*, p402.
80. *id*.
81. NHMRC, *op cit*, p10.
82. Webster, *op cit*, p456.
83. *Homelessness, Health and Human Needs*, *op cit*, pp50-51,60-62.
84. Allison, *op cit*, p406.

85. See later chapters of this report for more detailed consideration of these special needs groups.
86. Julie Felus, Irene Women's Shelter. Oral evidence, Adelaide 21.10.91, p295. Also NHMRC, op cit, p5.
87. Horton, op cit, p402; Gregory, op cit, p239.
88. Tracey Grime, Coordinator, Domestic Violence Outreach Service. Oral evidence, Adelaide 21.10.91, p283.
89. Gregory, op cit, p233.
90. *Our Homeless Children*, op cit, p238.
91. Horton, op cit, p402.
92. Vicki Gould, Department of Family and Community Services. Oral evidence, Port Lincoln 18.10.91, p15.
93. Horton, op cit, p402.
94. Tulley, op cit, p236.
95. Crossroads, op cit, p5.
96. Ozanam Community, op cit, p8.
97. Crossroads, op cit, p6.
98. id.
99. Ozanam Community, op cit, p8.
100. Leonard, op cit, p345.
101. The large hostels in inner Sydney are the Matthew Talbot Hostel (operated by St Vincent de Paul), Edward Eagar Lodge (Wesley Central Mission), Foster House (Salvation Army), Swanton Lodge and Campbell House (Sydney City Mission).
102. St Vincent de Paul Society, op cit, p8.
103. Society of St Vincent de Paul, National Committee for the Care of the Mentally Ill (since renamed the National Committee in Support of People with Mental Illness). Submission, p7.
104. Recognising the problems associated with the large inner city hostels, one of the main agencies which run them has embarked on a redevelopment program aimed at redistributing beds away from the large hostels into smaller facilities. Funded by Federal and State governments through the Supported Accommodation Assistance Program, the redevelopment aims to reduce the size of the hostels and provide alternative accommodation in cottages in the suburbs. This 'transitional' accommodation is less institutional and more likely to encourage long-term homeless people to develop the living skills they need. Outreach workers from the agency visit the cottages regularly, so the residents still get some of the support they had in the hostels — but without the loss of dignity and independence which hostel life entails. However, the redevelopment program is not directed specifically at people with a mental illness, who may need more support than this scheme — with its limited funding — can provide. Evidence concerning the redevelopment program was provided by Rosemary Kraegen, Redevelopment Officer, Matthew Talbot Hostel, Sydney, after the Inquiry's formal hearings.
105. St Vincent de Paul Society, op cit, p8.
106. Sister Catherine Hefferan, St Vincent de Paul Society, Queensland. Submission.
107. Sister Catherine Hefferan, St Vincent de Paul Society, Queensland. Oral evidence, Brisbane 15.8.91, p1611.

108. Buhrich, op cit, p135.
109. Webster, op cit, p464.
110. Meese, op cit, p407.
111. Gregory, op cit, p235.
112. Meese, op cit, p408.
113. Gregory, op cit, p233.
114. Grime, op cit, p284.
115. Shannon, op cit, p17.
116. Felus, op cit, p287.
117. Grime, op cit, p284.
118. Leonard, op cit, p345.
119. Eg Hefferan, op cit (submission), p1; Horton, op cit, p400.
120. Horton, op cit, p400.
121. Webster, op cit, p452.
122. id.
123. Horton, op cit, p402.
124. Hefferan, op cit (submission).
125. Horton, op cit, p400.
126. Webster, op cit, p449.
127. Horton, op cit, p401.
128. Webster, op cit, p453.
129. *ibid*, pp450-451.
130. *ibid*, p453.
131. Horton, op cit, p401.
132. *ibid*, p402.
133. Quinn, op cit, p1.
134. Webster, op cit, p451.
135. *ibid*, p453.
136. id.
137. *ibid*, p454.
138. Hagedorn, op cit, p410.
139. id.
140. Webster, op cit, p454.
141. Hagedorn, op cit, p410.
142. Quinn, op cit, p2.
143. Webster, op cit, p452.
144. Campbell, op cit, p405.
145. Hagedorn, op cit, p410.
146. J P Morrisey and I Shifren Levine, 'Researchers discuss latest findings, examine needs of homeless mentally ill persons,' *Hospital and Community Psychiatry* v38 No8, 1987, p812.

147. Webster, op cit, p453.
148. id.
149. Campbell, op cit, p404; Allison, op cit, p405.
150. Hefferan, op cit (oral evidence), p1614.
151. Hagedorn, op cit, p409.
152. Webster, op cit, p451.
153. ibid, p459.
154. Hefferan, op cit (submission).
155. Webster, op cit, p449.
156. ibid, p463.
157. ibid, p462.
158. ibid, p458.
159. id.
160. ibid, p455.
161. Hagedorn, op cit, p410.
162. ibid, p411.
163. Shannon, op cit, p17.
164. Society of St Vincent de Paul. Submission, p9.
165. Buhrich, op cit, p138.
166. ibid, p135.
167. Webster, op cit, p461.
168. Quinn, op cit, p2.
169. Horton, op cit, p400.
170. Allison, op cit, p406.
171. Meese, op cit, p408.
172. id.
173. Hamley, op cit, p103.
174. Ozanam Community, op cit, p4.
175. Grime, op cit, p283.
176. ibid, p284.
177. ibid, p283. Similar evidence was given by Sister Margaret Tulley from Catherine House in Adelaide (p236): 'We have women who self-mutilate, jump on chairs, shout out, do what the voices tell them to do, yet we're told that they have not a psychiatric disorder but a personality disorder. And we're at a loss to know where these women will be housed on a permanent basis.'
178. ibid, p284.
179. Meese, op cit, p407.
180. Hefferan, op cit (submission).
181. Hamley, op cit, p102.
182. Quinn, op cit, p1.
183. Hamley, op cit, p101.

184. Gregory, op cit, p234.
185. ibid, p239.
186. Paul McDonald, Program Director, Crossroads Crisis Contact Centre. Oral evidence, Melbourne 8.4.91, p104.
187. Crossroads, op cit, p21.
188. Felus, op cit, p288.
189. ibid, p286.
190. id.
191. ibid, p287.
192. Ruth Breen, Accommodation Service, Excell Enterprises. Oral evidence, Port Lincoln 18.10.91, p113.
193. Fanning, op cit, p904.
194. Michelle Knight, Ruth Women's Shelter. Oral evidence, Cairns 9.8.91, p1058.
195. Hagedorn, op cit, p410.
196. Allison, op cit, p406.
197. id.
198. ibid, p407.
199. id.
200. Campbell, op cit, p404.
201. Allison, op cit, p405.
202. Campbell, op cit, p404.
203. id.
204. Horton, op cit, p401.
205. Campbell, op cit, p404.

## Chapter 19

### WOMEN

Women are the most frequent users of mental health services in Australia, yet these services and the legislation which governs them generally fail to recognise the special needs of women.<sup>1</sup>

Any analysis of women and mental health must take account of the particular social pressures which affect women's lives — because sociodemographic factors 'may place women at a greater risk of mental health problems'.<sup>2</sup> These factors include poverty, single parenthood, sex role stereotyping, and discrimination in employment. The burden placed on women as primary carers in the family, and particularly as carers for the mentally ill, is another important issue<sup>3</sup> (See Chapter 15). Health policy-makers have acknowledged these areas as major factors in the provision of effective and equitable mental health services for women. The recent Report of the National Health and Medical Research Council's Expert Advisory Panel on Women and Mental Health concluded:

Any attempt to improve women's mental health must take into account the importance of equity and social justice in improving the lot of women. Their [physical health] and psychological state will be powerfully influenced by these factors.<sup>4</sup>

Evidence presented to the Inquiry focussed on four areas of particular concern to women: diagnosis and treatment of mental illness; post natal depression; the psychological effect of violence; and the absence of adequate shelter.

Research and practical experience in Australia and overseas have continually identified differences in the types of mental illness experienced by men and women. A wide range of studies has demonstrated that women are more likely than men to experience depression and affective disorders. (A number of recent studies — both in Australia and overseas — indicate that women are twice as likely as men to report extreme levels of psychiatric distress and are also twice as likely to report a history of affective or mood disorder.)<sup>5</sup> In contrast, men have a higher risk of substance abuse and personality disorders.<sup>6</sup>

### Diagnosis and Treatment

Available evidence suggests that sex role stereotypes influence the definition and diagnosis of mental illness, particularly depression, in women. A number of female witnesses also told the Inquiry they believed the traditional 'medical

model' is over-emphasised by many general practitioners and mental health professionals in diagnosing disorders.<sup>7</sup>

Many women expressed concerns about what they perceived as a lack of understanding and specific knowledge about mental illness on the part of general practitioners.<sup>8</sup> The local GP is frequently the first person women consult concerning depression and anxiety related illnesses. However, women complained they were not listened to or understood when they attempted to describe their experiences to doctors. This dismissive attitude was characterised by one witness as the 'it's all in your head syndrome'.

Several women claimed GPs and psychiatrists generally focussed on symptoms — to the exclusion of environmental factors which the women believed contributed to the stress and anxiety they experienced. This over-reliance on symptomatology — without appropriate attention to more complex psychosocial factors — can make accurate diagnosis difficult. It can also (even if inadvertently) lead to the neglect of significant aspects of the patient's presentation. An excessive focus on symptomatology and a tendency to ascribe medical causes to stresses resulting from normal occurrences have been identified as significant issues in recent studies.<sup>9</sup>

Conversely, research indicates that many women referred by GPs to psychologists, with diagnoses such as neurotic depression and anxiety and depression, may in fact be experiencing a normal reaction to stressful events in their lives. It has been suggested that this kind of misdiagnosis may be related to 'the relatively short consultations provided by doctors', which 'limit the chances of identifying the relationship between the stressful life events and physical illness, or between physical illness and a deterioration in someone's mental health'.<sup>10</sup>

A number of women believe they are not receiving adequate information about alternatives to drug-based treatment for depressive illnesses. A female consumer who suffers from a bipolar disorder expressed her frustration about the limited approach taken by doctors who subscribe to the traditional medical model:

There is no form of counselling for people to deal with emotional, relationship issues etc. Psychiatrists, in my experience, do not provide such counselling. They check mental health against a range of criteria by asking questions to elicit information relevant to those criteria, prescribe medication, sometimes provide some useful advice and that's it. The counselling they do give is severely limited by their rigid adherence to the medical model.<sup>11</sup>

The over-use of benzodiazepines and other drug treatments for women was also raised in evidence to the Inquiry. Many women expressed concern at the apparent ease with which doctors prescribe tranquillisers and other medication



for depression, without discussing alternative forms of treatment such as psychotherapy and stress management techniques. Other witnesses told the Inquiry that while they accepted some psychiatric disorders clearly had to be treated with psychotropic drugs, many anxiety related mental health problems could be effectively treated with alternative therapies or lifestyle changes — assisted by therapists or other professionals:

I have found the attitude of psychiatrists and other staff in the mental health system to be a major obstacle in my search for changes in lifestyle to prevent the recurrence of mental illness. The attitude has invariably been, at best, 'it won't do you any harm, but it won't do you any good'. I have found this negativity distressing at times, but have learnt to ignore it as best I can.<sup>12</sup>

This consumer's concerns were corroborated by a Sydney psychiatrist who regularly treats women, particularly women from non-English speaking backgrounds, who commented:

One thing which would help a lot with all the women with panic disorder, anxieties, agoraphobia is the provision of healthy lifestyle type programs such as relaxation therapy, stress management, assertiveness skills... You can't find these facilities generally. If you want to refer someone...they end up being on medication.<sup>13</sup>

The importance of including women in decision making about types of treatment and alternatives to drug-based treatments has been emphasised in several government reports on women's health. A 1986 report by the Women and Prescribed Drugs Working Party to the then Premier of New South Wales recommended that women be provided with more information about drugs commonly prescribed for mental illness and alternative drug-free ways of dealing with stress and anxiety. Similar recommendations were reiterated in the National Health and Medical Research Council's 1991 report on Women's Mental Health:

It is important that specific education programs be developed for undergraduate medical students and general practitioners aimed at increasing skills and knowledge about a range of management strategies including counselling and appropriate prescribing. Considerable care should be taken before prescribing psychotropic medication when other forms of treatment may be equally effective and synchronous with greater public interest in non-drug treatment.<sup>14</sup>

A number of witnesses, identifying the negative effects of sex role stereotyping by psychiatrists and other mental health professionals, expressed concern at the lack of psychosocial assessment offered and the tendency of doctors to 'pigeon-hole' women.<sup>15</sup>

It was suggested that women are indirectly discriminated against because the psychiatric profession itself is predominantly male, and is practised in a patriarchal social environment. Some women believed they had been labelled as 'dysfunctional' simply because they did not conform to a certain stereotype. Misgivings about this systemic discrimination are not confined to consumers:

Women, as consumers of health care, have often felt poorly understood and managed by those providing it. Further research is required to see if women receive different treatment or if some aspects of health care [have] adverse consequences for their mental health. It has often been suggested that women may be more likely to be seen as in need of mental health care or identified as having mental health problems. There have been questions as to how appropriate this is or as to whether there have been discriminatory or other negative consequences, eg identifying non-acceptable behaviour as madness in women.<sup>16</sup>

This may be because, in the words of one advocacy group:

Psychiatry...reflects and maintains the values and practices of...society. [It] lays claim to being scientific: an objective, rationally based, value-free and universal system of knowledge and practices. However, [it is] located in the broader societal context... It [is] necessary to question how notions of gender influence the definition, diagnosis and consequent treatment of mental illness in women.<sup>17</sup>

The significance of sex role stereotypes in clinical judgements of mental health was, a generation ago, the subject of a major US study in which the researchers hypothesised that abstract notions of mental health would be influenced by social stereotypes of masculine and feminine characteristics.<sup>18</sup> Clinicians were asked to characterise a healthy man, a healthy woman and a healthy adult (sex unspecified). The clinicians' concepts of a healthy man were similar to those of a healthy adult. However, concepts of a healthy woman were significantly different. The results of the study consistently demonstrated that clinicians were more likely to describe a healthy woman as being more submissive, less independent, less adventurous, less aggressive, more emotional and less objective than a healthy man. As the researchers commented, 'this constellation seems a most unusual way of describing any mature, healthy individual'.<sup>19</sup>

The authors of this study concluded that women are often placed in the difficult position of having to decide whether to exhibit the qualities deemed 'normal' for men and healthy adults, thus leaving their femininity open to question; or to behave in 'the prescribed female manner, accept second class adult status, and possibly live a lie to boot'.<sup>20</sup> These are clearly major issues which, a generation later, are still affecting women and their mental health. They are issues which urgently require further study and definition in Australia.

## Post-Natal Depression

There are a number of mental illnesses women experience which are related to their role as mothers. One of the most common is post natal depression (PND), also known as post partum depression.<sup>21</sup> It affects up to 1 in 7 women in mild, moderate or severe form.<sup>22</sup>

Extensive evidence was provided to the Inquiry by the Post and Ante Natal Depression Association (PaNDa), a community support group for women who suffer post natal disorders and for their families. Post natal depression occurs in 12 to 14 percent of cases at up to three months after birth and in 22 to 24 percent of cases within the first post natal year. However, PND has been known to occur as late as two years after birth. Expert opinion indicates that the aetiology of PND is best perceived within a multidimensional context — biological, psychological, social and cultural factors may all be relevant.<sup>23</sup>

The Inquiry was told that the exact combination of factors affecting an individual woman's susceptibility to PND is unclear. However, contributing factors include stress during pregnancy or delivery, a previous history of depression, depressive symptoms during pregnancy, prolonged breast feeding and being older than 30 at the time of birth.<sup>24</sup> The symptomatology for PND also varies, but there are four general characteristics: feelings of depression; a sense of loss; feelings of irritability, hostility and resentment; and changes in maternal feelings. Women with PND commonly experience long periods of depression, reduced appetite and libido, sleep disturbance and a low tolerance of partners and children.<sup>25</sup> One woman described the sudden onset of PND:

I had never confronted a life problem I hadn't coped with, nor experienced mood change or depression. I enjoyed my pregnancy and looked forward to having my baby... My experience of PND started suddenly. I [had] felt a deep feeling of inner contentment and happiness... But four days after the birth I also remember a most terrifying experience. During the night I woke up abruptly. I sat bolt upright in bed (thinking) 'there is something terribly wrong with me'. I experienced sudden waves of panic attacks and heart palpitations. I was dripping in perspiration from hot and cold flushes. I was shaking involuntarily. My head felt strange. My thoughts and language were disjointed and my brain wasn't functioning normally.<sup>26</sup>

This witness told the Inquiry of attempting to obtain assistance for her depression, but finding it difficult to locate a professional who could diagnose the problem. After visiting a number of general practitioners, psychologists and naturopaths who diagnosed stress and recommended rest and relaxation, all to no avail, she finally came across a psychiatrist who diagnosed her PND and treated it effectively with anti-depressant medication.<sup>27</sup>

Misdiagnosis is common<sup>28</sup> and:

Although some women are lucky in that their general practitioner, obstetrician, maternal and child health nurse happen to be familiar and knowledgeable [about] PND and either can well facilitate appropriate support themselves or can refer on to professionals who can, many women and their families find themselves experiencing what we refer to as 'a professional merry-go-round' looking for help.<sup>29</sup>

For those women who do not get assistance, PND can pose a major risk — not only to their own lives but to their child and others around them:

If they do not receive the help they need, the known effects of PND are: marital stress or breakdown; loss of quality of life for the woman, husband and children; deterioration of the woman's health which can lead to chronic illness — and in the most acute situations — the loss of life of the mother or infanticide.<sup>30</sup>

Representatives of PaNDa told the Inquiry that the lack of knowledge concerning PND among psychiatrists and other medical professionals is one of the major impediments to improving its diagnosis and treatment. Two major reasons for this ignorance were advanced. First, the aetiology of post natal depression is not yet clearly understood and more research into the illness is essential. Second, there is still considerable ignorance and stigma associated with PND. This was described to the Inquiry as 'the old 'pull yourself together, you've got a lovely baby, what more could you want' approach'.<sup>31</sup>

Early recognition and appropriate management of PND is crucial, and can often mean the difference between an excellent prognosis and immense personal distress and family breakdown. Evidence presented to the Inquiry indicated that effective diagnosis and treatment should include social and practical support for the mother. This may comprise medical care on an inpatient, outpatient or community care basis for both mother and baby (possibly including psychotherapy for the mother) or, if appropriate, psychotropic medication for the mother.<sup>32</sup>

One psychiatrist who specialises in treating PND told the Inquiry that medication can be extremely helpful in assisting women to recover from depression:

For those people who decide upon treatment, I find the use of medication very useful. I've seen people use osteopathy, homoeopathy, naturopathy and acupuncture. I'm not knocking these treatments as treatment programs, I want to make that quite clear. All of these treatments make a valuable contribution to health care...[but] I have not seen these treatments being successful in curing PND. Some people are reluctant to take medication and I respect that. But the problem is that you may have to keep the [depression] corrected for one to two years... If you take away the medication too soon, the depression returns.<sup>33</sup>

Evidence presented to the Inquiry suggested that confusion and ignorance concerning the type of treatment appropriate for PND is common:

Every woman who develops PND fears if she tries to get help her baby will be taken from her, and these fears are real... Women with severe PND are frequently admitted to general psychiatric wards, surgical wards, midwifery wards, gynaecological wards. Sometimes staff try to help but often the staff tell us they don't know what to do, others tell of less kindness and comments like, 'you don't belong here, go to a psychiatric hospital or go home, we don't want you here'.<sup>34</sup>

The Inquiry was also told that while medication and other therapies are an important part of the treatment for PND, 'the maternal infant relationship is fifty percent of the therapy' and if this relationship is not supported, it can be lost for a lifetime.<sup>35</sup> One of the difficulties raised in evidence was the lack of hospital facilities for women who may need inpatient psychiatric care, but who also need close contact with their babies. Appropriate inpatient support services are needed to ensure this is provided.

The Post and Ante Natal Depression Association submitted that maternity hospitals should have PND clinics attached to them — for three major reasons. First, they would enable women to be with their babies during treatment. Second, they would facilitate professional interest in the disorder and third, they would provide a focal point in the community for people who are not sure where to obtain assistance.<sup>36</sup> It was also suggested that similar units be provided in psychiatric hospitals so that women with acute PND are not separated from their babies during inpatient psychiatric treatment.

The provision of adequate emotional support to the partners and families of women with PND is also an important part of the treatment process:

[Partners] need to be involved too so that they are not separated from their wives and babies... This aspect is often overlooked or dismissed as not being important. What is the point of therapy and isolation for the woman to go home to hopefully pick up the [familial] relationships ad hoc. As one woman said, (and it is not the first time we have heard it), 'well, I'm over my PND now but I've lost my husband, my baby, my home'.<sup>37</sup>

One health professional employed by a community agency assisting women with PND told the Inquiry that many of her clients receive no support from their partners or their families. However, with suitable housing and adequate support and supervision, the majority could cope quite well and go on to raise their children.<sup>38</sup> As this witness noted:

It would be more economical, and certainly more humanitarian, to provide such support, either as a wing of an existing service or as a separate service altogether, than to deal with the consequences of the otherwise almost inevitable breakdown of family units.<sup>39</sup>

## **Puerperal Psychosis**

Puerperal psychosis is a severe disorder which is less common than post natal depression. It affects between 300 and 700 women a year in Australia<sup>40</sup> and usually occurs during the first six weeks after birth (generally between days three and fourteen). The symptoms of puerperal psychosis can be similar to those of schizophrenic-type illnesses and can include extreme mood swings, hallucinations, and delusions or thoughts of harming the baby or oneself.<sup>41</sup> Diagnosis may be difficult when symptoms first present because it may not be immediately clear whether the illness is depression or a schizophrenic-type illness.<sup>42</sup> This condition may be treated in special mother-baby psychiatric units which only exist in a few of our major cities or, if the child is at risk, in an inpatient psychiatric setting. It responds well to treatment but even after recovery the woman may be at risk of a recurrence or continuing disorder.<sup>43</sup>

## **Violence Against Women**

### **Domestic Violence**

A number of witnesses gave evidence concerning the relationship between domestic violence and the development of mental illness in some women. Research has consistently shown that women who have a history of violent and abusive relationships are more likely to be affected by a mental illness than women who do not. A recent New Zealand study found that approximately one third of women who had suffered domestic violence had also suffered mental ill health, including post traumatic stress disorder and depression.<sup>44</sup>

The Queensland Domestic Violence Task Force, reporting in 1988, found that the effects of domestic violence included constant feelings of helplessness, terror and entrapment and that women who have experienced violence are much more likely to suffer psychiatric problems than other women in the community.<sup>45</sup> Victims of domestic violence have higher stress levels and suffer more affective disorders than women from non-violent homes. They are also more likely to be substance abusers, to suffer from somatic complaints<sup>46</sup> and to attempt suicide.<sup>47</sup>

Much of the evidence presented came from community workers and the staff of women's shelters who regularly deal with women who have suffered domestic violence. They emphasised that the link between a history of domestic violence and mental illness is complex and requires some understanding of the psychological difficulties associated with surviving a violent situation:

A woman in a violent relationship is rarely open about it. [She is most likely to] cover up the violence from outsiders and the [conflict] between her understanding of what is happening to her day to day and her pretence about her life to family members, neighbours, doctors and lawyers makes her doubt her own sanity. In many cases her reactions may appear irrational to others — yet they are the way in which she makes sense of her reality. It is sometimes a short step for her from this into treatment with anti-depressants or other treatments which are ineffective because they do not help her come to terms with her real problem which is her partner's abuse. She may find herself in the mental health system where her presenting symptoms may include depression and/or attempted suicide. These are seen as the disease to be treated and the underlying cause, the violence and fear in her relationship with her partner, may not even be recognised.<sup>48</sup>

**The enduring psychological effects of domestic violence were described by a Melbourne minister of religion who told the Inquiry she regularly ministered to women who had been traumatised by living in violent situations:**

After being in an abusive relationship for many years, suffering emotional, physical, sexual, social and financial abuse...the women were able to leave the relationship with the help of women's refuges or other community support and move on to the independent living situation. It was during this period of independence when the [women were] faced with the sole responsibility of providing and caring for their children and also faced with the years of abuse to their... wellbeing and mental stability that they...experienced a mental and emotional breakdown.

These women had no previous history of mental illness. During this breakdown they were placed in a psychiatric hospital — separating them from their children. This placed the associated stigma on them [of having been] in a psychiatric unit. While the women were being treated in a psychiatric hospital their ex-husbands went to the Family Court and gained custody of the children on the basis that the mother was mentally unstable and unable to care for the children... We believe that this illness was a short-term, 'one-off' occurrence directly related to years of abuse.<sup>49</sup>

**The Inquiry was told that many women caught in such situations are labelled as 'mentally ill' when they are simply reacting — usually some time later — to a highly traumatic situation. It is important for clinicians and community workers to acknowledge the reality of their experiences, rather than trying to 'fit them into the disease model'.<sup>50</sup>**

This process turns a woman in crisis into a patient within a mental health system which is ill-equipped to react appropriately. Labelling her as a patient; prescribing drugs to allay her symptoms; but not treating the cause of her problem reinforces her feelings of low self esteem, lack of confidence and guilt which have already been engendered by her abusive partner. The end is worse than when she sought help.<sup>51</sup>

**In this situation the woman once again becomes a 'victim' — this time of the mental health system. When early intervention fails and misdiagnosis occurs, women may become hospital inpatients. The Inquiry was told that one survey of women in a psychiatric hospital in the United States found that half the**

patients had histories of physical and/or sexual abuse. It was suggested that 'there is no reason to believe that the situation is any different' in Australia.<sup>52</sup> (Indeed other evidence presented suggested it may be similar or worse.)<sup>53</sup>

Women are sometimes not safe from an abusive partner, even in hospital. The Inquiry heard that many women feel so frightened their partners will find them that they ask the hospital to keep details about their admission and date of discharge confidential. It was alleged that in some cases these requests had been ignored and the woman had been 'regarded as unco-operative at best and paranoid at worst'.<sup>54</sup>

Open access visits from their abuser, frequently under the guise of care and concern for their welfare, can be terrifying and provide excellent opportunities for the message to be reinforced that there was no secure place, not even in hospital. They may even be required to undergo combined interviews with their abuser while the underlying fear and stress is not acknowledged and the reality of their danger is not accepted.<sup>55</sup>

### **Sexual Assault of Women Inpatients**

The Inquiry heard disturbingly frequent allegations about sexual assault of women inpatients,<sup>56</sup> who sometimes find themselves in non-segregated areas where they are particularly vulnerable.

Women are subject to sexual harassment and abuse from male patients and staff within these [mixed] units. When they complain to staff women are ignored, blamed, not believed or told not to worry about it. For example, a young woman who had been sexually abused in the past complained to staff when a male patient continually masturbated in front of her. She was told to keep out of his way.<sup>57</sup>

Several women suffering from manic depressive disorders told the Inquiry that they were particularly vulnerable to sexual assault during a manic episode, when normal decision making processes may be impaired:

After he had sex with me I felt so ashamed. I felt this was the bottom of the barrel — in a psychiatric ward and just a thing to be used. I was so muzzy from the medication I couldn't resist and at the time I felt it was probably my fault I got raped.<sup>58</sup>

Many female consumers expressed concern that while they knew that they had been assaulted and their rights abused, the fact that they had a psychiatric disability worked against them:

I thought that if I complained they'd just say I was mad anyway and they wouldn't believe me.<sup>59</sup>



A psychiatrist in private practice in Western Australia, after informing the Inquiry of several female patients who had been sexually abused as inpatients, said:

In my opinion these women are the tip of the iceberg and demonstrate that not enough is being done to ensure the sexual safety of disturbed women. If a woman is locked up for her own safety it is ironic that she thereby suffers worse abuse in the place which is supposed to protect her.<sup>60</sup>

These fundamental abuses of women's rights to a safe and secure environment cannot be allowed to continue. As one women's organisation stressed:

It is the responsibility of all mental health service providers to ensure that women's personal safety is not under threat.<sup>61</sup>

### **Other Sexual Assault**

In addition to allegations concerning misdiagnosis and maltreatment of women inpatients, the Inquiry heard evidence concerning links between traumatic events such as domestic violence and sexual abuse and the development of affective disorders such as depression and post traumatic stress disorder.

One Victorian expert provided the Inquiry with the results of a study which investigated the relationship between child sexual abuse and mental health in adult life. The research sought to establish whether there is a causal connection between child sexual abuse and adult mental disorders and how any such connection might be influenced by other aspects of individual background and development. While there is a general relationship between child sexual abuse and the development of mental illness in adulthood, the researchers found that other contributing factors include an individual's personal history and socioeconomic status. These findings, together with other evidence presented to the Inquiry,<sup>62</sup> suggest that while child sexual assault cannot be identified as the single contributing variable in the development of some adult mental illness it often is a significant factor:

The overlap between the possible effects of child sexual abuse (CSA) and the matrix of disadvantage from which it so often emerges [are] so considerable as to raise doubts about how often, in practice, CSA operates as an independent causal element... CSA correlated with an increased risk for a range of mental health problems, but in most cases its effects could only be understood in relationship to the context from which it emerged and within the victim's subsequent psychosocial development.<sup>63</sup>

This research, however, represents a relatively conservative assessment of the long-term damage inflicted by child sexual abuse. Expert clinicians appearing

before the Inquiry presented more disturbing evidence, which is addressed in greater detail in Chapter 20 – Children and Adolescents.

Apart from the effect of childhood experiences, the Inquiry also heard evidence concerning a link between experiences of sexual assault and the development of affective disorders such as depression and post traumatic stress disorder.

A Melbourne psychologist provided several case histories of women who had experienced post traumatic stress disorder as a result of child and adult sexual abuse. In one case, a woman had been raped and suffered long-term psychiatric problems as a result. She undertook treatment for post traumatic stress disorder, but while she was receiving treatment her marriage broke down and her husband filed for custody of the children. In his decision, the judge found that the woman had been a good mother, but was unsuitable as a custodian for her children because of her psychiatric history. This judgement was despite representations and clinical histories from the woman's doctors stating that she had recovered from her mental illness. Her psychologist told the Inquiry, 'I believe that this blatant form of discrimination against people with post traumatic stress disorder goes on all the time'.<sup>64</sup>

## Shelter

The Inquiry heard evidence in all States and Territories concerning the large number of women affected by mental illness living in refuges, shelters for the homeless and other places providing emergency accommodation. (This issue is also addressed in Chapter 10 – Accommodation and Chapter 18 – Homeless People.)

A great majority of the women who stop [at the women's shelter] are from domestic violence situations. They are in crisis. Sometimes those women in crisis are not only showing signs of stress that accompany the crisis, but also evidence of psychiatric illness.<sup>65</sup>

While refuge staff do their best to support women with psychiatric problems they are 'not trained to assess or assist women suffering from mental illness' and regularly find themselves in difficult situations – trying to balance the needs of the individual who is ill against the wellbeing of other women in the shelter.<sup>66</sup>

The Inquiry heard there were several imperatives compelling many women with psychiatric problems to end up in refuges:

An important observation made by refuge workers is that many of the mentally ill women who prefer to come to the refuge rather than seek private accommodation in the

community, do so out of a need for support and for a safe place to stay with other women. [Furthermore] the income of women who are mentally ill is usually a social security benefit. This means that the only affordable accommodation is unsuitable and at times threatening. Women, particularly those living [on the street] have reported to refuge workers that they are subject to harassment and rape. Most of these women who have gained other accommodation are often unsuccessful in resettling and ultimately either become extremely distressed due to isolation and find themselves hospitalised, or turn to refuges for help.<sup>67</sup>

In Adelaide, workers from Catherine House, a refuge for homeless women, reported that over thirty two percent of their clients had a history of mental illness.<sup>68</sup> Evidence from women's shelters in Darwin<sup>69</sup> and Port Lincoln<sup>70</sup> indicated that approximately ten percent of their clients were affected.

Many of these woman first sought emergency accommodation after leaving violent relationships. Once it becomes apparent that they have a psychiatric problem, refuge staff are faced with the unenviable task of either having to care for someone in need of specialist mental health services which cannot be provided by the refuge, or refusing to accommodate the woman (and her children), knowing that she has nowhere else to go:

*In most instances, the women who come to [the shelter] who do suffer mental illness [present] three options for staff. One, they either refer them back to hospital or back to one of the referring agencies; two, the women go unsupported into accommodation on their own, and often end up back in hospital; or three, they are referred to [accommodation] which is primarily equipped to cater for single women, not women with children. Other than that there are no options available to women suffering mental illness.<sup>71</sup>*

Women with psychiatric disabilities are often referred to refuges by hospitals and other mental health services. In Darwin the Inquiry was told that the local women's shelter regularly receives referrals from the Royal Darwin Hospital, which sends women with behavioural and psychiatric problems to the shelter at the rate of approximately two per month. This is in spite of the fact that the women's shelter is not supposed to accommodate women with mental illness.<sup>72</sup>

Agencies accept inappropriate referrals because they know that women would otherwise end up on the streets. However, in doing so they create difficulties for the woman in question and other clients.<sup>73</sup>

The lack of appropriate accommodation services for women with psychiatric disabilities has now produced a completely unacceptable situation. It is clear from the evidence that staff working in emergency accommodation services are providing a variety of services for which they are either underqualified or completely unqualified. Several suggestions were made to the Inquiry concerning action needed to effectively redress this situation.

- Most of the research is about homeless men and men who live on the fringe — marginalised men with mental health problems. There's very little about women and women with children.<sup>74</sup>
- There are no statistics or hard data... There is an urgent need for research into this area to be conducted across the whole community. This research needs to be consistent in all areas, well coordinated, evaluated and include consumers... This is of prime importance.<sup>75</sup>
- There is an urgent need for the provision of accommodation for women suffering domestic violence and mental illness. Both crisis accommodation...and long-term accommodation... If accommodation is set up, we need to employ qualified staff; staff that can provide appropriate supports, who will be able to administer medication when required; can be able to identify behaviour, and support women and children.<sup>76</sup>

The evidence placed before the Inquiry clearly indicates that the human rights of women suffering mental illness are being both abused and neglected. Fear, ignorance, lack of self esteem and discrimination impair the ability of these women to effectively advocate for more appropriate services.<sup>77</sup> Clearly, governments and others responsible for providing these services need to address these issues urgently – not only for the sake of the many thousands of women affected, but also for the protection of their children and the wellbeing of their families.

## **The Need For More Research**

It is clear that each of the issues addressed in this chapter is sufficiently important to require an urgent response. It is equally clear that while several problems can and must be promptly addressed by appropriate programs, others require careful research to ensure an effective response. Indeed, it is not only the issues particularly affecting women which are mentioned above. There are other areas in which women confront problems which require special research and attention. The case for additional mental health research is presented in Chapter 26 of this report. In view of the evidence submitted to the Inquiry, research into women's mental health needs must be a priority.

The most recent study of the incidence of Alzheimer's disease, for example, indicates it is almost twice as prevalent among women aged 40 to 64 as it is among men in the same age-group.<sup>78</sup> The devastating effects of this disease on sufferers and their families highlight the urgent need for further research in this area. The impact of Alzheimer's disease is discussed in more detail in Chapter 17 — Elderly People.

1. Robyn James, Western Region Women's Human Rights Commission Response Group, Victoria. Submission, p3.
2. National Health and Medical Research Council (NHMRC), *Women and Mental Health: Report of the Health Care Committee Expert Advisory Panel on Women and Mental Health*, Monograph Series No1, AGPS, Canberra 1991, p1. The Expert Panel is chaired by Professor Beverley Raphael — the former president of the Royal Australian and New Zealand College of Psychiatrists and current Professor of Psychiatry at the University of Queensland. Professor Raphael acted throughout the course of the Inquiry as its specialist adviser.
3. *ibid*, p2.
4. *id*.
5. *ibid*, p5.
6. *id*. The NHMRC report notes that '...for most disorders women show higher levels than men, particularly depression, anxiety states, somatisation disorders, whereas men show higher rates for substance abuse disorders and antisocial personality disorder.'
7. This point was also raised by a number of women during community consultations conducted in capital cities and regional centres.
8. *id*.
9. NHMRC report, *op cit*, p48. 'Consumer groups as well as feminist organisations have suggested that there may be a tendency to prescribe psychotropic medication and medicalise normal life stresses.'
10. Z Mullaly, 'Counselling Depressed Women', *Healthright* v8 No2, Feb 1989, pp15-16.
11. Jennifer Lane, consumer, Victoria. Submission, p3.
12. *ibid*, p8.
13. Dr Elsa Bernardi, representative, RANZCP, NSW Branch. Oral evidence, Sydney 17.6.91, p114.
14. NHMRC report, *op cit*, p50.
15. Several women used this term during the Inquiry's community consultations in Port Lincoln.
16. NHMRC report, *op cit*, p48.
17. Robyn James, *op cit*, p5.
18. I K Broverman, D Broverman et al, 'Sex-Role Stereotypes and Clinical Judgements of Mental Health', *Journal of Consulting and Clinical Psychology* v34 No1, 1970, p1.
19. *ibid*, p5.
20. *ibid*, p6.
21. The Inquiry was told that post natal stress is not the same as post natal depression: 'The confusion between post natal stress, which all mothers and fathers know about, and post natal depression as a clinical disorder is causing a lot of problems. Stress is a normal reaction. Post natal depression as a disorder involves a dysfunction... For example, a mother suffering stress reactions has a two week holiday or a rest and respite and then she returns to normal. A mother with PND would have a two week holiday and be the same or worse afterward'. Terry Smith, President, and Jo Rogers, Secretary, Post and Ante Natal Depression Association (PaNDa). Oral evidence, Melbourne 10.4.91, p430.

22. Rogers, *op cit*, p431; and Professor Lorraine Dennerstein, Head of the Mercy Mother-Baby Unit and Post Partum Disorder Clinic, Melbourne, in information provided as part of PaNDA's submission to the Inquiry.
23. NHMRC report, *op cit*, p8.
24. *id.* There have been many studies undertaken in this area. For example, Boyce and Todd studied rates of post natal depression in women who had emergency caesarean sections rather than spontaneous vaginal births. The authors found that women having an emergency caesarean section were six times more likely than women having spontaneous vaginal delivery to develop post natal depression. The authors note that the identification of these additional risk factors is essential if early intervention and treatment of PND are to be successful. P Boyce and A Todd, 'Increased risk of post natal depression after emergency caesarean section', *Medical Journal of Australia* v157, Aug 1992, pp172-174.
25. These characteristics were described by Dr L Marinovich, senior psychiatrist, Royal Women's Hospital, Melbourne, in a paper provided as part of PaNDA's submission to the Inquiry.
26. Jo Rogers, 'When Motherhood Isn't Bliss — Post Natal Depression', address given at Mercy Maternal Hospital October 1991, pp1-4. This paper was included as part of PaNDA's submission to the Inquiry.
27. *ibid*, p6.
28. NHMRC report, *op cit*, p8.
29. PaNDA Submission to the Australian Health Ministers Advisory Council, Mental Health Working Party, Mental Health Discussion Paper January 1990. Included as part of PaNDA's submission to this Inquiry, p13.
30. Rogers, (oral evidence) *op cit*, p431.
31. *ibid*, p433.
32. See PaNDA evidence and NHMRC report, *op cit*.
33. Marinovich, *op cit*, p8.
34. Rogers (oral evidence) *op cit*, p434.
35. *id.*
36. *id.*
37. *ibid*, p435.
38. Margaret MacPherson, social worker, Pregnancy Help, Western Australia. Submission, p1.
39. *ibid*, p2.
40. Based on a frequency of between one and two per thousand births, as suggested by the NHMRC.
41. NHMRC report, *op cit*, p10.
42. *id.*
43. *id.*
44. Cited in *Mental Health in Australia*, December 1990, p33.
45. Queensland Domestic Violence Task Force, *Beyond These Walls*, Brisbane 1988, p67.
46. NHMRC report, *op cit*, p36.
47. *id.*

48. Topsy Evans, member, Domestic Violence Action Group. Oral evidence, Hobart 13.11.91, p313.
49. Pastor Robbi Dawson, social worker, Port Melbourne Baptist Church. Submission, p1.
50. id.
51. id.
52. id.
53. See Chapter 20, Children and Adolescents.
54. Evans, op cit, p314.
55. id.
56. These allegations are discussed in more detail in Chapter 8, Inpatient Care and Treatment.
57. James, op cit, pp12-13.
58. Evidence presented in a written submission by Meg Smith, Secretary, Manic Depressive and Depressive Association of NSW, pp6-7.
59. *ibid*, p6.
60. Dr Lois Achimovich, psychiatrist, Fremantle Hospital, Western Australia. Submission, pp1-2.
61. Thea Bates, Victorian Community Managed Mental Health Services Inc (VICSERV). Submission, p17.
62. Dr Aidene Urquhart, Director of Child Psychiatry, Mater Children's Hospital, South Brisbane. Oral evidence, Brisbane 16.8.91.
63. P Mullen, J Martin, J Anderson, S Romans, and P Herbison, 'Child Sexual Abuse and Mental Health in Adult Life', *The Lancet*, 1988, p841. This paper was provided as a submission to the Inquiry by Prof P Mullen.
64. Evelyn Field, Victorian Branch, Australian Psychological Society. Submission, p1. This is by no means an isolated case. As indicated earlier, the Inquiry was told that psychological and psychiatric reports written about women are regularly used against them in custody cases: Evans, op cit, p314.
65. Desley Boyle, Deputy Mayor, Cairns City Council, psychologist and Chairperson of Cairns Regional Health Authority. Oral evidence, Cairns 9.8.91, pp1109-1110.
66. Creina Scally, Dawn House Women's Shelter. Oral evidence, Darwin 21.7.92, p59. Evidence was also provided by Suzanne Fogerty, Director of Dawn House, who told the Inquiry of one case where a woman staying at a refuge attacked another woman with a brick. The refuge worker rang the hospital and asked the staff to check the client's medication. It was revealed that the medication, which was an anti-inflammatory drug, was reacting with other medication the woman was taking. The woman was referred to a doctor who stabilised her medication and her behaviour returned to normal. While this case was resolved satisfactorily, it illustrates the difficulties faced by services which are not equipped to deal with mentally ill women.
67. Dawn House Women's Shelter, Darwin. Submission, op cit, p6.
68. Sister Gregory, Catherine House. Oral evidence, Adelaide 22.10.91, p233.
69. Dawn House Women's Shelter, op cit, Appendix 1.
70. Irene Women's Shelter. Evidence presented by Tracey Grime, Coordinator, Domestic Violence Outreach Service. Oral evidence, Port Lincoln 21.10.91, p283.
71. Scally, op cit, p60.

72. A requirement of the Supported Accommodation Assistance Program (SAAP), which funds the shelter. (See Chapter 10 of this report for further discussion of SAAP.)
73. Julie Felus, Irene Women's Shelter. Oral evidence, Port Lincoln 21.10.91, p287.
74. *ibid*, p295.
75. Scally, *op cit*, p62.
76. *ibid*, p63.
77. James, *op cit*, p14.
78. G McGonigal and B Thomas, 'Alzheimer's in Scotland', *British Medical Journal* v30 No6879, March 1993, p680.



## Chapter 20

# CHILDREN AND ADOLESCENTS

We're looking at only around 30 [acute adolescent psychiatric] beds available in Victoria, a similar number in New South Wales, virtually none in Queensland, none in the public sector in South Australia, and [none] in Western Australia.<sup>1</sup>

## Incidence and Prevalence

The diagnosis of children and adolescents with mental illness is not clear-cut. Often the developmental aspects of behaviour lead to unrealistic diagnostic labels that may vary between settings, such as school and home, and often over time. Thus...it is common practice...to restrict the diagnosis of mental illness to the most extreme cases. While this is understandable, it means that children and adolescents with severe emotional and behavioural disturbance are often not categorised as having a mental illness, although they may fulfil the diagnostic criteria.<sup>2</sup>

Although very little epidemiological research has been conducted on the prevalence of mental illness among children and adolescents in Australia, there was substantial agreement about estimated levels of psychiatric disturbance in young people by experts presenting evidence to the Inquiry.

### Children

One leading child psychiatrist told the Inquiry that rates of mental illness for children and young people are much the same all over the world. In any given year, approximately 10 percent of children show significant psychiatric disturbance and 1 percent are in urgent need of psychiatric treatment.<sup>3</sup>

The Inquiry heard similar evidence in Melbourne:

About 15 percent of children have some sort of emotional or behavioural problem during childhood which requires some assistance...and about 1-2 percent of children have psychiatric disorders of sufficient severity to warrant specialist services. I emphasise that I am not only relating to psychiatric specialist services, but...specialist input from psychologists and social workers... Of those 1-2 percent who require specialist resources, much less than half actually end up getting them.<sup>4</sup>

In a major Australian study, Professor Helen Connell surveyed the prevalence of disorders among Queensland children aged ten and eleven, comparing a rural group with a Brisbane group of the same age. The study concluded that 23 percent of the children had mental health problems, and 14 percent fitted a diagnosis of mental disorder.<sup>5</sup>

## **Adolescents**

The Royal Australian and New Zealand College of Psychiatrists has estimated that 15 percent of adolescents suffer from recognisable psychiatric disorders, and 5 percent suffer from serious disorders which 'warrant intervention'.<sup>6</sup> About 1 percent have a 'severe psychiatric disorder'.<sup>7</sup>

In schizophrenia, the peak age of onset is in late adolescence and young adulthood. We estimate that in NSW there will be 1000 new cases per year — and most of those will be adolescents.<sup>8</sup>

These estimates conform with US data<sup>9</sup> which indicate that 90 percent of all psychiatric disorders have their onset in adolescence or early adulthood. Fifty percent first affect young people between the ages of 16 and 18. (These figures are important in appreciating the serious deficiencies in our mental health system chronicled in this chapter.)

### **The Number of Young Australians Affected**

Expert assessments of the number of adolescents in Australia affected by psychiatric problems are generally based on overseas epidemiological studies of prevalence, applied to Australian population estimates by age group.

∩ In Australia, there are approximately 246,500 15-20 year olds who have disorders which warrant recognition [based on an estimated 15 percent in this age group] and 82,000 adolescents who would likely benefit from psychiatric intervention [based on an estimated 5 percent in this age group].<sup>10</sup>

Expert evidence varied regarding the number of young people with illnesses severe enough to require specialist treatment, but all estimates were in the range of 1-5 percent.<sup>11</sup> Even based on the lowest figure of 1 percent (ie including only adolescents with schizophrenia and other forms of psychosis), over 16,000 young Australians are affected.

Witnesses stressed to the Inquiry that they were using overseas statistics because of the paucity of research in this area which has been conducted in Australia.<sup>12</sup> This evidence emphasises the urgent need for local epidemiological studies to be undertaken, specifically in the area of child and adolescent mental health. Without sufficient accurate data, it is difficult to plan either effective intervention strategies or appropriate treatment services.

## Definitions and Terminology

The definition of 'mental illness' in children and in adolescents — and its inter-relationship with 'emotional disturbance' and 'behavioural disorder' — is a complex and contentious issue. The co-existence of these problems in young people makes diagnosis (and prevention, therapeutic intervention or treatment) particularly difficult — requiring specialist knowledge, not only on the part of mental health professionals, but also from a range of other individuals involved in the young person's life. (See later sections of this chapter dealing with inter-agency co-operation and the training needs of allied professionals.)

The Inquiry was presented with a number of 'working definitions' by expert witnesses who emphasised that a range of contributing factors must be taken into consideration when diagnosing mental illness. These elements include environmental influences (parental conflict, family breakdown, abuse, and educational, social, or cultural factors); genetic pre-disposition (parental mental illness); and the developmental stage of psychological and emotional maturation of the young person.

Mental illness in the young tends to differ from mental illness in adults,<sup>13</sup> and where similar disorders exist in young people, different signs may occur — not only compared with adults, but also according to the different developmental stages of the young person. (These views are confirmed by recent overseas research.)<sup>14</sup>

One clinical psychologist quoted this definition of mental illness in children:

*A persistent presence of disturbed behaviour and/or disturbed emotions and/or disturbed relationships considered abnormal in the context of the child's sociocultural background and stage of psychological development, accompanied by impairment in personal and social functioning.*<sup>15</sup>

Witnesses also referred to the very wide definition of 'psychiatric disorder' given in a definitive study assessing the levels of psychiatric morbidity in Australian children:

*An abnormality of behaviour, emotions, or relationships sufficiently marked and sufficiently prolonged to cause handicap to the child and/or distress or disturbance to the family or the community, and not synonymous with 'maladjustment' or 'illness'.*<sup>16</sup>

The Inquiry was told that far too little attention has been paid to the withdrawn, quiet, depressed child or adolescent, whose problems may not be recognised or defined as emotional disturbance, because these children attract so little attention.<sup>17</sup>

The terms 'behaviourally disturbed' and 'emotionally disturbed' tend to be used interchangeably, although they sometimes accrue localised meanings.<sup>18</sup>

The Inquiry has concluded that in order to ensure effective provision of relevant services to young people it is essential to adopt a broad view of disturbance in childhood and adolescence (however 'untidy' this may be from a legal or clinical perspective). Indeed, the Head of Child Psychiatry at one major hospital recommended that children with non-psychotic disorders, (ie with emotional or behavioural problems) should be given access to services regardless of definitional distinctions.

Behavioural problems in children...are essentially associated with children getting into trouble. When they exist in a serious form in early childhood, they are the most persistent disorders of childhood. They are also very prevalent. They are the disorders which lead to severe personality disorders and substance abuse in adulthood. They are extraordinarily difficult to manage. Because of their persistence and the multi-modal nature of intervention which is most likely to be effective... They should be included within the definitions to provide them with access...to acute care [and to] rehabilitation services required to turn their lives around.<sup>19</sup>

Disturbed children and young people are frequently denied admission to psychiatric treatment services because they fall outside the narrow clinical definitions, admission criteria and legislative charters of the relevant departments or institutions.<sup>20</sup>

An inclusive but simple classification of childhood psychiatric syndromes has been proposed:

- Emotional disorders, characterised by a disturbance of expressed and felt emotion, predominantly anxiety, depression, or a mixture of both.
- Behaviour disorders, characterised by extremes of normal behaviour (under-activity, over-activity, passivity, aggressiveness), or persistence of immature behaviour (wetting or soiling).
- Somatoform disorders, in which physical and psychological factors are inextricably linked. Many were previously known as 'psychosomatic' disorders.
- Educational or 'learning' disorders (including dyslexia).
- Psychosis, characterised by loss of contact with reality and major deficits in personality development.
- Organic brain disorders, when physical disturbance of the brain has led to psychological symptoms.
- Abuse disorders, in which the child has been subjected to physical and/or sexual abuse.<sup>21</sup>

In many cases, some of these symptoms and conditions overlap.<sup>22</sup>

## Assessment and Diagnosis

Patients present to us because of emotional and/or behavioural symptoms. Our task is to understand those symptoms in the context of the individual's developmental level, both physical and emotional, [including] their physical health and social environment, which include home and school factors.<sup>23</sup>

Frequently there is a failure to recognise that a child is suffering from a disorder.

Children with problems often go unrecognised, especially in cases where the focus is on adult needs, such as in the case of marital discord, parental mental illness<sup>24</sup> or domestic violence, [which are] primary indicators of risk for children. When these situations aren't recognised, children's problems are rarely addressed.<sup>25</sup>

Expert witnesses canvassed several factors which make diagnosis in children and adolescents particularly complex:

Very few children with problems show signs that are the same as the major mental illnesses in adults... Normal adaptation and growth are fraught with difficulties that prove problematic for children, their families, school teachers and important others.<sup>26</sup>

A number of witnesses raised the issue of reluctance — both by parents and mental health workers — to identify a child or adolescent as being 'mentally ill', with the consequence that the young person often remains untreated or is handed over to another agency which does not have the expertise to help.

The reluctance to 'label' children [as having a mental illness] and thus to risk the many costs associated with it, is natural... In the absence of a label implying 'illness', the mental health system is not engaged in the treatment of this group...[so] the programs [to which they are referred] are managed by persons without the appropriate training and experience... Secondly, without being identified as...requiring special services [by] the label 'mental illness', children and adolescents can be discriminated against with impunity.<sup>27</sup>

The consequences of such unprofessional responses (reflecting either conscious or subconscious capitulation to the stigma and discrimination which still attach to mental illness) can be extremely serious.

A large number of these youngsters are suffering major depression, sometimes of a primary nature...but because of other adolescent behavioural and developmental issues, it tends to be not seen because it is masked... Very often, this serious medical aspect of their condition is not recognised, [or] sometimes it is misdiagnosed as schizophrenia. If one diagnoses an adolescent as schizophrenic in the years 15, 16, 17, it's a diagnosis of relative despair.<sup>28</sup>

Without an appropriate initial assessment and referral, many mentally ill adolescents who also have behavioural problems can get into very serious difficulty.

Generally speaking, perhaps two-fifths of those with serious psychological disorders are considered to suffer from behavioural disorders. They drift into all sorts of negative lifestyles, sometimes via drugs and other forms of substance abuse — a lifestyle which makes them at risk of running away from home, becoming homeless... And we have inadequate assessment and certainly inadequate hospitalisation for these youngsters. I am not suggesting we build more hospitals or provide more beds. The major issue today is providing adequate community treatment versus hospitalisation.<sup>29</sup>

Past reluctance to acknowledge that children can and do have serious disorders has meant there is insufficient investigation to identify them and to provide appropriate treatment:

There was a belief [on the part of clinicians] until a few years ago [that children did not develop conditions] which parallel those in adults, because they didn't talk to the children [in the course of diagnosis]; but now, once we look in detail using current research methods [including the child's self-reports of symptoms experienced], we find that children do have disorders like agoraphobia, depression, obsessive compulsive neurosis and so forth. These [may be] very young children — five, seven.<sup>30</sup>

Depressive illness in children is particularly difficult to diagnose because the child cannot readily communicate the experience. An adult witness to the Inquiry described her experiences of depression as a child:

The terms 'mental illness' and 'nervous breakdown' for me mean depression, which I have suffered from since my childhood. I can very clearly remember when I was five years old, sitting on top of the disused air-raid shelter at my school and cutting my knees with glass. I think that was the only way I could reach out to people to tell them how badly I felt inside. When I was 11, I can remember being very profoundly depressed. Part of my delusion in that depression was that I believed that I had cancer and that I was going to die, and I stopped eating. I think that sort of response — to stop eating, to become depressed, all of those things — were the only ways I could communicate such deep black pain. I can communicate that pain better to you now, because I'm older, I've got a large vocabulary, I'm tertiary educated, which helps me to put forward these things.<sup>31</sup>

### **Assessing Disturbed Children and Adolescents**

Expert witnesses in several States emphasised the necessity for more comprehensive, professional assessments of disturbed young people. One Sydney psychiatrist advocated an inter-sectoral assessment team established with an appropriately skilled coordinator:

Certainly one needs educational input, one needs psychological input — probably the single most valuable profession would be a neuropsychologist who specialises in learning disability. In practical terms, that person could provide insight into the deficits the child

or adolescent may have and what is required to make good those deficits. One also needs psychiatric input.<sup>32</sup>

## **Contributing Factors**

While I support [the evidence] on the contribution of child psychiatric disorder to family breakdown, the converse also needs to be taken into consideration, namely, the role of severe family discord in the [development] of emotional and behavioural problems in children and adolescents.<sup>33</sup>

While there is clearly a wide range of factors which can contribute to mental health problems in young people, these are not generally understood by the community and may even be overlooked by health professionals.<sup>34</sup>

Professional and academic witnesses identified the following high risk factors:<sup>35</sup>

- infant or childhood physical, psychological, sexual, or emotional abuse;
- genetic predisposition;
- dysfunctional family life and major domestic conflict;
- parental mental illness;
- other major trauma or disaster;
- parental alcoholism or habitual substance abuse;
- alcohol or substance abuse;
- pre-natal, perinatal and post-natal disease, trauma or distress in mother or baby or both;
- serious childhood physical illness, or physical or intellectual disability;
- family poverty or unemployment;
- homelessness;
- membership of an Aboriginal or Torres Strait Islander community;
- non-English speaking background or refugee status;
- living in a rural or isolated area;
- being held in protective or corrective custody.

In addition, there are the serious mental illnesses which have their onset in adolescence and occasionally in childhood<sup>36</sup> and which afflict a percentage of the population in all societies at similar rates.

## **The Role of Interactive Processes**

Evidence to the Inquiry indicated that there is a range of significant factors which interact within the family and between the child and its wider social environment. The evidence also reflected a growing understanding of some of the contributing factors which interact to influence the development of psychological and emotional disturbance in children and adolescents.

The Inquiry was informed that it is particularly important for therapists and clinicians working with troubled families to take account of ways in which one or a number of factors in the family dynamics interact with others, building up a network of interactions.<sup>37</sup>

One of these interactive processes is the connection between hyperactivity<sup>38</sup> in a child and resultant family breakdown:

I think it works both ways; dysfunctional families do create psychopathology in the child, and a disturbed child does produce dysfunction in the family. For example, a very severely hyperactive child puts tremendous pressure on the family — on both the mother and the father — and that drains their resources. If they are well-adjusted and resourceful and have social supports, they may cope... If they do not, that may lead to family breakdown. In many cases, professionals may be able to support the family, to help them to learn strategies and ways of dealing with the disturbance in the child.<sup>39</sup>

There is now more evidence coming up suggesting that hyperactivity is related to the development of antisocial personality in adulthood — it [appears that] it increases the risk quite substantially.<sup>40</sup>

A number of child and adolescent mental health specialists pointed to the urgent need for research in Australia to gain information about these and other possible contributory factors. For example, the relationship between learning difficulties and mental health problems was mentioned repeatedly:

So many child psychiatric problems [include] learning problems, language problems, other neuropsychological disabilities as an integral part of the problem. If numbers of young people are getting incomplete assessments, then it is likely they are not getting optimal treatment.<sup>41</sup>

Of the recognised contributory factors, the one which the Inquiry was told has received far too little acknowledgment and emphasis is the significance of childhood neglect and abuse in the development of concurrent or later disorder. For this reason, the Inquiry has taken the view that special attention should be accorded these issues in this report.

### **Child Abuse**

It seems to me that [one of] the big issues for the next decade [in child psychiatry] will be the damaging consequences of child abuse and neglect... Failure to develop a more appropriate response to these problems will keep our psychiatric facilities...fully occupied well into the next century.<sup>42</sup>

Child abuse<sup>43</sup> — one of society's most appalling phenomena — can lead to immense trauma and suffering. It is only relatively recently that health and



welfare services and the courts have acknowledged that many adults seriously harm or neglect their babies, children and adolescents.<sup>44</sup>

There is some evidence that adolescents suffer physical, verbal, psychological and sexual abuse — particularly physical abuse — much more than is commonly realised, and that it may be one significant reason why adolescents as young as 12 and 13 run away from home. It is, however, still difficult to determine accurately the extent of the various forms of child abuse and increased research in this area must be a priority.

*Child abuse is hidden. It occurs mainly in the privacy of the child's own home, hence exact numbers are impossible to calculate.<sup>45</sup>*

The Inquiry was told repeatedly that unless agencies were able to intervene to assist the whole family, professionals saw little point in removing children to a temporary safe home — only to send them back to further abuse. Appropriate counselling and support for abusing parents is essential before a child is returned to them.<sup>46</sup> However, the current dearth of resources means that in many cases this does not occur.

## **Neglect**

Physical neglect of infants and children is a form of child abuse.<sup>47</sup> Neglect is far more difficult to detect — even to estimate — than other forms of abuse.<sup>48</sup>

One reason the extent of child neglect cannot easily be estimated is that it is usually hidden until it becomes extreme. One of the most reputable bodies in the US<sup>49</sup> estimates that there are five times as many neglecting families as abusing families and that, as these agencies see only the most severe forms of neglect, the problem is probably extensive.<sup>50</sup> Both severe and moderate child neglect have been reported as potential causes of emotional and psychological damage,<sup>51</sup> in addition to physical damage — for example, emotional dependency in childhood, adolescence and adulthood, and chronic depression in adulthood.<sup>52</sup>

## **Effects of Abuse and Neglect**

The fact that childhood neglect and abuse can substantially contribute to the development of mental illness and behavioural and emotional disturbance was confirmed by many witnesses to the Inquiry, particularly clinicians working with children. The effects are appalling — and the gravity of the problem is not yet recognised by Australian society, or, indeed, by our governments.

The help needs to come when they are suffering in childhood... 40-60 percent of women in inpatient psychiatric care have experienced significant sexual abuse in childhood. Their adult diagnosis will be depression, phobias, obsessive compulsive disorder, personality disorders, or even schizophrenia if they have flashback memories of critical voices and shadowy figures.<sup>53</sup>

As one Queensland expert told the Inquiry:

In my 25 years' experience working in the child psychiatry field, the greatest noxious influence on the mental health of children...is child physical and sexual abuse and neglect. I would estimate that in 75 percent of our current cases at the Mater [child psychiatry clinic] we would find physical and/or sexual abuse and/or neglect, in either this or the previous generation — in either the parental generation or in the current children.<sup>54</sup>

The effects are not only tragic for the individuals concerned, but are massively compounded by the later effects on their families.

The importance of damaging stress in childhood cannot be underestimated as an underlying factor in adult mental illness, because we see such a lot of it in the parents of children that present to our service. And that would include the serious mental illnesses... A person can be rendered vulnerable early in life through being exposed to very damaging sexual abuse, for example, as a young child — it can really ruin that person's mental health for the rest of their life... Many of the mothers I see (because we work with the whole family) have been depressed for years as a result of physical and sexual abuse in their childhoods. They've just been chronically depressed — full-blown depressive illnesses — never diagnosed and never treated.<sup>55</sup>

This evidence was supported by a South Australian witness working in the Child Protection Service:

The potentially damaging early effects that sexual abuse has on the mental health of children...include anxiety, depression, anger and sexualised behaviour. Among young children there may be sleeping problems, nightmares, fears and phobias, [bed-wetting, soiling,] school problems, and psychosomatic disturbances. Longer term effects can include...unsatisfactory interpersonal relationships, sexual dysfunction, depression, suicide, alcohol and drug abuse, delinquency and runaway behaviour.<sup>56</sup>

One submission from a peak NSW non-government organisation also emphasised that a history of childhood abuse was common among women in psychiatric hospitals, but that little attention was paid to the long-term effects of such abuse in most hospitals — and no counselling had been offered to help them come to terms with its consequences.<sup>57</sup> (Also see Chapter 27 — Prevention and Early Intervention.)

## **Responses to Abuse and Neglect**

State and Territory governments have responded to the problems of child abuse and neglect with a range of mechanisms — including child protection services; orders providing for institutional care or temporary or long-term foster care; protective custody; and in three States — South Australia, NSW and Queensland — mandatory reporting by teachers, doctors, social workers and welfare officers of suspected cases of abuse.<sup>58</sup> (Individuals may report the suspected abuse of a child in those States where reporting is mandatory for professional groups.)

However, the mere fact of bringing a case to the attention of the authorities does not, in itself, constitute an effective response to this pervasive and pernicious problem. It may in fact be worse than useless if, after the report, nothing is done about intervention, counselling, treatment, and (where it is in the best interests of the child) removal from the care of the abusing adult.<sup>59</sup>

## **Child and Adolescent Psychiatric Services**

We have heard people say [to the Inquiry] today that psychiatric services is the poor cousin of the health dollar — I would say that child and adolescent psychiatric services is the poor cousin of the poor cousin.<sup>60</sup>

### **Range of Services**

There was general agreement among witnesses providing evidence to the Inquiry that the small number of child and adolescent services which do exist are of a high standard and are staffed by skilled and committed mental health professionals.<sup>61</sup> The problems they face, however, are enormous. They include a desperate shortage of services — with none at all in many regions; grossly deficient funding; a lack of appropriately trained staff; poor understanding by administrators of what is required to organise a multidisciplinary, multi-agency approach to child and adolescent mental health care; and unsatisfactory or incomplete mechanisms for integration with related services. (These issues are dealt with in detail later in this chapter.)

According to the evidence presented, those services which do exist can be divided into the following categories:

- Community centre-based comprehensive services (these constitute the majority of programs for children, families and adolescents);
- inpatient acute units for children up to 12-13 years;
- inpatient acute units for adolescents;
- inpatient behaviour disturbance services for children and families;

- inpatient behaviour disturbance services for adolescents;
- children's day patient programs;
- adolescent day patient programs;
- outpatient assessment or treatment services for both age groups;
- home-visiting (community) services;
- crisis outreach and regular 'home-based' or community outreach services for families, children and adolescents.

**A South Australian witness described the approach taken in Adelaide:**

We believe that we have adopted a model of service that is flexible enough to meet the needs of the community but sophisticated enough to provide all levels of service. After much deliberation and significant disagreement...two decentralised Child and Adolescent Mental Health Services were established [in the northern and southern suburbs] with the aim of making the services more community-based... [We aimed to get] more child psychiatrists in the public sector and an agreement that multidisciplinary mental health teams were the best option.<sup>62</sup>

The services, which are affiliated with Adelaide Children's Hospital and the Flinders Medical Centre respectively, operate 40 hours a week — although 'sometimes after-hours clinic sessions are offered if it is difficult for family members to come [in working hours].'<sup>63</sup> The teams consist of child psychiatrists, community mental health nurses, clinical psychologists, social workers, occupational therapists and, where possible, a speech pathologist. Both services work closely with the Education Department and operate day clinics for consultation and individual, group and family therapy. The hospitals to which the services are linked provide a 24-hour on-call crisis service. However, clinic staff consider there is still 'a gap there between what we provide and what could be provided.'<sup>64</sup>

A witness at the Hobart hearings described a child and adolescent outreach service which visits community health centres — not mental health centres. Although they are based at the child and adolescent psychiatric clinic, one or two professional staff members see new referrals and regular patients in the less threatening environment of the community centre.<sup>65</sup>

A Queensland expert<sup>66</sup> told the Inquiry that a comprehensive children's psychiatric service, such as those attached to children's general hospitals in a number of major centres throughout Australia, would include inpatient, outpatient and day patient services and consultation-liaison.<sup>67</sup> Both inpatient and non-residential child and family services would use a wide range of treatments and therapeutic approaches, including individual, family, parent, and group therapy, and such features as psychotherapy, stress management, play therapy, and therapy through creative expression.

## *A Model Service*

One effective inpatient service for behaviourally disturbed adolescents was inspected by the Inquiry in Perth. Hillview Terrace Hospital is a residential facility which provides therapeutic programs for emotionally and behaviourally disturbed adolescents aged 13-18 and their families. It treats young people who are so disabled by their symptoms that outpatient treatment would not be satisfactory. (However, the hospital accepts only voluntary patients whose families are prepared to involve themselves actively in the treatment program.)

This service provides an integrated program of three types of therapy — individual therapy, family therapy and milieu therapy (treating a disorder by making changes to a patient's circumstances and environment in order to enhance the effectiveness of other forms of therapy). The more severely disturbed or psychotic adolescents are not usually admitted, because they are considered unlikely to respond to any of these therapies. The young people who are admitted suffer from a range of conditions including depression, suicidal behaviour, anxiety, emotional or behavioural reactions to sexual abuse, obsessional disorders, reactions to dysfunctional family situations, anorexia and bulimia nervosa, and other psychogenic disorders.

The hospital is located in a gracious old two-storey building surrounded by lawns and trees:

It's a beautiful place — the bedrooms have a lovely outlook. It is so important to have this park-like atmosphere of peace and serenity.<sup>68</sup>

It accommodates up to 15 young people who, wherever possible, continue to attend school or work during the day. The average length of stay is four months, although this varies considerably, depending on the individual and their progress. A program of individual goals is established and regularly reviewed by the client and the nurse case manager.

Family therapy sessions help all members of the family work towards changing negative patterns of behaviour and interaction. The overall treatment approach emphasises the adolescents' basic normality and areas in which they are able to function effectively, rather than their difficulties.

Troubled adolescents in this program learn to modify unsatisfactory emotional responses and to practise more productive ways of managing their lives in a safe and reassuring environment. Evidence to the Inquiry demonstrated the importance of this type of intervention — before young people end up in the youth drug culture or the juvenile justice system.

Hillview Terrace's adolescent residential service is supported by an adjacent non-residential child and family service, which provides a comprehensive range of family interventions and child and family therapy programs. The Inquiry also heard evidence of several similar non-residential services in other cities.<sup>69</sup>

As previously indicated, at least 10 percent of adolescents are affected by the kind of disorders treated at Hillview Terrace Hospital (ie several thousand in Western Australia alone). This service, while excellent, is only available to a tiny fraction of those who need such assistance.

## **Difficulty in Obtaining Treatment**

Access to treatment is one of the most important rights that children and adolescents have to have. For many years, until quite recently in fact, people did not think that children and adolescents had psychiatric problems — child psychiatry [itself] is a fairly new discipline... As a consequence, services for children and adolescents have been very scarce.<sup>70</sup>

### **Difficulty of Access for Children**

There are problems with access to services. Children are mostly not able to seek help as effectively as adults. They rely on adults to firstly, recognise their needs, and then to seek help on their behalf.<sup>71</sup>

Children are relatively powerless in making decisions and accessing services in any field. Most do not have the knowledge or maturity to identify either the kind of problem they are having or the kind of assistance available. For a number of reasons, adults cannot or will not always respond appropriately:

[Some children] are prevented from receiving services by their families, because their families may have a view that they shouldn't be visiting the doctor or the psychologist or the social worker... Child psychiatry services have no mandate...with those children. We can't make them come... Children aren't usually mentioned in Mental Health Acts... The people who ultimately deal with children like that are social welfare services under certain care and protection applications... For some of those children it leads to disruptions of attachment, to deprivation, to secondary consequences which magnify the psychiatric disorder.<sup>72</sup>

Schools are potential points of referral to services for children, but (as discussed below) this system is far from satisfactory. Even when it works well, the summer break proves problematic:

The long Christmas school holiday is a period when all support [from within the schools] is removed, and I would suggest that more than 90 percent of these children don't have the skills to tap into other community resources.<sup>73</sup>

## **Difficulty of Access for Adolescents**

Many adolescents are also unlikely to acknowledge or identify an emerging mental health problem.

For young people generally, mental health is something they don't even begin to conceptualise. [They] are only vaguely aware of how their state of mind affects their overall social interaction... Typically, they view psychiatrists as 'people that stuff around with your mind'.<sup>74</sup>

Clinicians who gave evidence to the Inquiry emphasised that adolescents need to relate to their own age group. If they do accept the need for assistance, they frequently reject services which cater for children or adults — particularly if they are experiencing problems which already make them feel 'different'.<sup>75</sup>

Witnesses also emphasised the importance of making facilities for adolescents relevant and appropriate for young people.

Youth culture is a fact... Young people simply walk away from services that do not speak their language or share their outlook. Services which do not address adolescent needs separately are...a waste of time and money.<sup>76</sup>

A difficulty we have in young people accessing our service is the anti-authority stance of adolescents. A unit such as ours will be seen as part of the Government, perhaps wielding a big stick. Young people may access drop-in centres rather more freely.<sup>77</sup>

Some services have recognised the benefits of reducing bureaucratic procedures to a minimum:

To facilitate accessibility, no referral is necessary to our service — young people, or their families, can access us directly. A general practitioner, a specialist medical practitioner, guidance officer within a school, or a welfare officer from Community Services may approach us concerning a child that is known to them. We are quite happy to take up that referral, but we ask the family to contact us directly to make the arrangements. There is no charge for the service we offer.<sup>78</sup>

Services also have to contend with the extreme reluctance, by both adolescents and their families, to be associated with anything identifiable as 'psychiatric' or 'mental health' — due to prejudice against people who have mental illnesses.

The stigma of attending a psychiatric unit is one obstacle... The stigma is also [self] imposed in that individuals will be afraid of the idea of having a mental illness... Another situation which can result in non-referral is the belief by some lay people and some professionals that referral of a child to a psychiatric service means that child will be hospitalised and/or medicated.<sup>79</sup>

One of the problems we hassle with is our name — Child and Adolescent Mental Health Service. The average adolescent takes one look at that and runs a mile. One of my colleagues recently quoted two families who said they had driven up to the door, taken one look at the label, and said: ‘We can’t go in there!’<sup>80</sup>

This evidence highlights the need for adolescent services to include facilities such as youth drop-in centres — located, named, designed and equipped in a manner which appeals to adolescents and accords with the prevailing youth culture. Otherwise young people will avoid the facility and therefore not receive the treatment and support they need.

## **Deficits in Service Provision**

There are very few child psychiatry services in Australia, and I can particularly comment about Victoria... Children in the country miss out, because there are almost no psychiatric services in rural areas; ethnic groups miss out, because of access problems; Aboriginal groups miss out...and children in general miss out on services.<sup>81</sup>

Although Australian society pays lip service to the notion that our children are valued and our young people are ‘the hope of the future’, the serious deficiencies in child and adolescent mental health services exposed throughout the Inquiry suggest the opposite. Without exception, every witness presenting evidence about child and adolescent mental health referred to the appalling lack of provision for training, staff, facilities and services to assist children and adolescents in need of special care.

This serious inadequacy of services was quantified by several witnesses:

Children and adolescents comprise almost a third of our population. We can estimate that there would be, at any one time, approximately 13-15,000 children and young people in the ACT suffering from psychiatric or behavioural problems. A tiny proportion of this large group is receiving support and treatment of any kind.<sup>82</sup>

Because a comprehensive range of services is needed to meet the mental health needs of our most vulnerable children and adolescents — and because so few of these needs are being met — many witnesses identified particular areas in which they believed the need is most acute.

### **Lack of Community Crisis Teams and Support Services**

Experts agreed that it is generally preferable to keep adolescents out of hospital-based care whenever possible and to provide them and their families with treatment and support in their own surroundings. In order to achieve this, it is necessary to be able to mobilise experienced mental health workers to go to where the young person in crisis is — first, to assess their condition; and



second, to initiate treatment if appropriate, without having to physically remove the child or adolescent to a psychiatric ward. However, according to the evidence, there are very few areas in Australia where such services are available. The following evidence refers to South Australia, but similar accounts were presented to the Inquiry in every State and Territory.

[There are] two conspicuous lacks in the field of child and adolescent mental health. The first is a lack of a crisis assessment and treatment team particularly aimed at home [visits] and an accessible form of treatment for adolescents in the community. The second is developmentally-appropriate inpatient beds, either within the general hospital or as a free-standing unit.<sup>83</sup>

### **Lack of Inpatient Assessment Facilities**

Community or home-based care is not always appropriate for children or adolescents who become seriously disturbed or psychotic. A period of inpatient care may be required to carry out a full assessment of the young person's condition. However, suitable facilities for inpatient assessment are inadequate or non-existent in many parts of Australia — even in some of our major cities.

There would be somewhere between 30-40 young people in Perth each year from the ages of, say 12-18, who suffer the onset of either schizophrenia or manic depressive psychosis. Currently there is not a suitable facility for inpatient assessment of these young people.<sup>84</sup>

### **Lack of Inpatient Acute Beds**

Where acute inpatient admission is considered necessary, an adolescent in crisis often finds no suitable facilities exist, or else that a facility is full and no beds available. In every State witnesses deplored the lack of adolescent inpatient facilities.

- There are several psychiatric facilities [for young people] within the Melbourne metropolitan area. [When a young person] requires removal from their home, however, most of these have limited bed capacity and, more often than not, are unable to assist because they are full... The bottom line in the whole spectrum of juvenile psychiatric and emotional disturbance is the lack of resources available... It's not unusual for us as a [Community Policing] Squad when we are presented with a child with problems to spend several hours on the phone trying to find some sort of help for that child.<sup>85</sup>
- The two inpatient units [in metropolitan Brisbane] for children and for adolescents are often full and have waiting lists several weeks long. Officers of the Department of Family and Community Services are overwhelmed by child abuse referrals and only react to the most urgent cases.<sup>86</sup>
- In NSW, there are only two inpatient services that can deal with suicidal young people, and in Victoria, we've only currently got three.<sup>87</sup> They're always full. You have to wait about six to eight weeks to get a person into those services — if you're lucky.<sup>88</sup>

The Director of Psychiatry at a regional hospital decried the lack of acute inpatient facilities for either children or adolescents outside major city centres:

There are no adolescent beds. There are no children's psychiatric beds. There is no child psychiatrist. Last night at 8.30pm I went to the paediatric wards to see a child — a boy who had dived out of a window with his teddy bear screaming 'They are going to kill me'. I went to see him, but where can we send him? If we send him to the city to the adolescent unit, how will his family be able to be with him? And I'm sure we wouldn't get him in, anyway. My registrar spends up to three or four hours on the phone trying to find a bed for the people with serious mental illness who present — they come to our hospital and then we have to find a bed for them. Most of my registrars and resident's time is taken up in making phone calls.<sup>89</sup>

### **Lack of Community Centre-Based Services**

The major part of service provision for troubled children, adolescents and their families is — and should be, wherever possible<sup>90</sup> — through community-based child and adolescent mental health centres, which provide a range of services both mobile and centre-based, so that young people can stay in their homes and schools and take part in normal daily activities as far as possible, while still obtaining appropriate therapy. The added disruption and trauma of psychiatric hospitalisation is usually avoided, except where the young person is experiencing acute mental illness or extremes of emotional or behavioural disturbance.

Fully staffed multidisciplinary child and adolescent teams are only found in our largest cities — and not even in all of these:

The World Health Organisation estimates that you need one child and adolescent mental health team consisting of eight workers, for every 100,000 in the population. According to population ratios in 1986, Queensland required 26 teams; it had only 15. In 1991, I would reckon that we probably need 30 such teams. We still have 15. The whole 15 teams only cost \$6 million, and I think it would be a small investment on the part of the government to double this, to bring us up to par.<sup>91</sup>

Judging by the submissions received, and by inspections of child and adolescent clinics conducted by the Inquiry, a great deal can be achieved in adequately staffed, geographically accessible, community clinics for children and their families. But, the Inquiry was told, there are very few of them. A family whose members are desperate and a young person who is depressed, psychotic or seriously disturbed and needs the service urgently may have to wait months in some States:

Health Department child mental health clinics in Brisbane have waiting lists, many of at least a month, and in working-class areas, at least three to six months long — and most of the private child psychiatrists have waiting lists.<sup>92</sup>

The waiting list for young sufferers is appalling. Families are often told they have to wait three months before being seen. Usually a crisis occurs before this time, necessitating police intervention. To realise their child or adolescent is disturbed is traumatic enough to cope with, but to find that help for them is just not available in time of crisis is incomprehensible.<sup>93</sup>

### **Lack of Day Treatment Programs**

Day treatment and outpatient services can often provide a disturbed child or adolescent with quite substantial care and treatment, without the dislocation of being admitted to an inpatient facility. (They are also much less costly to run than inpatient services — which require meals, cleaning staff, laundry and kitchen services and greater capital expenditure, in addition to the clinical services.) However, professional child and adolescent mental health workers presenting evidence identified major inadequacies in this area.

There seem to be two major deficits in services — firstly, there is no day facility for children. This would require the co-operation of a number of inter-departmental agencies, and secondly, there are no separate facilities for older adolescents.<sup>94</sup>

An integrated network is the best way of treating disturbed adolescents in the community, that network to include outpatient facilities, which are already in place...and an adolescent day service... There is a large gap between the few beds in a general hospital setting, and the community clinics. There is no kind of in-between step where people can have a more intensive program, either in their own home, or through a...day service.<sup>95</sup>

### **Inpatient Planning Problems Caused by the Small Numbers**

The Inquiry heard differing professional views concerning bed requirements for inpatient care for disturbed adolescents. In the larger cities such as Sydney and Melbourne, clinicians and other service providers acknowledged the necessity for an extension of inpatient facilities for acutely mentally ill or disturbed adolescents. In some smaller cities, such as Canberra and Hobart, psychotic adolescents constitute a relatively small number of young people needing some kind of mental health treatment. Some specialists therefore regarded them as too few in number to warrant the construction and staffing of a specialist unit.

I do not believe [Tasmania's] population warrants a residential facility. The need to admit young people for psychiatric assessment or care is small... Of the patients that come to our facility, I have only four adolescent patients with diagnosed schizophrenia. Two of them have required very short admission [to the adult psychiatric ward]... That number does not warrant a separate residential facility... There is actually a greater need for children to have permanent and ongoing placements within the community, whilst at the same time receiving psychiatric help on an outpatient basis.<sup>96</sup>

In centres where the population is relatively small, there is clearly a need to examine a range of possible alternative approaches.

### **Deficits in Staffing**

It was common for witnesses to describe their own staff shortages, and the efforts their services make to cover the community's needs — because no other agency has the expertise in the field and because there are simply not enough trained staff anywhere in child and adolescent mental health. A witness from Clare House in Hobart told the Inquiry:

We provide a range of child, adolescent and family mental health services [on an outpatient basis]. Our sister clinic in Launceston and another in Burnie are both much more poorly staffed than our unit. We provide some consultant back-up to the Burnie clinic, but there is very much more needed in other parts of the State... At Burnie, the district [they are servicing] is very wide-flung...and they currently have only one and a half to two clinical staff. That has been a problem of recruitment to that area.<sup>97</sup>

Deficits in staffing sometimes mean that essential functions are not even attempted:

South Australia is a long way behind...in the range of facilities available for child and adolescent psychiatry, despite the sympathetic approach of the government... The problem is that there just aren't sufficient people working in the area... We can't provide access to services because we don't have the services, and we don't have the people. We have very good outpatient services for children and adolescents, but they have waiting lists of three, four months. That means we can't even **think** about providing services to the juvenile justice system, the drug and alcohol system, to the people working in primary health care, working with street kids, working with children with chronic illnesses.<sup>98</sup>

### **Lack of Child and Adolescent Psychiatrists**

A psychiatrist appearing on behalf of the Western Australian Branch of the RANZCP summarised the acute problem of staff shortages in child and adolescent psychiatry which the Inquiry heard about in every State and Territory:

One of the main things that is holding us back...is the serious shortage of child psychiatrists... One of my prime concerns...is to increase the number we have — we currently have about half the recommended minimum number of child psychiatrists for our population in WA...and they are primarily concentrated in the metropolitan area. A reasonable estimate is that we should have about 25, by the most conservative estimates of what is reasonable. We currently have 12. I have three child psychiatrists in training...[but] a number of things put that in jeopardy too — there are no designated training jobs in child psychiatry; I would need to prevail on the good offices of other people to 'lend' me jobs to train child psychiatrists... It is also a problem in other States. It has recently become a serious problem in Queensland, that I am aware of —

[psychiatrists who wish to train as child psychiatrists] have actually been leaving that State because they cannot get training.<sup>99</sup>

## **Lack of Specialist Mental Health and Allied Health Workers**

Specialist psychiatrists with training and experience in working with disturbed children and adolescents are essential to the provision of appropriate services. However, for every trained psychiatrist in this field, a larger number of mental health and allied professionals is required: child mental health nurses, adolescent mental health nurses, family therapists, social workers, counsellors, specialist clinical psychologists, remedial education teachers, occupational therapists, and sometimes speech therapists.

Many services around Australia are juggling the time of too few workers in too few disciplines to attempt to provide an effective service.

This is the case even in major metropolitan areas, but it is especially true in more sparsely populated areas where, in many instances, even if funds are available, qualified staff are not. In North Western Tasmania:

The child and adolescent unit [provides] only 20 hours of clinical psychology and two social work positions, one of which has been unfilled for the last eight weeks because we are unable to get a suitably qualified person... A psychiatrist is available to the child and adolescent unit only one day per month and is therefore...available only to the staff [to provide case consultation] and not to the patients.<sup>100</sup>

## **Inequitable Distribution of Scarce Resources**

Most workers attempt to fit as many children, families and adolescents into the daily schedule as they possibly can. Despite their efforts, however, they can often only respond to those in most urgent need. One reason is the maldistribution of the limited resources which are available.

Brisbane has two children's hospitals, but with the advent of regionalisation, [one] now has 200,000 more people in its catchment area than does the other. Both hospitals' departments of child psychiatry cater for approximately 500 new client families per year, with a similar number of problems and conditions. [One] hospital has a full-time staff of 36 people; [ours] has a full-time staff of four. This means that staff...are under constant stress, with huge caseloads, long hours, sub-standard working conditions and minimum resources. Because patient needs are paramount, few resources remain for teaching, research, staff training, and primary prevention work. In the long term, everyone — the staff, the children, the community as a whole — pays the price. There's no saving in the long term.<sup>101</sup>

## **Deficits in Training in Child and Adolescent Mental Health**

The general training needs of mental health professionals and others who work with those affected by mental illness are discussed in Chapter 6. However, the lack of training in child and adolescent mental health warrants special attention.

### *Psychiatrists*

Child and adolescent psychiatry has been extremely slow to develop as a specialty area in Australia.

Until recently, there's been very little support for academic positions -- my Chair was the fourth in Australia,<sup>102</sup> and that's a major problem.<sup>103</sup>

The undersupply of specialists and the urgent need to encourage more psychiatrists to enter the field was raised by numerous witnesses:

The training of people in the mental health area — whatever professional discipline they come from — has been dominated by a cross-sectoral adult-oriented view. Very few academic institutions or training programs have taken up a developmental [child and adolescent] line, [so] it's hard for the products of that system to envisage the need in the other areas.<sup>104</sup>

**Academic endeavour in the area is essential:**

There has always been a training program for child psychiatrists for the past decade or longer...[but] there is no academic child psychiatry department within this State — there is a vacuum in leadership.<sup>105</sup>

Because there are so few specific services for children and adolescents, the opportunities for specialist training are also extremely limited. In some States, such as Western Australia, they are non-existent.

If you want people to work in...child and adolescent psychiatry, you have to provide good training experiences for them and good facilities through which they can provide the services. At the moment there is no service — no acute service for adolescents — so it is very difficult for anyone who wants to specialise in that area to be able to work.<sup>106</sup>

### *Allied Professionals*

There are a number of professional groups whose members come into contact with young people in the course of normal school and community interaction. Members of all of these groups may be involved with children who are mentally ill or seriously disturbed. These professional groups include teachers, psychologists, counsellors, social and welfare workers, family therapists,

Family Court counsellors, youth workers, police officers<sup>107</sup> and court officers. The fact that members of all these professions need some special training<sup>108</sup> was raised repeatedly in evidence to the Inquiry:

Adequate training [is required not only] in medical schools and post-graduate medical schools and in nursing schools, [but] for all professionals involved in mental health [so that there is] adequate assessment and adequate diagnosis.<sup>109</sup>

Fortunately, there are exceptions:

Our psychiatric unit has recently been accredited as a career child psychiatry training facility... Graduate psychologists and social workers-in-training come on placement and...psychiatrists-in-training [for adult services] are [now] required to spend six months of their training within a child and adolescent psychiatric unit. At undergraduate level, senior medical students come on placement with us as a mandatory part of their training... I would hope in future we will be able to offer such packages for, say, community welfare officers, guidance officers and so on, to increase their awareness of emotional and behavioural problems in children and what our facility offers.<sup>110</sup>

### **Inadequate Funding**

Witnesses in all jurisdictions drew the Inquiry's attention to the grossly inadequate funding provided for mental health services for young people:

I really have one thing to say and that is that child and adolescent mental health services in this State get about 6 percent of the total mental health budget, and it is not enough. These services really need about twice that proportion just to get to first base.<sup>111</sup>

Fluctuations in funding and lack of forward planning compound the problem:

What is needed is stable core funding in an ongoing way — not uncertainty every six months about whether the service is going to get sufficient funding to keep going for the next six months.<sup>112</sup>

Witnesses speaking from very different professional perspectives identified both State and Federal budget priorities among the most fundamental problems:

The dramatic financial squeeze on the States by the Commonwealth Government, in combination with the low-spending policies of the Queensland Government, has meant that State government services to the mentally ill have been a low priority.<sup>113</sup>

In the 1990-91 Victorian Budget, resources allocated to [child and adolescent] mental health services were reduced. One facility was actually closed, and it was the only facility in the State which provided an inpatient service to the late-adolescent group aged 16-20. Other facilities had staffing and general running-cost cuts. There was some expansion, which is most welcome — some...occurred in the country and [there was] the establishment of an adolescent inpatient unit at Monash Medical Centre, but this has been at the

expense of the Parkville Adolescent Unit. These cuts have been made worse by the reduction in other services for children and adolescents in general health, education, welfare. These have traditionally provided preventive mental health programs to support and augment work that's done by our own services, so that the pressure on us has become even greater.<sup>114</sup>

In addition to the serious deficiencies in even basic services for young people, the Inquiry received evidence concerning shortfalls in related services which exacerbate the difficulties. These included suitable adolescent accommodation, both supported and independent; training and employment; education; and social and recreational activities for adolescents recovering from a mental illness. (These issues are addressed in several other chapters.)

## **Inappropriate Placement**

I think it's appalling for 13 and 14-year-olds to be admitted to adult psychiatric wards... It's difficult enough when they're admitted to general medical wards, where there are not adequate psychiatric staff, but there is a real danger... in the psychiatric hospital that these children can be exploited where there are some very disturbed [adults] and levels of supervision may not be appropriate.<sup>115</sup>

Because there are so few services for children and adolescents, the Inquiry was repeatedly told that young people in crisis are frequently placed in highly inappropriate facilities — sometimes at great personal risk.

This evidence included instances of mentally ill or seriously disturbed children being placed in children's general medical wards; adolescent acute wards; adult psychiatric hospitals; and inappropriate temporary foster care.

If we have a child who is traumatised in some way — who, for example, has attempted suicide — then we have to admit them to a public hospital before we can get them to Wynyard [an adult psychiatric clinic], which is the only facility which will receive children in these unfortunate situations. There was a case this year where a child had taken an overdose... It wasn't appropriate for her to stay at Wynyard because the other patients who were there on that particular night made it far more dangerous for her to stay in the institution than it was to put her back into a deplorable home situation, which is where she finished up... Often a referral does not take place, because the [available] places are seen to be inappropriate and, on the occasions when those waters have been tested, have been shown to be inappropriate.<sup>116</sup>

**Adolescents with serious psychiatric illnesses who require inpatient assessment and care face similar problems:**

- Young people can be admitted to the psychiatric units of adult general hospitals — Sir Charles Gairdner Hospital, Queen Elizabeth Medical Centre and Royal Perth Hospital. This is a less than optimal environment for treating psychotic illnesses, particularly with young teenagers — there is virtually no facility there for education... And there are



problems...where young people are exploited emotionally or in other ways by adult patients... The other alternative is the adult psychiatric hospitals, which are...really quite unsuitable for similar reasons.<sup>117</sup>

- Every year, a large number of young people unable to gain access to adolescent psychiatric services end up as inpatients at adult psychiatric services. Over the past eight years, on average around 15 young people per year aged 13-15 have been admitted into the adult psychiatric system. This figure jumps significantly...in the 16-18 year old bracket, with the average [per year] being around 166 admissions.<sup>118</sup>

- The only place available for students requiring hospitalisation is essentially designed for adults and not for adolescents... The programs are not essentially therapeutic... Some young people have already been subjected to all forms of abuse and, depending on the other people who have been admitted to the [adult psychiatric] clinic, it may not be safe for an adolescent girl to be admitted with a large number of older youths and young men.<sup>119</sup>

**Another relatively common practice — placing adolescents in children's wards — is equally inappropriate:**

[There are] no specific inpatient facilities for adolescents... [They are] either admitted to Princess Margaret Hospital, which is the children's hospital and theoretically has an upper age limit for admission of 14. Very disturbed teenagers do not fit well into the children's hospital environment — we have an inpatient ward with eight beds, and some of the patients would be as young as three or four. It is not appropriate to put these young [children] with very disturbed teenagers. Children's hospitals have...problems with teenagers.<sup>120</sup>

**The Inquiry also heard damning evidence of children and adolescents entering the juvenile justice system by default — simply because no one had been able to provide assistance at an early stage and there were no mental health facilities available when the crisis occurred.**

Inevitably, many young people with psychiatric problems languish within the correctional system and within youth training centres, because the mental health system will not appropriately deal with them.<sup>121</sup>

**In many instances, the only care and protection society provides for these severely troubled young people is a remand centre, a lock-up, or a prison cell. Dr David Wells, the Director of the Office of Forensic Medicine in Victoria, told the Inquiry:**

Even this week, we have had to put young people into police cells for hours, waiting for the phone call back. That's an appalling situation...The impact on the individual — a person who has committed no offence is put into a cell. And then [there is] the impact on the family — a 16-year-old boy with his first schizophrenic manifestations is locked up while they try to find a bed. It is devastating!<sup>122</sup>

The police themselves are appalled by what they are forced to do with some young people who are in an extremely vulnerable state:

A 15-year-old girl was so violent towards her family...that she had to be removed [and was] presented at court. Because there was no other placement available, she had to be remanded in custody for six weeks, pending her release to a child psychiatric centre for treatment... These children and adolescents [do not] require removal to remand detention centres. The juvenile sufferer does not understand what is happening to him or herself when suffering psychiatric or emotional illness. Being incarcerated and appearing before a children's court can only add to their bewilderment... The hardest thing for me is to be there when a child says to me, 'What have I done wrong? Why am I going to court? Why have I got to be locked up?'... The placement of these children and adolescents in remand detention facilities because of incredibly inadequate resources can no longer be tolerated... Is it not the same as placing a mentally ill adult into Fairlea or Pentridge?<sup>123</sup>

In another case brought to the attention of the Inquiry, a 12-year-old boy in Newcastle was 'locked up like a criminal, when his major sin is a mental illness that no-one has been able to help him with'.<sup>124</sup> The boy, who was diagnosed as suffering from an obsessive-compulsive disorder, was charged with a minor stealing offence and given bail. When he breached bail conditions by refusing to take medication and became violent and destructive in his home, he was referred to the Worrimi Detention Centre — after both the Departments of Community Services and Health were unable to find anywhere else to place him. He was kept there for seven nights. After the second night, he was found hiding in a broom cupboard in the lock-up.

The Children's Court Magistrate who heard the case said publicly that it 'highlighted the complete lack of facilities for mentally ill children in the area.' The Professor of Psychiatry at Newcastle University<sup>125</sup> commented on the case, saying that a population the size of the Hunter region should have 'about eight to ten beds' for disturbed children and adolescents. (The publicity generated by this controversy achieved a breakthrough in this instance — a new team was formed in the Hunter area, with officers of the Community Services and Health Departments given responsibility for arranging the assessment and care of children with mental, emotional or behavioural problems not catered for by existing services.)

It is appalling that a disturbed child had to be incarcerated in an ill-equipped facility, with no health or welfare staff to treat or care for him, before the implications of his situation were acknowledged and alternative arrangements made. However, it should be noted that the boy was eventually admitted to an **adult** psychiatric hospital (notwithstanding the unanimous view of experts that such placements are completely inappropriate) — because there is no inpatient adolescent facility in Newcastle.

## Prevention and Intervention

A separate chapter of this report deals with prevention and intervention in detail. However, there was a considerable body of evidence from clinicians and service providers concerned about disturbed children and young people coming into their services too late or not at all. Numerous witnesses expressed their frustration and dismay that frequently nothing is done for seriously at-risk children or young people.

*It is not clearly recognised how important it is to deal with people with mental illness and to bring to light the potential for future problems, particularly in terms of the children. There is quite a lot of literature now recognising that women having problems during pregnancy and post-natally has an impact on the child's development... Obstetricians tend to focus on the problems of the woman, rather than on the implications for the health of the baby too, after it is delivered.<sup>126</sup>*

One peak community organisation maintained that it is important for all pregnancy services to aim at 'reducing anxiety and depression in prospective mothers' and at teaching expectant mothers about the development of beneficial mother-child relationships — on the basis that 'child mistreatment prevention [has] to start during pregnancy'.<sup>127</sup>

A Sydney psychiatrist referred to the earliest possible preventive strategies — starting with informing expectant mothers of the services available; continuing with the provision of outreach obstetric follow-up; and most particularly, maintaining and promoting early childhood services, which she considered 'one of the most valuable preventive agencies this nation has' for early identification of children at risk, troubled children and dysfunctional families.<sup>128</sup>

Another psychiatrist from a children's residential service expressed frustration that the necessary network of early detection and intervention strategies has not been developed:

*In many cases, children with problems can be identified at the age of two, three, or four years old, and help for them can be organised. It's also very clear that families at risk can be identified very early. [These categories would include] teenage parents, parents having severe financial difficulties, parents from broken homes and so on. [If] these were identified fairly early, some intervention could be organised for them.<sup>129</sup>*

Two Sydney psychiatrists informed the Inquiry about the long-term effects of poor childhood intervention services.

*The majority of the most disabled adults with severe mental illness show significant mental health problems prior to entry into adulthood, and yet children showing early problems — particularly those in which intervention may well have an important preventive role — are*

often denied access to services through inadequate provision of services...or services which are either inappropriate or insufficient.<sup>130</sup>

We [the psychiatric profession] have been concentrating on treating disorders when they are already fully developed — when they have already produced the handicap. Often, people are being treated when they have already had the disorder for ten years and then they are treated. But that is too late in most cases: most of the handicap takes place in the formative years of development — the years in which people develop their working skills... When they are treated in their thirties and forties, their lives have already been largely destroyed.<sup>131</sup>

The effects of this paucity of appropriate services are, the evidence suggests, not confined to the individuals themselves — but have a major impact on their families and society generally.

In the case of young people...with early-onset major psychiatric illness, there is some evidence which suggests that what you actually do to help these young people...does have an effect on the prognosis. Unless we can modify something in our management of these young people, they will go on to become long-term dependents on welfare, chronically unemployable; they do not fit back into the school system, and [place] great stress on their families and siblings.<sup>132</sup>

## **Model Intervention Services**

Several excellent intervention initiatives are being undertaken in pockets around Australia. One example is the Warwick Child and Adolescent Clinic in Perth, which provides services in conjunction with the Education Ministry for children in school-years seven to eight (the transition period between primary school and high school). 'The New School' provides day programs for one or two terms for children who have difficulty adjusting to the transition, due to psychological, behavioural or psychiatric problems.<sup>133</sup>

In Canberra there is a

very successful program at Phillip (Secondary) College with a group of school children with problems from eight to twelve years old, brokering a supported involvement for them by volunteer senior students working with them, getting the kids to do things together in a group in a structured way, which is really a very important way of helping [troubled young people] to fit in.<sup>134</sup>

## **Role of Schools**

### *Identification and Referral*

Clearly, our schools have an important role in identifying young people with mental health problems and referring them for assessment or counselling.

It is quite often schools who are the first to see the beginnings of mental illness... For the last ten years in Tasmania we have seen an unheralded increase in the degree of disturbance amongst young people — perhaps in response to increased unemployment; certainly in response to a gradual breakdown of the family unit. That has been evidenced in increasing amounts of teenage depression, in homelessness and the associated trauma... With these children who are at risk, often schools have a chance to act far more proactively...because by anticipating the need, quite often we can act to remove the trauma... Schools [can] provide an enormous safety net for children through guidance and student support services<sup>135</sup>...picking up...children who need immediate psychiatric treatment [or] perhaps in the pre-psychiatric stage.<sup>136</sup>

In instances where a school does have the benefit of child psychiatric assessment by a skilled professional, such as one Queensland 'special school' visited by a child psychiatrist who gave evidence to the Inquiry,<sup>137</sup> the school principal can take steps to refer students who appear to be at risk. The witness told the Inquiry that, from the school population of 90 children and adolescents, he was asked to provide psychiatric help for 17.<sup>138</sup>

In the opinion of Queensland teachers in one recent study,<sup>139</sup> nearly 17 percent of children and adolescents had significant problems and approximately 4 percent were classified as having severe problems. (The majority of teachers felt that problems were increasing and over 80 percent believed inadequate levels of assistance were available to address the problem.)

The failure of education authorities to implement policies which effectively address the rights of both school students in need of specialist intervention and of teachers and other students to conduct their schooling in an efficient and stress-free manner is a reflection of the same general ignorance, widespread confusion and denial of the existence of mental illness and serious disturbance among young people that exists in the wider community.

This ignorance, confusion and denial of the problem at a policy level also results in the failure of teacher training courses to adequately train and equip teachers (who will all, at some stage, be faced with the stress of dealing with severely disturbed students), with some understanding, some techniques, and a realistic appreciation of likely levels of back-up support.

### *Exclusion of 'Disturbed' Children from School*

School staff who are not trained in identifying and referring disturbed young people tend to respond by deflecting the problem to some other area. This situation was referred to frequently in evidence:

We have got a problem with administrative boundaries... Children who are mentally ill are at the margin of responsibility. The central task of education is learning, so there is

often a lot of pressure to get kids with severe behaviour disorders 'out of my school' and somewhere else. A vast amount of time is wasted by schools dodging their responsibility for such tasks.<sup>140</sup>

Some of these children end up homeless<sup>141</sup> as well as deprived of their right to an education, after suspension or expulsion from school.<sup>142</sup>

A witness from a child and adolescent mental health clinic told the Inquiry in our national capital that she 'increasingly [sees] six-year-olds who have been kicked out of school — kids who just cannot be contained within the school system':

It's a much bigger problem than anyone is prepared to acknowledge... We get at least one referral a week of a kid who has been kicked out of school... We are not saying it's easy for the schools. But we need to be dealing with this problem differently, because if this child falls out of education, all the mental health systems in the world are not going to help — you cannot work with a kid who is not at school or at least in some daily program of activity. Mental health services cannot deal with deprivation, abuse, and lack of a system of care which emphasises the needs of the child — they can only deal with fall-outs from the system...and I'm talking about systems other than just mental health... Mental health services for children and adolescents depend entirely on the quality of services provided by education and family services.<sup>143</sup>

Rather than excluding vulnerable children and adolescents who are seriously disturbed, our system should ensure that adequate resources are provided to assist them.<sup>144</sup>

### *Professionals in Schools*

The lack of professional support staff in schools was frequently referred to in evidence. Such individuals include school psychologists, counsellors, child guidance officers, social workers, special education and remedial teachers. Some of these professionals are employees of departments other than education departments — such as community services or health. This creates one of the major blocks to providing appropriate and timely identification, assessment, intervention and referral services for disturbed children.

A big problem we have is resources for children and adolescents with mild to moderate problems. We have a good deal less [resourcing for these] than we used to have. Up to 20 years ago, there was widespread development of Child and Family Guidance clinics; there were specialist child health nurses, who undertook counselling; there was long-term involvement by Baby Health Centre sisters in supporting families. Now, the best setting to deliver such services is often school-based, in that it's a good place to have counselling services and to run parenting skills courses. But there are massive barriers, because the education administrators do not see that as part of their function and the Teachers' Unions, particularly in this Territory, utterly oppose the appointment of any staff [to positions within] the Education Department who do not have teaching qualifications, whereas in

Victoria, for instance, you can appoint school psychologists and social workers. In Western Australia, there is a big role for nurses in schools. That cannot happen here. In [Canberra], we have a good example in the Catholic school system, where there is a service including mainly social workers and some psychologists, who are non-teachers, working in schools and having the option to see families as well... It is much easier for families to trust someone whom they perceive does not have the school principal 'breathing down their necks.'<sup>145</sup>

**In schools where the teachers have the skills to know where referral is appropriate, however, trained professionals — and the services in which they operate — must be available to follow through.**

Now that Canberra no longer carries out universal checks of three-year-old children within the health system, the next opportunity...occurs in the school. Teachers and school counsellors have told mental health workers that they are able to identify certain children in grades one and two who have some particular difficulty, either with their schoolwork or in terms of their behaviour. If assistance could be offered to those families at that point, it would help to ensure that these children's problems do not become compounded as they grow older... A much broader strategy is required for troubled children involving a range of services.<sup>146</sup>

**The role of school psychologists, school social workers, counsellors and guidance officers is crucial in two respects — they provide teachers with a resource to which they can refer individual young people whom they identify as needing attention, and they work directly with or refer those individuals to appropriate sources of assistance.**

An association of school psychologists in Victoria<sup>147</sup> told the Inquiry their work includes counselling and assisting children at risk; helping students, teachers, and parents with problems in the school community; acting as behaviour consultants; assisting with strategies for management of aggression or lack of motivation among students; and providing professional support both to other school staff and to children experiencing emotional and psychological difficulties.<sup>148</sup>

However, the association also told the Inquiry that 'the future of school psychology services in Victoria is uncertain, and the service is likely to disappear through natural attrition', due to cuts in numbers and restructuring of the service, coinciding with administrative changes to all the State's student support services in 1987.<sup>149</sup> It also reported the results of a national survey which indicated school psychologists throughout Australia were finding it almost impossible to respond to the number of requests for their services made by teachers, due to a major increase in administrative duties and reductions in staff numbers.<sup>150</sup>

There have also been cutbacks in the number of individuals entering the profession, as indicated in evidence from NSW.<sup>151</sup>

Across the State, [there are] 1513 students to every counsellor... [Because] Special Education schools and classes receive additional allocations, many counsellors in fact have over 1800 students in their district. There was a time when the Government asserted that a large number of students per school counsellor was unavoidable, [due to] a shortage of trained counsellors. In recent years the situation has changed. There is now an excess of unappointed new counsellors. The Government's response has been to reduce the numbers of counsellors in training... In 1990, there were 36 full-time and 18 part-time counsellors in training; in 1991, there were 34 full-time and 18 part-time; and in 1992, there were 29 full-time and 13 part-time.<sup>152</sup>

These cuts amount to a reduction, over two years, from 54 counsellors in training to 42.

## The Juvenile Justice System

If you evaluate the juvenile detention centre populations...what you find is that young people in these facilities are about as badly off from a mental health perspective as the children who come to our mental health clinics — they are almost transposable. The major difference is that one group have committed some sort of offence for which they have been apprehended and the other group haven't.<sup>153</sup>

Disturbed and mentally ill adolescents often end up in the juvenile justice system because no one has been able to recognise or deal with their underlying problems.<sup>154</sup> This was starkly illustrated by a recent study conducted in the South Australian Youth Remand and Assessment Centre (SAYRAC).<sup>155</sup> The study found that 17 percent of young people in the centre had been living on the streets prior to being remanded in custody, another 23 percent had been living with friends, and 18 percent had been in institutional care — ie, only one quarter of the remanded group (aged 11-17 years) had lived at home before being detained. The majority had left school between 13 and 16. According to one witness, they were 'unemployable, uneducated kids without any support, with multiple handicaps, [for whom] we have to shift the concepts away from discipline, to disability.'<sup>156</sup>

Reluctance to identify young people as being mentally ill 'leads to them being treated in a default system'. Without assessment and an appropriate range of intervention services they just 'slip between the cracks of the various systems and end up in the juvenile justice system.'<sup>157</sup>

The number of young people who have thus been consigned to incarceration rather than treatment is in the thousands.



One would expect that 30-50 percent of the children in correctional facilities would have a mental health problem — [that is,] young people for whom the separation diagnosis [ie the diagnosis made on discharge, release or referral] was a mental health diagnosis. We find that incarcerated young people have very similar backgrounds to those of young people in psychiatric care — family breakdown, poverty, parents with [problems which include] personality disorder, alcoholism, mental illness, or drug abuse.<sup>158</sup>

**Mental health services must also give priority to identifying and protecting those young people who have the less common but more serious mental illnesses and who are very likely to commit offences if untreated:**

*It is important that [there is] a mental health service for these young people to provide a safety net for some of the rarer psychiatric conditions [of young people], such as schizophrenia, manic depression, or obsessive compulsive disorder, [all of which] can lead a young person to offend and which are often not detected in the juvenile population, or detected too late for [early] treatment.<sup>159</sup>*

### **Lack of Adequate Assessment, Management and Treatment**

*At the present time...it costs over \$1000 a week to keep a juvenile in custody, but most of that expense seems to be taken up with pure custody, rather than treatment or diagnosis... Very often, there's a lack of diagnosis when there are serious symptoms indicative of some sort of mental illness.<sup>160</sup>*

**The needs of disturbed young people in correctional institutions have largely been overlooked in this country<sup>161</sup> and are only just beginning to be dealt with in some States.<sup>162</sup>**

*With regard to adolescents in custody...a number of studies...have identified that approximately two-thirds can be identified as having soft neurological signs, and of that group, at least 40 percent have a serious learning disability. Early identification of these young people at their first point of entry into the juvenile justice system is a very substantial area of need which, if addressed, could provide...considerable cost-effectiveness and lessening of suffering, both human and economic.<sup>163</sup>*

**It was clear from evidence presented to the Inquiry that, once a disturbed or mentally ill young person is in a correctional facility, or even in a care and protection residential centre, they have little chance of receiving assessment and treatment. In fact the services appear to be diminishing in some areas:**

*Access to specialised mental health services is particularly critical [for] juvenile offenders. There has never been, in NSW, a comprehensive mental health service for juvenile offenders who are...in either detention facilities or affiliated residential facilities... A decade ago, there appeared to be more facilities available — they never came anywhere near meeting the need — but there has been a serious contraction in these services steadily over the last decade to the point where there are now almost no services; yet, at the same time, it is well established that there is an acute need for these mental health services.<sup>164</sup>*

The custodial facilities and environment were also described in evidence as being potentially harmful, in themselves, to the mental and emotional state of the young people detained.

When young people enter detention, the institution itself may give rise to significant mental health problems... Depressed delinquents are a case in point — they often try to counter their feelings of depression by seeking exciting, dangerous, daring, illegal activities in an attempt to relieve their restlessness and boredom. So it is hardly surprising that, when they are incarcerated...if it fosters hopelessness...[they are] vulnerable to suicidal depression. A psychologist...has referred to NSW detention centres as environments in which hope is crushed.<sup>165</sup>

In South Australia, the Youth Remand and Assessment Centre was described by one psychiatrist as being ‘diabolically designed for young people’:

There is no natural light, the bars are just terrible, and personally, I couldn’t last more than 48 hours in there.<sup>166</sup>

Questions raised during the Sydney hearings canvassed the suggestion that psychiatric treatment in correctional or detention facilities compromises the correction process:

There has been a lot of debate about mental health services in detention centres — [one view is] that to incorporate mental health services is to cave in to a ‘soft option’ approach. The debate is, in some ways, another enactment of the ‘mad versus bad’ argument about the causes of juvenile delinquency. In my view, this is a total distraction. I don’t think there is any mental health specialist these days who seriously suggests that the primary focus of mental health services in detention centres is to mitigate the offences of these young people, but I think they share my belief that juvenile offenders have a right to competent mental health care for legitimate mental health needs.<sup>167</sup>

The Inquiry was told that young people with diagnosed mental illness who have committed offences may be dealt with in a range of different ways by the Courts, depending on a number of factors, including chance. If the young offender is found guilty of the offence, they may be committed to a juvenile institution, where they may or may not receive appropriate care and treatment.<sup>168</sup> Older adolescents may be committed to an adult jail.<sup>169</sup> They may be found not guilty on account of a mental illness, with varying consequences for the individual’s subsequent disposition and welfare:

It depends on the luck of the person... If they are found guilty and directed into a humane and informed, competent and caring team, that guilty finding can be worked through. On the other hand, if they are found not guilty, [they may be] discharged into the great unknown to deteriorate psychologically.<sup>170</sup>

The services that do exist vary greatly between States.<sup>171</sup> In Western Australia:

In relation to Children's Court services there is currently no equivalent to facilities like the Children's Court Clinic in Victoria to provide pre-sentence reports to Magistrates... There is an inadequate structure for providing psychiatric back-up to the juvenile institutions. They do have a small number of psychologists, but there is no specific mechanism to allow for a group of psychiatrists and a formal child psychiatric treatment team to have regular input to these young people, whom we know are a group at increased risk of emotional and behavioural disturbances... Currently, once they are in institutions, all they can do is send them to the psychiatric hospital on certificate. And that is not an environment where their needs are best understood, or any plan of management can be evolved that will be integrated into what they have to go back to [in the institutions].<sup>172</sup>

In South Australia, the Chairman of the Inquiry opened a unit in mid-1992 which was developed as a result of growing concern that the psychiatric needs of young people in the juvenile justice system were not being adequately met. The Forensic Psychiatry Unit, established by the South Australian Child and Adolescent Mental Health Service, is a co-operative agreement (with joint funding) between that service and the Department of Family and Community Services. It provides assessment and treatment services for young people in residential facilities operated by the Department, as well as those in juvenile detention.

## **Youth Suicide**

### **Statistics**

Adolescent suicide ranks...second to car accidents as the most frequent cause of adolescent death. The suicide rate for [young] males has tripled in the last ten years... The male rate for this age group is between three and five times the rate for females. The rate of attempted suicides for females is higher than that for males.<sup>173</sup>

In recent years, there has been an alarming increase in the suicide rate among adolescents aged over 15. A psychiatrist who specialises in the area of youth suicide told the Inquiry:

The problem of suicide among Australian youth has been rising steadily for 25 years. After traffic accidents, it is the greatest killer of Australian young people...particularly males aged 15-19 and aged 20-24. The rate amongst 15-19 year old males has increased from 7.3 per 100,000 population to about 21 per 100,000 in 25 years. The rate amongst girls has gone up about two-fold.<sup>174</sup>

The rate of young people who unsuccessfully attempt suicide has also increased greatly:

The rate of attempted suicide has also doubled since 1965 to about 130 per 100,000 in the 12-15 age group and about 350 per 100,000 in the 16-20 age group.<sup>175</sup>

## **Risk Factors**

The Inquiry heard evidence from a number of child and adolescent psychiatric specialists who have been working on identifying factors contributing to the increase in youth suicide. One important risk factor is a prior suicide attempt:

We know that once a young person has attempted suicide, the chance of them attempting it again is increased at least five-fold... The majority of young people who attempt suicide receive **medical** treatment only. They attend Accident and Emergency services and, because of limited resources and the reluctance of general hospitals to send young people to psychiatric hospitals...most of these young people are just sent home... And their cry for help which the suicide attempt represents goes unheard.<sup>176</sup>

Other risk factors for suicide include mental illness or emotional disturbance (especially depression); those factors contributing to mental illness listed earlier in this chapter; risk-taking behaviour; pressure of societal role expectations (particularly in the case of young males); media coverage of other youth suicides; and poor education or leaving school early.<sup>177</sup>

However, there is no reliable way to predict which individuals will commit suicide.<sup>178</sup>

## **Rural Young People**

There is often a major problem of access by suicide attempters to counselling [after the attempt]...and the final point is there is no-one there to advocate for them — they are an invisible group, a marginalised group. Rural youth suicide victims are...nearly always psychiatrically disturbed and sometimes identifiably mentally ill... Mental illness figures extremely prominently in the list of risk factors. Most of the young people who kill themselves are in fact suffering from a psychiatric disorder — usually a major depression or a conduct disorder or substance and alcohol abuse, and they have been exposed to suicide or have had suicide in their families.<sup>179</sup>

The most alarming increase in male youth suicide rates has been in rural areas and small towns:

The rural rates have gone up substantially, particularly in the smaller country towns and farming communities. They have gone up about four-fold, from about 1.4 per 100,000 to about 5.7 per 100,000 in NSW — that's double the percentage of total suicides. [The rate in] 15-19 year old males in rural shires has increased five or six-fold over the same period.<sup>180</sup>

Witnesses emphasised just how vulnerable rural young people are — at the same time as being affected by the same compounding factors as urban adolescents.

Rural families have been affected by the economic downturn over the last 25 years, which has led to...the decline of small country towns. The problems...include chronic unemployment and poverty, lack of local tertiary opportunities, lack of transport... There is a gap between idealised myths of the bush and the harsh reality of life on the land, so that young males really have problems coming to grips with expectations and their diminishing actual status.<sup>181</sup>

Specific factors contributing to this tragic escalation in rural youth suicides include:

exposure to higher levels of domestic violence and parental alcohol consumption and homicide, higher personal alcohol consumption, and ready access to firearms. They lack access to health services, including mental health resources, and they face a lack of confidentiality [due to the small size of the community] if help is sought.<sup>182</sup>

There's tremendous stress on rural families... A key ingredient...is alcohol use... Just about everything harmful young people do to themselves they are much more likely to do in an intoxicated state.<sup>183</sup>

The way the media reports youth suicides was cited as one significant factor:

Several researchers have studied the effects of media reports on the potential rise in suicidal behaviour...and demonstrate a clear causal link. On the other hand, the media [could] play a positive role in changing community awareness through programs which provide informative material of a health promotional nature.<sup>184</sup>

It is barely defensible for the media to continue handling suicide in an insensitive manner when there is evidence to suggest that this...may be functioning as a catalyst for other young people to suicide. On the other hand, there is little suggestion that carefully planned, responsible reporting...of the topic has the same likelihood of contagion.<sup>185</sup>

In more general terms, one commentator has pointed to

the possibility that, behind youth suicide...lies a profound and growing failure of the culture of Western industrial societies — a failure to provide a sense of meaning, belonging and purpose in our lives, and a framework of values... I believe we are witnessing the cultural abuse of an entire generation of young Australians [who are] being culturally dispossessed.<sup>186</sup>

This perception is supported by much of the evidence presented to the Commission several years ago and analysed in the report *Our Homeless Children*.<sup>187</sup>

## **Gender Differentials**

There is a significant gender difference in the rates of male and female youth suicide, with a heavy predominance of young males committing suicide; while the reverse is true for attempted suicide, where young females predominate.<sup>188</sup> There has been insufficient research in Australia to draw informed conclusions from these differences. However, it has been suggested that the impact on girls and young women of known predisposing factors may be quite different from their impact on boys and young men.

The role of alcohol may be one significant factor:<sup>189</sup>

*A study of two years of suicides in Western Australia showed that...males were more likely to be under the influence of alcohol [at the time of the suicide] than females. Just under half of the teenagers and people aged 20-24 years showed positive blood alcohol tests... Attempted suicides among youth have also been increasingly linked to alcohol intoxication.<sup>190</sup>*

However, it has been suggested that use of drugs or alcohol should not be viewed as a cause of youth suicide in itself — but rather as symptom of more serious underlying problems.<sup>191</sup>

## **Strategies for Prevention, Intervention and ‘Postvention’**

### *Prevention*

*Prevention strategies which target youth in general include things like self esteem courses, provision of crisis counselling, training of health staff and education staff, setting up peer support systems... We need to identify high risk groups like attempters, those who have been exposed to suicide or suicidal behaviour, those with associated or cumulative risk factors.<sup>192</sup>*

Recommended prevention strategies covered a range of areas, including the development of media guidelines for reporting youth suicides; access to specialised adolescent mental health assessment and treatment services;<sup>193</sup> better liaison between officers of community services and health departments to ensure proper assessment of young people;<sup>194</sup> data collection from hospitals, the police, employment services and other government and non-government agencies; and health education and promotion programs.

Witnesses also advocated increasing rural youth mental health counselling services; consulting with general practitioners in rural areas and providing additional training for rural health professionals.

## *Intervention*

It is hard to know how many of these young people made an attempt to get help. Some of the cases we've dealt with...were known to community health facilities, or had made a previous suicide attempt which had been registered with the local hospital. [Some] had been to their general practitioner, had made a number of contacts within the community. But appropriate help did not seem to have been forthcoming.<sup>195</sup>

Intervention strategies include emergency hotlines, suicide crisis counselling and post-attempt counselling. Witnesses pointed out that people dealing with adolescents in crisis need special training in crisis intervention and there would be benefit in developing hospital protocols, linked to accreditation, for the assessment and management of youth suicide attempters.<sup>196</sup>

Specific at-risk groups — such as homeless youth,<sup>197</sup> young people in custody, or those from minority groups — need to be assessed by individuals with specialist expertise. A small number of secure residential beds are also required for suicidal youth in both metropolitan and rural centres.<sup>198</sup>

### *Critical Incident Counselling*

The term 'critical incident counselling' (or 'postvention') is used to describe various strategies employed following a suicide to deal with the aftermath of the death. They include supportive counselling for the bereaved, debriefing of health workers and members of the police, special debriefing and support for school staff and students<sup>199</sup>, provision of information about community mental health resources and, possibly, training in stress management and coping strategies.<sup>200</sup> (A school postvention research study submitted to the Inquiry is discussed in the following section on youth suicide research.)

### **Responses to the Increase in Youth Suicides**

Concern about the seriousness of youth suicide as a social problem is reflected in the large number of reports and conferences on the subject in recent years.<sup>201</sup> Specialist child and adolescent units have also conducted several important studies.

The Western Australian Department of Health provided the Inquiry with the 1988 report by the Youth Suicide Working Party.<sup>202</sup> Recommendations included improvement and extension of treatment services, engaging schools and other agencies who deal with young people in preventive work, undertaking research and other primary prevention strategies and the implementation of a common policy for all hospitals in the management of suicidal young people.

A submission from the Mental Health Branch of the Queensland Department of Health dealt with the establishment of the Suicide Research and Prevention Program as a response to the problem of increasing youth suicide.<sup>203</sup>

The Queensland Department of Health has also recently launched a major campaign<sup>204</sup> aimed at all potentially suicidal people, but specifically targeting young males aged 15-24. The rate of death by suicide in this group has for the first time exceeded road accident fatalities in Queensland. Strategies introduced include a departmental request to all hospital and community health centres to provide 24-hour facilities for potential suicides and the review of hospital procedures to ensure rapid responses to telephone calls or arrivals of suicidal people at hospitals.

### **Recent Youth Suicide Research**

The Inquiry received evidence concerning recent research studies covering risk factors and prevention;<sup>205</sup> diagnostic instruments used to identify depression; data collection from coroners; the effects of youth suicide on school classmates,<sup>206</sup> and the possible 'cluster effect';<sup>207</sup> as well as an examination of adolescent attempted suicides in a juvenile detention centre.<sup>208</sup>

The study which examined imitation and the 'clustering' factor in suicides of school students found sufficient evidence to suggest there is a real possibility for effective prevention, intervention and postvention work.

The researchers had been providing therapy to a number of friends of Adelaide teenagers who had attempted or committed suicide. They retraced connections and found 'compelling [indications] that teenagers do imitate their peers'. Nevertheless, the study revealed that

Suicide is a personal affair...and the teenagers...were depressed and had suicidal thoughts... In most cases...[they had] a troubled home life with a particular crisis triggering the act. The suicide or suicide attempt does not come out of the blue.<sup>209</sup>

However, the most sobering outcome of the team's work with young people was the finding that:

Increasingly, teenagers believe that suicide is simply a reasonable option, to be chosen or not, when circumstance demands.<sup>210</sup>

This research has demonstrated that in a closed school community, effective postvention work can be done to identify vulnerable adolescents, and to provide special care, counselling and therapy — necessary processes which the



researchers conclude may 'help curb...the spread of a pseudo-normality — an apparent acceptance by adolescents of suicide as OK'.

A national research study of youth suicide<sup>211</sup> is expected to report in 1993.

## Appropriate Responses

### Priorities for Service Provision

While it is difficult to establish service priorities when services are either inadequate or non-existent, a number of witnesses identified specific priority areas.

#### *Community centre-based services*

Many witnesses emphasised the need for intensive psychiatric care facilities or services for young people and their families:

Many child and family mental health problems are best dealt with in...facilities in their local community. However, approximately 10 percent of children and families presenting for psychiatric assistance need intensive assessment and/or treatment, either as day patients or inpatients. Prevalence and incidence studies indicate that, for every million total population, there is a requirement for one intensive child psychiatry treatment facility offering approximately 10 inpatient and up to 20 day patient places.<sup>212</sup>

Teenagers with major psychiatric illnesses like schizophrenia and manic depressive psychosis...[have] needs which are very special... Whilst I think the absolute numbers for a population like Perth do not justify a specific unit, there is a need for some [special service] — perhaps a team — in one of the general hospitals that could have other input from educational authorities to help these young people.<sup>213</sup>

Another proposal — to use existing adolescent psychiatric beds in the private sector — was advanced by an expert witness in Adelaide:

There is a private hospital in South Australia for children and adolescents with about 30 beds. We at the Adelaide Children's Hospital have been trying for about two years to get the Government to rent four or five public beds there. We could provide the medical services, they could provide the hostel services [cooking, laundry, etc] because it's ridiculous to duplicate such things. That would be a good public-private mix. Unfortunately...no decision has been made. I believe that place will close within the next couple of months because, financially, it cannot exist. [Neither] the private or the public [facilities] can exist separately. A city of one million people just can't support a private system and a public system for adolescents — you have to bring them together in some sort of partnership — there's nothing wrong with that, it's perfectly reasonable. But I believe the private hospital will close, and we will lose that. What will happen then is that there won't be any private adolescent beds, so the [private] patients will come to the Adelaide Children's Hospital.<sup>214</sup>

In addition to acute admission facilities for young people with serious psychiatric disorders, the Inquiry was told that major centres also need medium-stay residential facilities for mentally ill or disturbed adolescents who need transitional treatment and accommodation between hospital and home.

In Tasmania the Inquiry was told:

[There is a need for] something that is specifically designed around adolescent needs that is seen by young people themselves as being therapeutic care for them specifically. I think that would remove a lot of the trauma associated with both the psychiatric visits to these clinics and also to the times when they have to be hospitalised... The ideal vehicle to drive that facility [would be] the Child and Adolescent Unit — it already deals with children on a day-to-day or visit-by-visit basis. It would seem a pretty natural extension for it also to take over responsibility for residential and therapeutic care as well.<sup>215</sup>

### **The Need for Inter-Sectoral Collaboration**

Great improvements in the care and treatment of psychiatrically affected adolescents could be made by the joint management of cases by services such as schools, medical and welfare services. Currently, there appears to be buck-passing, to the detriment of the children.<sup>216</sup>

We have no residential facilities with trained staff that offer therapeutic programs for adolescents... There would need to be collaboration, understanding and commitment from many departments, including Education, Community Services, Mental Health and Police departments.<sup>217</sup>

The necessity for effective coordination and co-operation between the various agencies which are, or should be involved in the integrated care of children or adolescents' psychological, psychiatric or other disturbances was a consistent theme in evidence presented to the Inquiry.

However, even where there is consensus that services must be coordinated, the Inquiry heard that many individual workers and agencies have repeatedly been frustrated in their efforts by the strength of traditional bureaucratic boundaries, and have found that achieving a functional model of coordinated service provision is extremely difficult. When a coordinated approach was cited in evidence, so was the necessity to train staff from non-mental health agencies:

One to 2 percent of children [would be] expected to be referred to child psychiatric facilities. Others receive help from a wide range of other facilities...which also cater for emotionally and behaviourally disturbed [children]... A number will be managed by the Department of Youth and Community Services, the Education Department, and services provided by Anglicare, Centacare, and other community drop-in centres. One of our tasks as a Child and Adolescent Psychiatry Unit is to find ways to make available our collective expertise so that it can be utilised by those other agencies.

Our greatest difficulty has been to set up a formal process of secondary consultation with other Government departments such as the Department of Community Services and the Education Department. We have attempted to break down the barriers between agencies... But it seems that no sooner do we seem to be forging some links with workers in those departments than the structure changes — workers move on and we are back to square one again. There is a real need for liaison from administrators in the three departments to coordinate the process of secondary consultation.<sup>218</sup>

One example of the difficulty government departments have in sharing important resources (even information) was given by a witness in Devonport:

At a recent meeting we asked the Department of Youth and Community Services for a simple [list of] the people who worked in the Department in the Devonport area — their names and [their jobs] — because that gives us an avenue to tap into. [The answer was] that some pamphlets would be provided in March or April of next year... Quite often, several agencies will be dealing with the same person. It is quite possible for a child to walk around until they find the agency that gives them the answers they want... On the very rarest of occasions do these agencies actually get together to work the case through and provide a...referral where one person is in charge of that person's treatment.<sup>219</sup>

Such bureaucratic inefficiency and obstructionism is obviously unnecessary; when the lives and futures of children are involved it is inexcusable.

Evidence to the Inquiry suggested that many existing services fit the individual into the area provided by their own programs, effectively disaggregating the child's problems into only those elements which they are equipped to deal with, but not viewing and treating clients as an integrated whole.

Relatively few children are seen by child and adolescent facilities, compared to the number expected to be in need of assistance. There is very little cross-referral to more appropriate services — that is, inter-agency co-operation — which suggests that people are attending the appropriate service the first time; that services offer a sufficiently wide range of appropriate interventions; or that services fit people into the service they provide.<sup>220</sup>

The deleterious effects of enforced bureaucratic segregation of professional functions were emphasised in evidence by a Perth child psychiatrist:

There has recently been restriction on the capacity of psychologists within the education system to provide formal cognitive and other psychological assessments. This has thrown a tremendous burden on the health system, with people being referred to...Princess Margaret Hospital primarily for educational assessments... This throws an unreasonable [cost] burden on families, because there are not any Medicare rebates for psychological assessment... Unless these families go on expending substantial amounts of money, they get an incomplete assessment of complex interacting problems... Another anomalous situation regarding health care refunds [is that] there are rebates for general practitioners for doing family therapy, but not for psychiatrists to do family therapy.<sup>221</sup>

Nor are there rebates for appropriately trained psychologists!

### *Examples of Successful Service Collaboration*

Evidence about inter-sectoral collaboration was not universally negative. Initiatives have been taken in some centres to facilitate the involvement and co-operation of relevant departments and agencies.

The Inquiry was advised about several government initiatives, such as the South Australian interdepartmental program for dealing with suspected cases of child abuse<sup>222</sup> and the Troubled Youth Support Service in Western Australia. This is a joint Commonwealth-State initiative in which the Health Department, the Drug and Alcohol Authority and several non-government agencies provide an integrated preventive health service to young people.<sup>223</sup> (The Child Protection Council interagency guidelines in NSW have already been mentioned.)<sup>224</sup>

### **Research**

There is a glaring lack of resources in the research area [for] child and adolescent psychiatry... In terms of the research budget, [it] receives even far less than does adult psychiatry.<sup>225</sup>

In addition to research into youth suicide, important areas requiring research in child and adolescent mental illness include vulnerability to disturbance and treatment approaches.<sup>226</sup>

Several witnesses also advocated research into service-level requirements for future resource planning:

We need [to know] what are the minimum community service requirements in these areas... We work in the dark — we really have no idea of the base level requirements for our student population and no idea what provisioning of an adequate program for these children is either... I am arguing for a better and healthier framework in which the existing resources can be delivered. If we have to cut up the same cake, then I am suggesting that the youth portion of it should be better than 5 percent.<sup>227</sup>

Another key area clearly justifying significant research resources concerns factors in the development of psychosis in mid to late adolescence.

### *A Model Research Program*

The Early Psychosis Research Centre was recently established in Victoria<sup>228</sup> to research first-episode and recent-onset functional psychosis, particularly schizophrenia. The Centre will focus on prevention in high-risk groups; early case detection and intervention to minimise the severity of a disorder; and

evaluation of the effectiveness of the Centre's prevention and intervention programs — particularly with patients experiencing their first psychotic episode.

## **Conclusion**

Evidence to the Inquiry on the status of mental health services for children and adolescents demonstrated that there are few areas where adequate services exist, and access to them is limited. Several very promising programs have been initiated since the Inquiry began. However, the overwhelming picture is one of inadequate funding, inadequate provision of facilities, inadequate staffing, inadequate training of health and other workers, inadequate inpatient care, inadequate community and home-based care, inadequate coordination between agencies, inadequate knowledge, inadequate research, inadequate data collection and inadequate commitment to the establishment of prevention and intervention services.

All these deficiencies are compounded in access and service provision for Aboriginal and Torres Strait Islander young people; for those living in rural and remote areas; for children and adolescents from non English speaking backgrounds; and for children and adolescents with dual or multiple disabilities. The human rights of disturbed and at-risk young Australians are being seriously denied by such glaring omissions, with often tragic consequences for the individuals and families involved and for our entire community.

1. Prof Bruce Tonge, Faculty of Child Psychiatry, Royal Australian and New Zealand College of Psychiatrists and Head of the Centre for Developmental Psychiatry, Monash University. Oral evidence, Melbourne 9.4.91, p242.
2. John Gardiner, clinical psychologist, Warwick Child and Adolescent Clinic, Western Australia. Submission, p1.
3. Dr Aidene Urquhart, Director of Child Psychiatry, Mater Children's Hospital, Brisbane. Oral evidence, Brisbane 16.8.91, p1683.
4. Tonge, op cit, p235.
5. H M Connell, L Irvine, and J Rodney, 'Psychiatric disorder in Queensland primary schoolchildren,' *Australian Paediatric Journal* v18, 1982, pp177-180. Two other child prevalence studies are: M Rutter and P Graham, 'Psychiatric disorders in ten and eleven-year-old children', *Proceedings of the Royal Society of Medicine* v59, 1966, pp382-7; and M Sawyer, A Sarris, P Baghurst, C Cornish, and R Kalucy, 'The prevalence of emotional and behaviour disorders and patterns of service utilisation in children and adolescents', *Australian and New Zealand Journal of Psychiatry* v4, 1990, pp323-30.
6. Royal Australian and New Zealand College of Psychiatrists, *Psychiatric and Social Treatment Facilities for Adolescents*, 1984, p4.
7. Tonge, op cit p237.
8. ibid, p238.
9. The Epidemiological Catchment Area Study was undertaken by the National Institute of Mental Health in five US cities in 1981-1985. It measured prevalence in an identified 'catchment' area, administering Diagnostic Interview Surveys to the entire population of the area — thus removing the common problem of having to rely on people who come to the attention of service agencies and having no measure of those people who never seek attention for mental health problems. DA Regier, JK Myers, M Kramer et al, 'The NIMH Epidemiological Catchment Area Program: Historical context, major objectives and study population characteristics,' *Archives of General Psychiatry* v41, Oct 1984.
10. M Sawyer, D Meldrum, B Tonge, and J Clark, *Mental Health and Young People*, (Report to the National Youth Affairs Research Scheme), Research and Evaluation Unit, Child and Adolescent Mental Health Service, Adelaide Children's Hospital, 1991, p14.
11. Tonge, op cit, p235. Professor Tonge put the number at between 1 and 2 percent.
12. Eg Sawyer et al, op cit.
13. Prof Robert Adler, Director, Child and Family Psychiatry, Royal Children's Hospital, Melbourne. Submission, p1: 'Very few children are affected by mental illnesses such as schizophrenia...or manic depressive psychosis.' Also Rosemary Nairn, Phillip Clinic Child and Adolescent Service, ACT. Submission, p1: 'Developing a full-blown mental disorder under the age of 17 is relatively rare, whereas behavioural disturbance is more common and may or may not lead to or be symptomatic of a serious disorder.'
14. See, for example, A E Kazdin, 'Childhood depression', *Journal of Child Psychology and Psychiatry* (UK) v31 No1, 1990, p135.
15. Rosemary Laver, Australian Psychological Society. Oral evidence, Hobart 12.11.91, p172.
16. Connell et al, op cit.
17. Prof Beverley Raphael, Professor of Psychiatry, University of Queensland. Information provided to the Inquiry.
18. Nairn, op cit, p2.

19. Prof Brent Waters, Head of the Department of Child and Adolescent Psychiatry, Prince of Wales Children's Hospital. Oral evidence, Sydney 17.6.91, p23.
20. Parliament of Victoria, Social Development Committee, *Young People at Risk*, First Report upon the Inquiry into Mental Disturbance and Community Safety, 1991, pp63,4,6.
21. B Waters and J Brennan, 'Child and Adolescent Psychiatry: Psychiatric Syndromes of Childhood'. In P Beumont and R Hampshire (eds), *Textbook of Psychiatry*, Blackwell Scientific Publications, Melbourne 1989, p186.
22. Kazdin, op cit, p149: 'Increasingly [it is found] that children may meet criteria for more than one disorder, a phenomenon referred to as co-morbidity. For example, epidemiological studies have found that, among children and adolescents who meet criteria for a psychiatric diagnosis, approximately half also meet criteria for at least one other disorder as well. Many disorders are known to co-exist, including, for example, conduct disorder and attention deficit hyperactivity disorder... Studies have shown that depression and anxiety are often related and that children who have one of these disorders often meet the criteria for the other as well; even in cases where they don't meet the diagnostic criteria, they are likely to show symptoms [of] the other disorder.'
23. Dr Stephen Morgan, psychiatrist, Clare House Child and Adolescent Psychiatric Service, Tasmania. Oral evidence, Hobart, 11.11.91, p96.
24. See also Chapter 16.
25. Laver, op cit, p175.
26. id.
27. Gardiner, op cit, p2.
28. Dr. Marie Bashir, psychiatrist and Director, Community Health Services, Central Sydney Area Health Service. Oral evidence, Sydney 20.6.91, p497.
29. ibid, pp497,498,503.
30. Assoc Prof Joseph Rey, Director, Rivendell Child, Adolescent and Family Services, Royal Prince Alfred Hospital, Sydney. Oral evidence, Sydney 18.6.91, p247.
31. Anne Greener, consumer, NSW. Oral evidence, Sydney 20.6.91, p519.
32. Bashir, op cit, p502.
33. Adler, op cit, p1.
34. Bashir, op cit, p497: 'Often, a serious medical aspect of their condition [adolescents with behaviour disturbance] is not recognised. On the other hand, sometimes it is misdiagnosed.' Stephen Pinkus, clinical psychologist, Clare House Child and Adolescent Psychiatric Service, Hobart. Oral evidence, Hobart 12.11.91, pp175,6: 'The special problems of children in relation to mental illness involve, firstly recognition of children with difficulties... Children with problems often go unrecognised; [even] in situations in which there are primary indicators of risk factors, children's problems are rarely addressed.'
35. These 'high risk factors' are matters of correlation, and are not necessarily causal.
36. As mentioned earlier in this chapter, schizophrenia, major depressive illness and manic depression together affect at least 1 percent of young people. However, they account for approximately only one tenth of the mental health difficulties of young people warranting specialist professional treatment.
37. Raphael, op cit.
38. Sometimes now referred to by education and health professionals as 'attention deficit disorder' or 'attention deficit-hyperactive disorder' (ADD).

39. Rey, op cit, p249.
40. ibid, pp247,248.
41. Dr John Dingle, Assistant Director, Department of Psychiatry, Princess Margaret Hospital for Children. Oral evidence, Perth 10.2.92, p26.
42. Urquhart, op cit, p2, and oral evidence, Brisbane 16.8.91, pp1688,89,91.
43. J Mathias, 'Cycles of violence and abuse', in *Breaking Out: Challenges in Adolescent Mental Health In Australia*, National Health and Medical Research Council, Canberra 1992, p108: 'There is no standard definition of abuse... Child abuse has been defined by the National Committee on Violence as the physical and psychological damage experienced by children and adolescents resulting from the abusive behaviour of a person in trust or authority. This definition therefore includes physical, emotional and sexual abuse, as well as neglect.'
44. Australian Family Law Council, *Child Sexual Abuse*, AGPS, Sept 1988, pp7,8. The report cites a landmark 1966 paper by US researchers Helfer and Kempe, 'The Battered Baby Syndrome', published in the *American Medical Journal*, claiming for the first time publicly that caregivers, including parents, harmed children in their care. These claims were 'greeted with shock and denial, which gradually gave way to acceptance of the reality of child physical abuse and neglect... The same shock and denial greeted reformists when they first began to say that adults, including caregivers, were also sexually abusive to their children... The community has been reluctant to acknowledge that child sexual abuse occurs, and not infrequently... It is no longer possible to deny this phenomenon... The taboo about acknowledging [it] has been broken down by sheer weight of evidence for its existence as...medical practitioners, social scientists and reports from adults molested as children began to reveal what they had found. The cost to society is only just being counted... Victims are over-represented in mental institutions, prisons, drug and alcohol programs and amongst 'street kids'. The effects of abuse are of short-term and long-term duration and are usually devastating for the child and family.'
45. Abused Child Trust, Queensland. Submission, attachment A, p1.
46. Nairn, op cit, p158.
47. Mathias, op cit.
48. Raphael, op cit.
49. L Young, *Physical Child Neglect*, National Committee for the Prevention of Child Abuse, Chicago, 1986, p1.
50. id.
51. K Oates, *Child Abuse and Neglect: What Happens Eventually?*, Brunner Mazel, New York 1986. This study includes case studies of Australian children and describes the effects of abuse or neglect.
52. Young, op cit, pp1,3,7. '[Neglected] children are deprived of the physical care and protection that normal human growth requires. Because their plight is the result of inaction, they are easily overlooked until the severity of the neglect shocks adults around them into recognition... Children of severe neglect sometimes die as a result - of malnutrition, of accidents, of fire. Most of them survive; but they are almost inevitably psychologically 'starved', since severe neglect is so often accompanied by emotional indifference that is nearly total... Even in the more moderately neglecting families, there is often not a dependable routine, so a baby cannot know exactly when he or she will be fed, it will not be soothed and comforted and will become apathetic. The apathy cloaks an anxiety that would otherwise be intolerable.



53. Dr Terry Heins, psychiatrist, Phillip Child and Adolescent Clinic, Canberra. Oral evidence, Canberra 18.3.92, pp37,44.
54. Urquhart, op cit, p2, and oral evidence, Brisbane 16.8.91, pp1687-91.
55. ibid, pp1689,90.
56. P Mulhearn, social worker, Child Protection Service. Oral evidence, Adelaide 21.10.91, p43. The Child Protection Service is a multi-disciplinary service attached to the Child and Adolescent Mental Health Service in Adelaide. It comprises clinical psychologists, social workers, doctors and nurses who liaise with staff from Family and Community Services, the police, and therapists from the Child and Adolescent Mental Health Service. It assesses children and young people who are suspected of having been physically, emotionally or sexually abused, or victims of neglect. Where assessments confirm the existence of abuse, or therapy is recommended for the child, the appropriate referrals are made and parents are provided with the opportunity to get help to modify their abusive behaviours. This is particularly important, because many abusive parents who were abused themselves as children did not receive any acknowledgment or assistance to break the cycle. The client is listened to, supported and respected in the process of assessment — which may have a therapeutic function in itself for the young person.
57. Christine Flynn, Policy/Administration Director, Mental Health Coordinating Council, New South Wales. Submission, p10.
58. Mandatory reporting of suspected child abuse is also being considered in Victoria.
59. NSW Child Protection Council, *Interagency Guidelines for Child Protection*, Sydney, 1991. The guidelines delineate the roles and responsibilities of agencies involved in protecting children who have been or are at risk of being abused, including the Departments of Health and Community Services, the Police, the Courts and relevant non-government agencies. The guidelines were developed by the Child Protection Council to facilitate case management by the agencies concerned.
60. Patrick Marwick, senior social worker and Head of Clinical Services, Warwick Child and Adolescent Clinic, Perth. Oral evidence, Perth 10.2.92, p97.
61. Prof Robert Kosky, Professor of Child Psychiatry, University of Adelaide at the Children's Hospital. Oral evidence, Adelaide 21.10.91, p140.
62. Cathy Caust, administrator, Southern Child and Adolescent Mental Health Service, Adelaide. Oral evidence, Adelaide 21.10.91, pp15,16.
63. Dr Stephen Allison, psychiatrist, Southern Child and Adolescent Mental Health Service, Adelaide. Oral evidence, Adelaide 21.10.91, p20.
64. id.
65. Morgan, op cit, p97.
66. Prof Beverley Raphael, Professor of Psychiatry, University of Queensland. Information provided to the Inquiry.
67. Liaison psychiatry is the term used to describe the practice by a consultant psychiatrist of providing psychiatric assessment and referral (where appropriate) of people with physical illnesses, injuries or conditions and who may have concurrent mental health needs.
68. Kosky, op cit, p141.
69. For example, Clare House in Hobart; Phillip Clinic in Canberra; Avoca Clinic in Sydney; Arndell and Rivendell in Sydney, which both provide inpatient services for emotionally and behaviourally disturbed young people, as well as non-resident child and family therapy; child and family mental health services or departments affiliated with or attached

to children's general hospitals, such as those in Melbourne, Adelaide and Brisbane; and a number of others providing a range of child and family therapy services.

70. Rey, op cit, p242.
71. See, for example, Pinkus, op cit, p175.
72. Tonge, op cit, p237.
73. M Brakey, Principal, Ulverstone High School, Tasmania. Oral evidence, Devonport 14.11.91, p452.
74. Tony Blackwell, Coordinator, Link Youth Health Service, Hobart. Submission (attachment), p1.
75. Pinkus, op cit, p175.
76. G Mason, *Youth Suicide in Australia: Prevention Strategies*, Report of a study commissioned by the Commonwealth Youth Bureau of the Department of Employment, Education and Training, conducted by the Australian Institute of Criminology. Canberra 1990, p159.
77. Morgan, op cit, p96.
78. ibid, p97.
79. ibid, pp96,97.
80. Dr Graham Martin, Clinical Director, Southern Child and Adolescent Mental Health Service, Adelaide. Oral evidence, Adelaide 21.10.91, p58.
81. Tonge, op cit, p236.
82. Nairn, op cit, p(i).
83. Allison, op cit, p18.
84. Dingle, op cit, p19.
85. Senior Constable Helen Adams, Community Policing Squad, Victoria Police. Oral evidence, Melbourne 9.4.91, pp189,193.
86. Dr William Bor, RANZCP, Queensland Branch. Oral evidence, Brisbane 15.8.91, p1599.
87. This was the situation in April 1991.
88. Tonge, op cit.
89. Name withheld, psychiatrist. Oral evidence in private hearing.
90. Raphael, op cit.
91. Bor, op cit, p1598.
92. ibid, p1597.
93. Adams, op cit, pp189,191,193.
94. Pinkus, op cit, p173.
95. Allison, op cit, p18.
96. Morgan, op cit, p99,104.
97. ibid, pp98,99.
98. Kosky, op cit, p140,148,149.
99. Dingle, op cit, pp21,22.
100. ibid, p451.
101. Urquhart, op cit. p1683.
102. A Chair in Child Psychiatry was established at the University of Western Australia at the end of 1992. See Chapter 7 — Developments Since the Inquiry Began.

103. Tonge, op cit, p239.
104. Kosky, op cit, p145.
105. Bor, op cit, p1597.
106. Dr David Lord, RANZCP (Western Australian Branch). Oral evidence, Perth 11.2.92, p148.
107. R Hearn, *Locked Up, Locked Out: The Denial and Criminalisation of Young People's Mental Health Crisis*, Victorian Community Managed Mental Health Services Inc, Melbourne March 1993, p41. This report refers to a survey conducted in co-operation with Victorian Police which found that: 'Police do need more training in...working with this group... 83.5 percent of the [police] respondents did not think they knew enough about mental health problems to work effectively with [young people]... Communication with the target group appears to be the major area of need... Training could [also] be useful in relation to working with aggressive behaviours.'
108. B Raphael, 'Psychiatry at the coal-face', Presidential address to the 1986 Annual Congress of the RANZCP, in *Australian and New Zealand Journal of Psychiatry* v20 1986, p324.
109. Bashir, op cit, pp497,8.
110. Morgan, op cit, p98.
111. Kosky, op cit, p138.
112. Dr Aidene Urquhart, Brisbane. Information provided to the Inquiry after the close of formal hearings.
113. Bor, op cit, p1595.
114. Jennifer Luntz, President, Coalition of Child and Adolescent Mental Health Professionals. Oral evidence, Melbourne 8.4.91, p38.
115. Waters, op cit, p25.
116. Brakey, op cit, p451,454.
117. Dingle, op cit, pp19,20.
118. Hearn, op cit, p21.
119. Jenny McCulloch, Secretary, School Crisis Intervention, Tasmania. Oral evidence, Devonport 14.11.91, pp453,4.
120. Dingle, op cit, p19.
121. Neil Rees, President, Mental Health Review Board, Victoria. Oral evidence, Melbourne 8.4.91, p25.
122. Dr David Wells, Director, Office of Forensic Medicine, Victoria. Oral evidence, Ballarat 11.4.91, p603
123. Adams, op cit, p190,198.
124. *Newcastle Herald*, 2 July 1992, p1, 'Mentally ill boy, 12, locked up like a criminal'; and *Newcastle Herald*, 10 July 1992, p3, 'Hunter working team seeks to avoid repeat of anguish to mentally ill child.'
125. Prof Vaughan Carr, who also gave evidence at the Newcastle hearings of the Inquiry.
126. Dr J Cubis, psychiatrist. Oral evidence, Canberra 18.3.92, p47.
127. J Krupinski and G Burrows, 'Mental Health Promotion: Policy Strategies for Australia'. Survey commissioned by the Australian National Association of Mental Health (ANAMH) and the Mental Health Foundation. Included as an appendix to ANAMH's submission to the Inquiry.

128. Bashir, op cit, p501.
129. Rey, op cit, pp243,6,7.
130. Waters, op cit, pp15-16.
131. Rey, op cit, p249.
132. Dingle, op cit, p20.
133. Marwick, op cit, pp94,95.
134. Heins, op cit, p37.
135. See, for example, Jenny McCulloch, op cit.
136. Brakey, op cit, p451,452.
137. Bor, op cit, p1595.
138. id.
139. ibid, p1596, quoting survey undertaken by the Queensland Advisory Council on Special Education Needs Working Party.
140. Heins, op cit, p39.
141. Human Rights and Equal Opportunity Commission, *Our Homeless Children: Report of the National Inquiry into Homeless Children*, AGPS, Sydney 1989, p273.
142. A Bain, 'Issues in the suspension and exclusion of disruptive students', *Australasian Journal of Special Education* v12 No2, 1988, pp19-24.
143. Nairn, op cit, pp157-60.
144. Gardiner, op cit. The US has federal legislation (public law 94-142) specifying criteria for categories of students who need special education and providing for special funding for this group.
145. Heins, op cit, p38.
146. Nairn, op cit (submission), p11.
147. Gordon Walker, Ailsa Drent and Mardi Whitla, Australian Guidance and Counselling Association, Victoria. Submission.
148. ibid, p1.
149. ibid, Appendix C, pp1,2.
150. ibid, p1.
151. Lenore Grunsell, Secretary, School Psychologists Australia Inc, NSW. Submission, p1.
152. id.
153. Waters, op cit, p21.
154. Bashir, op cit, p497.
155. The Centre is for young offenders under 18 and is administered by the South Australian Department of Community Welfare. The study compared adolescents from two-parent families attending Adelaide child and adolescent psychiatric clinics with a group of 78 young offenders held in the remand centre. Reported in: RJ Kosky, MG Sawyer, and JC Gallant, 'Adolescents in custody: Hidden psychological morbidity', *Medical Journal of Australia* v153, 2 July 1991, pp24-27.
156. Kosky, op cit, p143.
157. Danny Sandor, youth worker. Oral evidence, Melbourne 9.4.91, pp177,8.
158. Waters, op cit, pp21,29.
159. ibid, pp21,22.

160. Peter Nordan, Brosnan Centre Youth Service, Catholic Prison Ministry. Oral evidence, Melbourne 9.4.91, pp288,9.
161. R Kosky, 'Adolescents in custody: A disciplining or a disabling experience?' in *Breaking Out: Challenges in Adolescent Mental Health In Australia*, National Health and Medical Research Council, Canberra 1992, p132.
162. For example, the Victorian Department of Health and Community Services commenced a reorganised and upgraded range of psychiatric and psychological services to juvenile justice clients in February 1993. Also, see below regarding the Forensic Psychiatry Unit for Children and Adolescents opened in 1992, by the South Australian Government.
163. Bashir, op cit, p501.
164. Waters, op cit, p20.
165. id.
166. Kosky, op cit, p144. Prof Kosky also states in 'Adolescents in custody' (op cit, endnote 160), p133: 'Current youth detention centres are ugly, austere and psychologically brutalising... The opposite is needed: centres to provide pleasant, comfortable, warm and nurturing environments.
167. Waters, op cit.
168. Robin Gurr, President, NSW Council of Social Service. Submission, p2.
169. Dr Yvonne Skinner, psychiatrist. Oral evidence, Sydney 8.7.91, p670
170. Bashir, op cit, p506.
171. In February 1993, the Victorian Department of Community Services and Health reorganised psychiatric and psychological services to juvenile justice clients, including assessment and treatment functions in youth training centres, and access to child and adolescent psychiatric services for those in juvenile justice facilities. These services are, it is claimed, to be integrated into a comprehensive health service, with specialist resources. The Children's Court Assessment Service will be restructured.
172. Dingle, op cit, pp20,21,25.
173. G Martin, M Clarke and C Pearce, 'Adolescent suicide: Music preference as an indicator of vulnerability', Unpublished paper, 1992, p1.
174. Dr Michael Dudley, psychiatrist, Avoca Clinic Child and Adolescent Service, Prince of Wales Hospital, Sydney. Oral evidence, Sydney 18.6.91, p198.
175. Tonge, op cit, p238.
176. id.
177. M Dudley, B Waters, N Kelk, and J Howard, 'Youth Suicide in New South Wales: Urban-Rural Trends, 1964-1988,' in S McKillop, *Preventing Youth Suicide*, Conference Proceedings, Australian Institute of Criminology, Canberra 1990, pp17-35. The study analyses official suicide statistics for young people aged 10-19 in NSW from 1964-88, noting increases in firearm suicides particularly in rural areas. Prof Waters and Dr Dudley both gave evidence at the Inquiry's hearings in Sydney.
178. R Goldney, 'The prediction of suicide', in *Preventing Youth Suicide*, op cit, pp49,50. C Cantor, 'Suicide and community psychiatric care', Paper presented to the 16th Annual Symposium, RANZCP — Social and Cultural Section, Townsville, 26-29.9.91, pp2,3.
179. Dudley, op cit.
180. id.
181. A Patience, in *Breaking Out: Challenges in Adolescent Mental Health in Australia*, National Health and Medical Research Council, Canberra 1992, pp44-60.

182. Dudley, op cit, p198.
183. Waters, op cit, p28.
184. *Report of the Youth Suicide Working Party*, op cit, pp13,15.
185. Mason, op cit, pp144-147. This report suggests guidelines for responsible media reporting, some of which include references to suicide as 'an unnecessary and tragic means of resolving... problems, emphasising that help is available...[including] where such assistance can be obtained.' The report also makes reference to guidelines developed by the RANZCP in its 1989 submission to the Australian Broadcasting Tribunal, stating: 'Guidelines should discourage repeated or romanticised coverage of suicide... Depiction of the method [used] should also be discouraged.'
186. R Eckersley, 'Failing a generation: The impact of culture on the health and wellbeing of youth', Paper presented to the Australian Rotary Health Research Fund Fifth International Conference, *Adolescent Health Behaviour: Identifying Vulnerability and Resilience*, Canberra, 11-14.11.92, pp3,6,18.
187. *Our Homeless Children*, op cit.
188. One possible explanation for the higher rate of attempted suicide by young females and completed suicides by young males is the effectiveness of the more direct and violent methods chosen by males. I Hayward, R Moyle, B Hart and V Gardner, 'Availability of method and suicide rates', *Report of the Youth Suicide Working Party*, op cit, Appendix 4.4, p63: 'More males (approximately 45 percent Australia-wide) under 20 years and 20-24 years use firearms. The under 20 year age group's next most preferred methods are hanging, poisoning by solid or liquid substances and carbon monoxide poisoning. Females in these two age groups used [poisonous substances]...most often.'
189. Dudley, op cit, p202.
190. Hayward et al, op cit, p67.
191. Mason, op cit, p42.
192. Dudley, op cit, p199.
193. Waters, pp20,22.
194. Dr Dudley described this area as 'a shambles... We have to provide the workers with supports. Supervisory processes haven't been set up, or they've only been set up very piece-meal.'
195. Waters, op cit, p28.
196. Dudley, op cit, pp199,202,3.
197. The Homeless Children's Inquiry and other studies have clearly established that homeless young people are at very high risk. In a 1989 survey conducted by the Salvation Army, 34 percent of homeless young women and 17 percent of homeless young men had attempted suicide.
198. *ibid*, p203.
199. This aspect of postvention is particularly important. Young people close to the individual who has suicided need assistance to come to terms with their loss and to help them overcome any consequent guilt, anger or depression.
200. Mason, op cit, p134.
201. *eg Preventing Youth Suicide*, op cit; St Michael's Uniting Church, *Preventing Suicidal Behaviour in Young People*, Melbourne 1992; Centre for Adolescent Health, *Youth Suicide Prevention*, Melbourne 1992; Australian Association for Adolescent Health, 1990 Biennial

Conference, *Future Shock into Future Health*, Workshop: 'Teenage Suicide — What Can We Do?' Perth, 1990.

202. *Report of the Youth Suicide Working Party*, op cit.
203. Dr Christopher Cantor, Director, Suicide Research and Prevention Program, Queensland Department of Health, Mental Health Branch. Submission, pp1-4.
204. 'Driven to Suicide', *Sunday Mail*, Brisbane, 8 Nov 1992.
205. *Report of the Ministerial Task Force to Review Child and Adolescent Psychiatric Services in Western Australia*, Department of Health, Perth, 1993, p2; and G Martin and S Waite, *Parental Bonding and Adolescent Suicide*, Child and Adolescent Mental Health Service, Flinders Medical Centre, South Australia. Paper provided to the Inquiry by the authors.
206. Two recent South Australian studies examined the effect on adolescents of the suicide of another student: One study looked at a school where two young people had suicided. It found that adolescents with pre-existing depression or a preoccupation with suicide may be at high risk of 'copy cat' suicide: G Martin, N Kuller and P Hazell, 'The effect on adolescents of the completed suicide of another student', *Youth Studies Australia*, Autumn 1992, pp20-22. The other study was conducted in an Adelaide school after the suicide of a teenage girl. In this study it was those who were already depressed and had suicidal thoughts, or those who had already attempted suicide, who were apparently influenced by the death to actively imitate. G Martin, 'Adolescent suicide: Postvention in a school', *Youth Studies Australia*, Autumn 1992, pp24-27.
207. G Martin, 'Adolescent Suicide: Imitation and the Clustering Phenomenon', *Youth Studies Australia*, Autumn 1992, pp28-32.
208. The study at the Longford Remand Centre in Perth examined the incidence and nature of serious suicide attempts made by adolescents. The 12 young attempters were all male and ranged in age from 11 to 17. Four were Aboriginal. The study found that in this group family breakdown had been chronically stressful: most of the subjects had either been in foster care or institutions. Seven had experienced physical violence from caregivers, but none reported sexual abuse. Nine of the twelve had been living with relatives or friends or on the streets. Few received visits from families while detained. Eleven of the twelve suicide attempters had histories of some level of alcohol and drug use. Eleven of the twelve had been charged with a violent offence, but only a quarter of non-suicidal detainees had been so charged. Three quarters of the group had made a previous suicide attempt. In five cases, the preceding circumstances were similar — occurring after an angry confrontation with staff, followed by isolation.
209. Martin, op cit ('Adolescent Suicide: Imitation and the Clustering Phenomenon'), p32.
210. *ibid*, p32.
211. The National Health and Medical Research Council has established a task force, chaired by Dr Peter Baume, to examine issues related to youth suicide nationally.
212. Urquhart, Submission, p2.
213. Dingle, op cit, pp18,19,20.
214. Kosky, op cit, p149.
215. Brakey, op cit, p455.
216. Libby Steeper, Convenor, ACT Council of Social Services. Submission, p2.
217. McCulloch, op cit, pp453,456-7.
218. Morgan, op cit, pp96-99.
219. Brakey, op cit, p452.

220. Pinkus, op cit, pp174-5.
221. Dingle, op cit, p22.
222. Peter Mulhearn, social worker, Child Protection Service, Southern Child and Adolescent Mental Health Service, Adelaide. Oral evidence, Adelaide, 21.10.91, p45.
223. Western Australian Department of Health, Submission (including Report on the Troubled Youth Support Service, and Report of the Ministerial Task Force to Review Child and Adolescent Psychiatric Services in Western Australia), p3.
224. See endnote 59.
225. Tonge, op cit, p239.
226. Rey, op cit, p249.
227. Brakey, op cit, p452.
228. The Early Psychosis Research Centre in Melbourne was opened by the Inquiry Chairman in July 1992.



## Chapter 21

# PEOPLE WITH DUAL AND MULTIPLE DISABILITIES

There is a huge number of intellectually disabled people who receive no treatment for their psychiatric disorder because it is not available.<sup>1</sup>

Many thousands of Australians who suffer from mental illness are also affected by some other disability. While there are many forms of 'dual disability', evidence presented to the Inquiry predominantly focussed on four areas — the difficulties confronting individuals with psychiatric problems in addition to an intellectual or sensory disability; the problems of people with mental illness compounded by a substance abuse disorder; the effect of brain injury on mental health; and HIV/AIDS related psychosis.

Dual diagnosis is a really big problem area. It's not just a problem area with intellectual disability and mental illness. It is a problem with drugs and alcohol. It is a problem with people who have sensory disability. It is certainly a problem with people who have a physical disability. There are no services targeting [the needs of these people].<sup>2</sup>

## Mental Illness and Intellectual Disability

Expert evidence from several psychiatrists emphasised the important but widely unrecognised phenomenon that people who are intellectually disabled<sup>3</sup> are more likely than the non-disabled to experience mental illness.<sup>4</sup>

Two percent of the population is intellectually handicapped and the prevalence of mental illness in that population is — depending on the study — between 30-50 percent, so one is looking at around 1 percent of the population.<sup>5</sup>

This is an extremely large number of Australians — between 100,000 and 170,000.

One of the difficulties associated with treating people who have an intellectual disability and suffer from mental illness is that:

[While] a number of psychiatric disorders in the intellectually disabled area are the same as [those in] general psychiatry, there are some special areas which do not fall easily into the normal classification system.<sup>6</sup>

Mental ill health also often results from a variety of factors which particularly affect the intellectually disabled. These include 'lack of friends, not having a

valued social role, not having a job and not having a home'.<sup>7</sup> The Intellectual Disability Services Council of South Australia told the Inquiry that:

If significant emphasis were given to resolving these issues, we may see fewer people actually having to become riders on the mental health merry-go-round'.<sup>8</sup>

Psychiatric difficulties confronting many intellectually disabled people are compounded by a scandalous shortage of appropriate psychiatric services.

There are almost no mental health services for disturbed people with developmental disabilities. It is quite appalling... It is not because of a lack of will on behalf of the developmental disabilities people who desire these services. There has never been adequate provision of such services.<sup>9</sup>

Evidence to the Inquiry by psychiatrists familiar with intellectually disabled patients established that their needs are often ignored because they fall between two areas of service delivery: non-psychiatric services which cater specifically for people with disabilities — and services which provide expert psychiatric care but are unfamiliar with the needs of the intellectually disabled. The Intellectual Disability Services Council of Victoria told the Inquiry that this division of services leads to further disadvantage<sup>10</sup> because the client is treated as if the 'two conditions are mutually exclusive'.<sup>11</sup>

Several psychiatrists presented evidence concerning the negative effects of this 'compartmentalisation':

The psychotic complications of the intellectually handicapped can usually be handled in a relatively straightforward way and can be managed. [However] the chronic problems relate more to intellectual [disability]... I will say, 'Yes, we will treat this person'...but that is going to be a matter of two to three weeks. We then run into the problem of who is going to be responsible for the continued management when the family is no longer able to cope. That is where the arguments often get acrimonious... The problem is that we have ended up with carve-ups which have been done for administrative reasons and the patients, reasonably of course, refuse to fall into the pigeonholes that we use.<sup>12</sup>

Since the Inquiry began the Commonwealth and the States have (in July 1991) entered into the Commonwealth-State Disability Services Agreement. This Agreement is aimed at improving service delivery to people with disabilities, and reducing the kind of administrative confusion and 'pigeonholing' referred to above.<sup>13</sup> Under the Agreement, State and Territory governments assume responsibility for accommodation and all other support services for people with a disability. The Commonwealth government retains responsibility for employment under its Disability Services Program, and both levels of government retain responsibility for advocacy services.<sup>14</sup>

In November 1991 the Commonwealth also introduced the Disability Reform Package, which is aimed at providing a more effective system of income support payments for people with disabilities and facilitating the involvement of disabled people in open employment.<sup>15</sup>

However, several witnesses, in evidence concerning reforms to disability services and their impact on people with intellectual and psychiatric disabilities, claimed that the process disadvantages people with dual disabilities:

The vocational programs administered under the *Disability Services Act* fail to recognise that many [intellectually disabled] persons also suffer mental disorders. Currently the vocational programs are only funding those persons who are employable in open employment and withdrawing funding from other vocational programs who provide a more supportive environment. It is obvious to parents, workshop managers and professionals in the field...that persons with both developmental disability and mental disorders will not be able to achieve productivity in open employment... Many parents have shared with me their great anxiety of the threatened withdrawal of Commonwealth finance to work and activity facilities for disabled persons with extra support needs on account of [their] mental illness. A concept of the so-called least restrictive alternative must also consider the most advantageous alternative.<sup>16</sup>

Similar concerns were also expressed by Australian Parent Advocacy, a non-government organisation advocating for the intellectually disabled:

Persons with a joint intellectual/psychiatric disability are not being fairly treated in the process of implementation and devolution of the *Disability Services Act* (DSA)...evidence proves that the severely and multiply disabled are being left out of the process of empowerment being created by the DSA. There is a distinct gap in services and money for the multiply disabled — because the nature of their disability requires massive amounts of support — and this support costs dollars.<sup>17</sup>

The Inquiry was told that dual or multiply disabled people can be disadvantaged in accessing appropriate disability services because of the criteria used to assess the level of their disability. The manager of a sheltered workshop for intellectually disabled people in Newcastle, for example, gave evidence that her clients had to be diagnosed as 'moderately to severely' disabled in order to obtain government assistance. However, they are only assessed on the level of their intellectual disability and not for psychiatric disability. This poses difficulties for people who are mildly intellectually disabled but are also affected by a psychiatric disability. While the extent of their intellectual disability may not affect their ability to work in open employment, the psychiatric disability can make unsupported employment extremely difficult or impossible:

[For example I had a client]...who was assessed as having mild intellectual disability but [he also] has very distinct psychiatric problems. He lived independently and was not coping. I tried to find some assistance through Disability Services...[but they said] he was

too high functioning...this young man eventually ended up being quite suicidal because I was unable to find criteria he fitted to get support.<sup>18</sup>

I go home very frustrated and worried that I am encouraging people to utilise their rights but without the support systems to back that up... I feel that we are encouraging people to do wonderful things on the one hand but we are setting them up for failure on the other...<sup>19</sup>

The lack of specialist services leads to what one psychiatrist described as errors of both 'omission' and 'commission'.<sup>20</sup> Errors of omission occur because of a lack of specific services for people with mental illness and an intellectual disability. Errors of commission, on the other hand, include:<sup>21</sup>

the inappropriate use and indiscriminate use of medication in an attempt to control [the patient's] behaviour because other people cannot manage it. [T]his is not to say that intellectually disabled people should not receive medication: many of them should and do not. My view is that they are receiving medication inappropriately, not based on proper diagnosis and assessment.<sup>22</sup>

Such inappropriate use of psychiatric medication was described by another psychiatrist as a 'chemical straitjacket'.<sup>23</sup>

In addition to evidence about the misuse of medication, the Inquiry heard allegations that intellectually disabled women living in psychiatric hospitals were being sexually abused. (This evidence has subsequently been corroborated in Victoria by the Inquiry into Aradale hospital.)

When the issue was raised among staff [the response] was that she is on Depo Provera so it is not a worry... [In other cases] women have been sexually abused by practitioners or other staff, or indeed male clients, and they have been labelled as manipulative or having personality disorders and therefore not to be believed.<sup>24</sup>

This evidence illustrates the extreme vulnerability of intellectually disabled patients. The Intellectual Disability Services Council of South Australia presented evidence that more scrutiny is necessary to 'ensure that there are adequate ways in which people [can] have their conditions reviewed within psychiatric hospitals'.<sup>25</sup> The Council suggested that organisations such as the Office of the Public Advocate have an important role to play in such a process. In addition, the involvement of carers and relatives is particularly important:

We have found that in the area of intellectual disability the continued involvement of families, friends and advocates has been a powerful force to deal with many of the injustices that can otherwise creep into any service system.<sup>26</sup>

It is clear from evidence presented to the Inquiry that the professional distinction between medically-based services and rehabilitation and support services

must be effectively addressed if the needs of patients with both intellectual and psychiatric disabilities are to be met and their rights respected. Appropriate professional training is one critical area.

[In addition] there has not been a program of training mental health professionals, or people with a mental health focus, to go into this kind of work. [We need to address] the huge problem of the lack of trained staff to specialise in this area.<sup>27</sup>

The Inquiry was told that there is, at least in one State, a precedent for joint service provision to people with intellectual and psychiatric disabilities. Since October 1990:

In NSW both health and welfare and disability services accept joint responsibility for people with both developmental disability and mental disorder... [A] number of responsibilities are delineated for each service. Although this does not solve the problems of inadequate expertise and inadequate service, it at least enables the first step to be taken and that is to go beyond the position of both services saying 'it's not our problem'.<sup>28</sup>

This policy was expressed in a directive by the Directors General of the Departments of Health and Community Services, in which staff were informed that 'persons with developmental disability who have a psychiatric disturbance are the joint responsibility of [both Departments] and priority in management in both Departments is given to persons with more serious conditions'. The policy sets out procedures for client management and specifies the particular responsibilities of each Department — as well as their joint responsibilities. The Inquiry was told that this new approach to service delivery is monitored by joint regional committees comprising representatives from each Department — and that it has been successful and could be easily implemented in other States and Territories.<sup>29</sup>

Since the Inquiry began there have been several other developments aimed at improving training among psychiatrists in relation to the needs of people affected by mental illness and intellectual disability. The Royal Australian and New Zealand College of Psychiatrists has recently increased its requirements to ensure that prospective fellows have more adequate knowledge about this area. The College's examination process will also be changed to reflect this initiative. The NSW Institute of Psychiatry also advised the Inquiry that it will enhance programs to include intellectual disability and mental illness.

Notwithstanding these developments and promises, evidence to the Inquiry established there is an urgent need for academic research, increased clinical expertise and substantially increased resources in this much neglected area of dual disability. In the United Kingdom there are seven full university chairs in the psychiatry of intellectual disability and 'a greater number of junior

positions.<sup>30</sup> In Australia, by contrast, there are currently no academic positions 'solely devoted' to this area of expertise.<sup>31</sup>

## **Mental Illness and Substance Abuse**

The dual diagnosis of mental illness and substance abuse covers two overlapping but distinguishable groups of individuals:

One subgroup has, [under] DSM-III-R, both a major substance abuse disorder and another major psychiatric illness. The other subgroup uses alcohol and/or other drugs in ways that affect the course and treatment of mental illness.<sup>32</sup>

The Inquiry received little evidence from the individuals directly affected. However expert evidence and recent overseas research clearly indicate that mental illness compounded by substance abuse is a major problem. One of the largest studies of the causes and prevalence of mental illness and chemical addiction is the United States Epidemiological Catchment Area study.<sup>33</sup> This survey of 20,000 Americans found that 47 percent of individuals with a drug or alcohol problem also reported that they suffered from some form of mental illness.<sup>34</sup> Although no quantitative research of this kind has been undertaken in Australia, expert information available to the Inquiry suggests that the prevalence of mental illness and substance abuse in our population would be comparable to if not similar to that found in the United States.<sup>35</sup>

Although diagnoses of substance abuse and mental illness may be related, they are also quite distinct and may require quite different types of treatment. Research undertaken both in the United States and Australia has established certain commonalities in relation to people with mental illness who also have substance abuse problems. Mental illness can, for example, lead to alcohol and drug dependence when clients resort to self-medication to control the symptoms of depression and other affective disorders. Conversely, psychiatric disorders can result from the abuse of alcohol and other substances.<sup>36</sup> Psychiatric symptoms can thus contribute to the tendency to use drugs, while substance abuse can accentuate psychiatric symptoms.<sup>37</sup>

Notwithstanding these recognised links, evidence to the Inquiry established that there are very few services available to effectively treat individuals affected by both mental illness and substance abuse disorders:

Attention needs to be given to people with specific problems such as [dual diagnosis]. There need to be specific services for people [with mental illness and chemical addiction] — with staff who are trained adequately to deal with people who have those dual problems. At present such patients fall between services with the mental health service saying, 'well, look, really they have got an alcohol problem: it is not for us, it is more for you;

and the alcohol services saying 'it is really a mental health problem, not their alcohol'. I think there ought to be a designated service...attached to the mental health services...[with staff who are] specially trained to deal with the unique problems of that particular group.<sup>38</sup>

The evidence also indicated a serious lack of communication and integration between the mental health system and substance abuse services. In both of our largest States the Inquiry was told that many people with a dual diagnosis 'fall through' the gaps in the health care system because mental health services are unwilling to admit them due to their chemical addiction, and detoxification centres and other organisations treating substance abuse are unable or unwilling to provide treatment for the mentally ill:

If somebody with a psychiatric disability has a drug problem and is on medication, to try and get them into a detoxification centre is impossible because detox centres will not take anyone on medication...[and] to try to get anyone with a drug problem into an accommodation service designed for psychiatrically disabled people...is almost impossible.<sup>39</sup>

The main problem in the area of dual diagnosis appears to be...the lack of communication between the mental health and drug and alcohol fields... As a result of this division, services in both fields are unclear as to who should take responsibility for dealing with the dual diagnosis patient.<sup>40</sup>

Expert evidence to the Inquiry indicated that in the past, mental health professionals tended to avoid 'patients who show hazardous or harmful drug use'.<sup>41</sup> Similarly, drug and alcohol services are often unaware that a client's disturbed and erratic behaviour may be due to mental illness, not just substance abuse. In fact, experts generally agreed that it can be extremely difficult to tell which symptoms are due to substance abuse, and which may be due to a psychiatric problem.

Psychiatric services and services for alcoholism and drug addiction have different philosophies and approaches to treatment.<sup>42</sup> For example, mental health workers generally aim for an assertive follow-up model, pursuing clients if they miss an appointment. In drug and alcohol services there is a greater reliance on self motivation, which can inadvertently — but seriously — disadvantage mentally ill clients.<sup>43</sup> For many drug and alcohol services, helping a client abstain from any form of substance use is a primary goal. This can obviously create major difficulties for people with mental illness and substance abuse problems, who may depend on psychiatric medication for their mental health and stability.<sup>44</sup> There are also fundamental differences of professional opinion, both within and between services, as to whether substance abuse is a cause or a symptom of psychopathology and how it should be treated.<sup>45</sup>

There is a clear correlation between substance abuse and the development of certain affective disorders and other mental illnesses, particularly among adolescents.<sup>46</sup> To illustrate the complexities which sometimes characterise this connection, one psychiatrist presented the case history of a young man whose mother had manic depressive illness and had been hospitalised frequently over many years. The boy had started using, growing and selling marijuana during the first few years of high school. He continued to get into trouble at school and with the police and was sent for regular therapy sessions — to no avail. The psychiatrist told the Inquiry:

We [the therapist and other professionals] believed that his use of marijuana on a daily basis, more than once a day, was in fact quite deleterious to his mental health and we believed that unless we could get him off the marijuana we did not have a fair chance of working with the boy or getting him to settle into any kind of therapeutic relationship... I believe he has major mental health problems and he probably has the early beginnings of the illness very similar to his mother, and he is attempting to deal with it in his own way by using marijuana.<sup>47</sup>

The Inquiry also examined the preliminary results of a survey undertaken by the same psychiatrist, which indicate that adolescents who use drugs such as alcohol, marijuana, LSD and analgesics, are more likely to experience depression and suicidal thoughts.

While the evidence presented to the Inquiry was often anecdotal, it is reinforced by recent research which indicates that mental illness and substance abuse are significant problems for many adolescents. Researchers have suggested two major reasons for this. First (as set out in Chapter 20), many of the major mental disorders have their onset in adolescence; and second, drug and alcohol use is generally high among adolescents.<sup>48</sup>

Witnesses from non-government agencies gave evidence that many people with dual diagnosis are not receiving any assistance for their addiction or their mental illness:

There has been considerable administrative confusion and 'buck passing' over service responsibility for people with alcohol/drug abuse and mental health problems. The end result is often that these people receive no treatment or service and often end up in the homeless population.<sup>49</sup>

According to expert evidence such individuals are frequently 'severely disorganised people, usually extremely poor, [who] have disrupted or chaotic relationships, few social supports and are very unhealthy physically'.<sup>50</sup> This may account for the high incidence of this particular dual disability in the homeless population. A recent study undertaken in the American city of Baltimore found 'a high prevalence' of mental illness and alcohol and substance abuse disorders



among the homeless compared to the general population.<sup>51</sup> The authors concluded that the comorbidity of mental health and substance abuse problems reflects the 'disaffiliation' of the homeless population. (As detailed in Chapter 18, the homeless are one of the groups least likely to obtain assistance for psychiatric and other problems.)

Evidence to the Inquiry indicated that the high incidence of mental illness and substance abuse among the homeless is partly related to the fact that people are not able to obtain treatment because they are not in a stable enough environment to keep appointments or to detoxify. The chief executive officer of Hanover Welfare Services (an organisation which provides support services to homeless people in Melbourne) told the Inquiry that his organisation is not equipped to deal with people with dual diagnosis. Nevertheless, the organisation's workers regularly have to deal with difficult clients like 'James' who have nowhere else to go:

'James' displays erratic and self destructive behaviour. He is socially isolated, withdrawn and therefore vulnerable to exploitation. He has had contact with a wide variety of health services and accommodation and welfare agencies. James has had multiple psychiatric admissions and treatments, multiple public hospital admissions and [has participated in] multiple drug and alcohol treatment programs. There has also been some police intervention.<sup>52</sup>

The situations of people like James illustrate the dilemma faced by service providers who have to choose between providing accommodation to people with dual diagnosis who are disruptive to other clients, and protecting the rights of other residents to a safe, secure environment. 'The weight of this decision is enormous' and it is not appropriate for generalist services to be dealing with it.<sup>53</sup> It was suggested to the Inquiry that these problems indicate the urgent need for a closer interaction between mental health and drug and alcohol services:

Health and welfare agencies are not adequately equipped to assist people who suffer multiple problems, and whose behaviour is particularly disruptive. We have found that there is often a lack of service delivery coordination between agencies dealing with the one individual. This can be compounded by the failure of major health services to work in a way that enables them to reach the homeless person in their own environment... We believe that hospitals and clinics need to make a greater effort at tailoring more flexible service delivery methods that will meet the particular needs of psychiatrically disabled individuals who also suffer from significant alcohol or drug dependence.<sup>54</sup>

A submission by the Western Australian Council of Social Service effectively summarised recommendations made by many witnesses who called for a more integrated approach to people with mental illness and substance addictions:

[There is] a need for the integration of services, including the designation of a 'primary care' worker (regardless of discipline of agency) to be responsible for the complete care of a person. The coordination of services was seen as being achieved by establishing a single service based on consultative contact and closer liaison between the various agencies servicing the needs of the same clients. Emphasis was placed on the importance of adopting a holistic approach to treating people and that all agencies should consider themselves part of a team and accordingly coordinate all treatment.<sup>55</sup>

## **Mental Illness and Deafness**

To be totally deaf is like having a thick panel of glass between oneself and the world.<sup>56</sup>

There are no precise figures available on the number of Australians who are deaf. However, approximately 17,000 (0.1 percent of the population) are profoundly deaf<sup>57</sup> and the most recent research available indicates that one in seven Australians is hearing-impaired.<sup>58</sup> Definitions of deafness vary — but deafness is not the same as hearing impairment:

It is best not to confuse hard of hearing or hearing impaired people with deaf and deafened people because the kind of communication problems the latter face are quite different from those of the hearing impaired.<sup>59</sup>

Many in the deaf community have a distinct culture and language which differ from those of the dominant hearing culture and people who experience marginal hearing loss.<sup>60</sup> Evidence was presented that most people who are profoundly deaf can be described as 'prelingually deaf'<sup>61</sup> (that is, individuals who suffered hearing loss at a very early stage of childhood development and whose hearing loss has precluded the acquisition of normal language skills). People who are prelingually deaf usually use sign language.<sup>62</sup>

The Inquiry was told there are two major issues facing deaf people in relation to mental illness; both involve communication. First, deaf people are sometimes mistakenly perceived as being mentally ill by hearing relatives and professionals because of difficulties in communication. Evidence to the Inquiry established that hearing people sometimes perceive deaf people's behaviour as 'abnormal' or 'dysfunctional' because it is different.<sup>63</sup> Second, evidence was presented that mental health staff sometimes fail to communicate effectively with deaf patients, which has resulted in mistaken diagnosis and inappropriate treatment.

Deaf people may appear to be affected by mental disorder when in reality [they may] under severe stress and — unable to express themselves verbally — exhibit what is perceived by hearing people as being unusual or socially unacceptable behaviour.<sup>64</sup>

Evidence presented to the Inquiry also indicated that during adolescence deaf young people may exhibit behaviour problems as they 'act out' their frustration

and anger and seek to assert their independence from their hearing parents. This can lead to conflict in the family as parents attempt to assert their authority, and the deaf adolescent resists their control. Sometimes these difficulties lead to an act of violence on the part of the adolescent and subsequent intervention by community services and/or the police. The Inquiry was told that it is at this stage that 'young deaf people are particularly vulnerable to referral abuses':<sup>65</sup>

Most youngsters remain in an unaltered domestic environment in which further infringements are inevitable. Re-offending leads either to police involvement as a deterrent, [or] the administering of tranquillisers or admission to a hospital psychiatric ward for observation.<sup>66</sup>

[I am] aware of young deaf people who have been subjected to harrowing experiences of restraint, admission and periods of incarceration [in a psychiatric institution] without fully understanding the events, without representation and being discharged believing themselves to be or believed by others to be, mentally unstable.<sup>67</sup>

It is difficult to estimate the number of deaf people who may also suffer from a diagnosable mental illness. However, the Queensland Deaf Society told the Inquiry that there are approximately 6,500 prelingually deaf people in Queensland. The Deaf Society was aware of 14 clients in the Brisbane metropolitan area who were receiving services from mental health professionals.<sup>68</sup> The Victorian Deaf Society, which presented data on contacts with clients who required assistance with mental health problems, estimated that during the 1990-91 financial year a total of eight working weeks were spent dealing with deaf clients who were also experiencing mental illness.<sup>69</sup>

Ignorance about deafness can have extremely serious consequences.

One of the main reasons for admissions of deaf people to psychiatric hospitals was 'impulsive, aggressive behaviour'... A large number of deaf patients in some hospitals were considered 'subnormal' until careful diagnostic review showed that there was no evidence to support this view. In fact it can be difficult, even for psychiatrists with an understanding of deaf people and an ability to communicate with them to make a diagnosis at times. The main factors for this difficulty include the combination of mental disorder, communication difficulty, lack of language sophistication, and the effects of hospitalisation.<sup>70</sup>

Difficulties associated with treating deaf people who are also mentally ill were illustrated in a case study presented to the Inquiry by the parents of a deaf man who started exhibiting disordered and violent behaviour as an adolescent:

[Our son] was born profoundly deaf, the victim of rubella... His early life was one of great frustration and suffering, but in spite of this, he was a loving and loved member of the family... In his late teens he became difficult to direct and advise. Attempts to control

him were met with physical response and life with him was now a strain on the family... He [also began exposing himself in public]. His breakdown mentally was to follow and was the beginning of the past 14 years in and out of hospital.<sup>71</sup>

This man has spent many years in and out of the psychiatric system. He first received psychiatric treatment after attempting suicide and subsequently became increasingly disturbed and violent towards his family. While his parents recognised the need for their son to receive specialised inpatient care, they believed that his condition has deteriorated as a result of his experiences in psychiatric institutions.

The Inquiry heard allegations concerning inappropriate treatment by medical staff, with serious consequences which could have been avoided if steps had been taken to communicate effectively with patients and understand their disability. In one instance a nurse entered a ward and told the patients to get out of bed. One man, unable to hear, kept sleeping. The nurse interpreted this as disobedience and struck him.<sup>72</sup> This incident was not isolated. Evidence to the Inquiry indicated that hospital and medical staff frequently failed to consider the deaf man's disability in their interactions with him. Staff regularly talked to him even though they knew he was deaf and doctors did not explain the nature of the treatment and what was happening to him.<sup>73</sup>

As the evidence presented throughout this report indicates, the experience of mental illness is often terrifying and isolating. This is certainly the case for deaf people whose sensory isolation compounds the problem. While there is no excuse for the kind of behaviour described above, the Inquiry was told many mental health professionals are unaware of the particular needs of deaf people:

Ninety-nine percent of professionals, including mental health workers, are unaware of the differences between the deaf and the hearing. Their image of a deaf person is based on their contact with the post lingually deaf... who can comprehend English; can lipread, can communicate orally and do have [the same] cultures and norms as hearing people. [To them], a deaf person is no more than a hearing person with blocked ears. Significant cultural and language factors are regrettably not part of the diagnostic and intervention equations in mental health.<sup>74</sup>

There is no doubt that involvement of interpreters for the deaf and other communication strategies can make a major difference to the quality of care and the prospects of recovery or rehabilitation.

We believe many of these problems could have been alleviated had [our son] been given counselling by a psychiatrist or at least had an interpreter present to communicate for him. In spite [of our many representations] he has had no counselling, occupational therapy or an interpreter. Only once in the last six years has an interpreter been present at an interview between him and a doctor.<sup>75</sup>

Clearly, the effective treatment of mental illness depends on effective communication between clinicians and patients:

It is this very area of communication that causes so much anxiety and frustration for people who are deaf.<sup>76</sup>

Equally clearly, improved communication and consultation are essential if the rights of deaf Australians to appropriate services are to be ensured.

The issue is the provision of appropriate services that will enable the language and cultural differences of the deaf community to be taken into account when professionals are working with deaf clients who have a mental illness.<sup>77</sup>

## **Mental illness and HIV / AIDS**

Evidence presented to the Inquiry identified two general dimensions associated with mental illness and AIDS. First, serious mental illness can be precipitated or caused by infection with the Human Immunodeficiency Virus (HIV).<sup>78</sup> Second, people who have a pre-existing mental illness which impairs their judgement may be particularly vulnerable to HIV infection because they may be more likely to engage in high risk sexual or drug taking behaviour.<sup>79</sup>

Recent research in Australia and overseas has identified a number of affective and organic mental disorders associated with AIDS. When diagnosed with AIDS, many individuals experience 'adjustment' disorders, including depression, changes in self esteem and suicidal ideation. These forms of illness are generally treated in the same way as other affective and mood disorders — using anti-depressants if necessary, and individual and group therapy.<sup>80</sup>

The major organic disorder associated with AIDS is AIDS dementia complex (ADC). This 'complex' refers to a range of symptoms that can result from the later stages of the syndrome. These include progressive cognitive change and deficits in cognitive functioning, which are often accompanied by motor and behavioural disturbances.<sup>81</sup>

The NSW Health Department has estimated that in that State, 20 percent of people with ADC/AIDS have significant neuropsychiatric impairment which diminishes their ability to perform activities of daily living.<sup>82</sup> Dr Neil Buhrich, Coordinator of the Sydney Inner City Mental Health Service, presented several case studies of AIDS patients who had developed psychoses as a result of ADC, 'with symptoms indistinguishable from those observed in the functional psychoses'.<sup>83</sup> Individuals affected require psychiatric assessment and are sometimes prescribed psychotropic drugs to treat their psychotic symptoms.<sup>84</sup>

The Inquiry was also told that many people with a mental illness such as schizophrenia are at increased risk of developing AIDS:

In persons with schizophrenia, social skills and social judgement are seriously impaired. Sexual contact and needle use may be quite chaotic. Education concerning safe sex practices and drug usage may be ignored or not be properly understood. One of the problems here is that the progression from HIV infection to full AIDS takes many years... During that time, the patient may have many unprotected sexual contacts and many dirty needle exchanges.<sup>85</sup>

It is unclear how many people with mental illness are also infected with HIV, because no research has been undertaken in this area. However, the Inquiry heard evidence that between 1-5 percent of the inpatients at one major hospital's psychiatric clinic are, or are likely to be, HIV seropositive.<sup>86</sup> This figure is much higher than the incidence in the general population.

The evidence clearly indicated that people with a dual diagnosis of mental illness and AIDS can be difficult to care for because their psychiatric illness may impede their judgement, making them more likely to engage in risk taking behaviour.<sup>87</sup> The Inquiry was also told that it is extremely difficult to find appropriate placements for mentally ill people who have AIDS and engage in high risk behaviour which puts other members of the community at risk of contracting HIV. There are currently four options available for placing these patients, none of which is 'a good solution'. First, they can be admitted to hospital. Second, they can be charged and brought before a magistrate. Third, they can be placed in a hostel. Finally, as Dr Buhrich put it, '[the] option is to ignore the problem. But at what cost?'<sup>88</sup>

Each of these options is problematic. Many people with mental illness and AIDS may not need psychiatric care, but still require suitable accommodation in the community — an option which may put other residents in shared accommodation at risk because of erratic behaviour. Legal proceedings are also unlikely to benefit these individuals or achieve any change in their behaviour. Dr Buhrich suggested that one way of ensuring appropriate care and a stable environment for these clients is to provide special residential facilities with 24-hour medical and psychiatric care.<sup>89</sup> The Inquiry would also support the use of liaison-consultation psychiatry for people undergoing treatment in specialised facilities for AIDS or AIDS-related illness.

## Head Injury

The Inquiry also studied evidence concerning the incidence of mental illness among the many thousands of Australians affected by head injury. While there is little recent research in Australia, United States evidence suggests that up to

60 percent of head injured individuals subsequently suffer serious depression or other significant mental health problems or emotional disorders — often as a result of cognitive impairment or dysfunction.<sup>90</sup>

The Inquiry was told that while head injury is not confined to any particular group in the community, it is frequently young people who are affected:

[Head injury] is complicated by the onset of adolescence, resulting in frustration, anger, withdrawal and acting-out behaviours. For the young adult, just beginning to establish him/herself as an individual, head injury means becoming dependent on family members, loss of employment, loss of friendships/relationships, loss of skills, loss of income. It means boredom, frustration, anger, confusion...<sup>91</sup>

The confusion and frustration which often accompany head injury can result in emotional outbursts and violent behaviour towards family and friends. As the young person 'acts out' their frustration, family problems develop and the police sometimes become involved; this can aggravate the problem:

These [domestic] incidents are usually inappropriately labelled and the young person subjected to police and psychiatric intervention that only serve to exacerbate the situation and lock the person into a system that cannot offer appropriate assistance.<sup>92</sup>

Depression is also common after head injury. As individuals come to terms with the nature of the injury and its impact on their lives, they experience a profound sense of loss. In this context, anxiety and depression are understandable. However, research indicates that in some people this reaction develops into a depressive illness requiring treatment by a psychiatrist.<sup>93</sup>

The Inquiry was told that one of the major difficulties associated with treating head injury patients is the lack of appropriate services for supported accommodation, crisis intervention, ongoing support and behaviour management programs for individuals suffering behaviour disorders, and counselling for family and friends.<sup>94</sup>

## **Conclusion**

Clearly, Australians suffering dual or multiple disabilities are among the most vulnerable and disadvantaged in our community. It is a disgrace that for some of these groups there are pathetically few appropriate services available.

1. Professor Bruce Tonge, Faculty of Child Psychiatry, Royal Australian and New Zealand College of Psychiatrists. Oral evidence, Melbourne 9.4.91, p240.
2. Robert Ramjam, coordinator of planning, Schizophrenia Fellowship of New South Wales, Oral evidence, Sydney 19.6.91, p323.
3. Intellectual disability is often referred to as developmental disability. In using the term intellectual disability, the Inquiry has adopted the terminology used by most of its witnesses.
4. Tonge, op cit, p239. Professor Tonge told the Inquiry that 'Psychiatric disorder is significantly more common in the intellectually disabled. At least 30 percent of intellectually disabled persons have an emotional or behavioural problem of major severity.'
5. Dr Stewart Einfeld, New South Wales Branch, Royal Australian and New Zealand College of Psychiatrists. Oral evidence, Sydney 17.6.91, p122.
6. Tonge, op cit.
7. Intellectual Disability Services Council, South Australia. Submission, p2.
8. id.
9. Professor Brent Waters, child psychiatrist. Oral evidence, Sydney 17.6.91, p25.
10. Intellectual Disability Services Council, op cit.
11. id.
12. Dr S Rosenman, Director, Ward 15, Woden Valley Hospital. Oral evidence, Canberra 18.3.92, p102.
13. The Commonwealth-State Disability Services Agreement is a five year agreement between the State and Territory governments and the Commonwealth aimed at reforming the administration of services for people with disabilities by clarifying which level of government has responsibility for particular types of services. The Disability Support Program is discussed in detail in Chapter 9 — Community Care and Treatment.
14. Under the Agreement, State and Territory Governments are required to introduce legislation complementary to the Commonwealth *Disability Services Act 1986* before any transfer of responsibilities is effected. Victoria, Tasmania, the Australian Capital Territory, Queensland and Western Australia have passed complementary legislation. While they have not done so at the time of writing it is expected that New South Wales, South Australia and the Northern Territory will pass similar legislation in 1993.
15. The Disability Reform Package involved reforms to a number of areas of government policy and service provision, including the provision of social security benefits and employment assistance. The cornerstone of the Package is the restructuring of the financial benefit system for people with disabilities. One of the main features of the new disability support system is that to qualify, a person must have a physical, intellectual or psychiatric impairment of 20 percent or more and a continuing inability to work for the next two years in order to qualify for a disability support pension.  
As discussed elsewhere in this report, the Commonwealth Rehabilitation Service's funding of 1200 new placements nationally for vocational rehabilitation schemes is part of this reform strategy. The Inquiry was told that although these new places are a welcome initiative, considerable funding is needed to provide appropriate employment opportunities.
16. Einfeld, op cit, p119.
17. Mary Walsh, National President, Australian Parent Advocacy, Queensland. Submission p3.
18. Lyn Mason, Manager, MATARA. Oral evidence, Newcastle 9.7.91, pp797-798.



19. *ibid*, p797.
20. Tonge, *op cit*, p240.
21. *id*.
22. *id*.
23. Waters, *op cit*, p26.
24. Trish Quinn, community worker and psychiatric nurse. Oral evidence, Melbourne 10.4.91, pp482-483.
25. Intellectual Disability Services Council, *op cit*.
26. *id*.
27. Waters, *op cit*, p25.
28. Einfeld, *op cit*, p123.
29. Further evidence from Dr Einfeld indicated that the joint approach to service delivery was operational at the time of drafting this report.  
Einfeld, *op cit*, p119.
31. *id*.  
Information since made available to the Inquiry indicates that the University of Sydney has recently advertised a position of Senior Lecturer/Associate Professor of Developmental Disability in the Faculty of Medicine — a position which would involve teaching and research in mental health and intellectual disability.
32. Western Australian Council of Social Service (WACOSS), Discussion Paper on Dual Diagnosis, forwarded as part of Submission, p3.
33. Regier et al, *op cit*. The ECA study is also discussed by R G Pols, 'Psychiatric illness and substance abuse disorders: A case of neglect', paper presented at the World Federation for Mental Health, Pacific Regional Conference, Sydney 12-15 April 1992.
34. About 34 percent of the survey population reported that they suffered from a diagnosable psychiatric disorder. Of that 34 percent, nearly 14 percent of people reported having a non-alcoholic substance abuse problem.
35. Several expert articles, (see, for example, E C Penick, E J Nickel, et al, 'The Emerging Concept of Dual Diagnosis: An Overview and Implications', in O'Connell (ed), *Managing the Dually Diagnosed Patient: Current Issues and Clinical Approaches*, Haworth Press, New York 1990) including that by Pols, refer to the ECA study as a 'benchmark' for the prevalence of mental illness and substance abuse disorders.
36. Pols, *op cit*, p6.
37. WACOSS Discussion Paper, *op cit*, p4.
38. Dr John Hoult, Director, Clinical Psychiatry, Glebe Community Centre, Sydney. Oral evidence, Sydney 20.6.91, p411.
39. Thea Bates, Director VICSERV. Oral evidence, Melbourne 8.4.91, p147. Also see F McDermott and P Pyett, *Not Welcome Anywhere*, VICSERV, 1993.
40. L Butt, 'Dual Diagnosis', *Connexions* v12 No5, Sept/Oct 1992, p20.
41. Pols, *op cit*, p7.
42. WACOSS discussion paper, *op cit*, p5.
43. Butt, *op cit*, p23.
44. *id*.

45. WACOSS, op cit.
46. The link between affective and other mental disorders and substance abuse has been well documented. C Penick, E Nickel et al, 'The merging concept of dual diagnosis: An overview and implications', in *Managing the Dually Diagnosed Patient: Current Issues and Clinical Approaches*; and H Gregorius and T Smith, 'The adolescent chemical abuser: Special considerations in dual diagnosis', *Journal of Adolescent Chemical Dependency* v1 No4, 1991.
47. Dr Graham Martin, psychiatrist, Child and Adolescent Mental Health Services. Oral evidence, Adelaide 21.10.91, p53.
48. Gregorius and Smith, op cit, p82.
49. WACOSS Submission, p5.
50. Pols, op cit, p9.
51. Breakey et al, 'Health and mental health problems of homeless men and women in Baltimore', *Journal of the American Medical Association* v262 No10, Sept 1989.
52. Tony Nicholson, Chief Executive Officer, Hanover Welfare Services, Victoria. Submission, p2.
53. id.
54. id.
55. WACOSS, Discussion Paper, op cit, p1.
56. J W Flynn, Executive Director, The Victorian Deaf Society. Submission, p16.
57. id.
58. This figure is taken from a study by the Environmental Health Service in Adelaide, published in *The Australian Journal of Public Health* in December, 1992.
59. id.
60. R Hilsdon, Community Services Coordinator, Queensland Deaf Society. Submission, p2.
61. id.
62. Hilsdon, op cit, told the Inquiry that the preferred language for deaf communication is the Australian sign language, Auslan: 'Auslan is a visual, manual language. Its syntax and semantics differ vastly to that of English. It has no written form...as a communication tool it is as effective as English is when it's used by a native speaker. Most deaf people acquire fluency in Auslan only after leaving school, when they elect to participate in the deaf cultural community.' The Victorian Deaf Society also said the use of sign language is one of the defining characteristics of the deaf community. Sign language is crucial not only for communication between deaf people but also as a 'minority language' which 'is used as much as a mark of group membership' within the deaf community.
63. See Flynn, op cit and Hilsdon, op cit.
64. Dr A J Blackmore, cited in Flynn, op cit, p18.
65. Hilsdon, op cit, p3.
66. id.
67. id.
68. Hilsdon, op cit, p2. It was not stated whether the reference to *mental health professionals* related to private and public or outpatient/inpatient services.
69. Flynn, op cit, p4.

70. Dr A.J. Blackmore, cited in Flynn, op cit, p19.
71. Names withheld. Submission No 459, p1.
72. *ibid*, p5.
73. *ibid*, pp5-15.
74. Hilsdon, op cit, p2.
75. *ibid*, p12.
76. Anonymous Submission, Western Australia, p1.
77. Hilsdon, op cit, p3.
78. Dr Neil Buhrich, Clinical Director, Sydney Inner City Mental Health Service, Bill Davies, clinical nurse consultant and Susan Johnston, mental health coordinator. Joint Submission, p1.
79. *id*.
80. G Polk-Walker, 'Treatment of AIDS in a psychiatric setting', *Perspectives in Psychiatric Care* v25 No2, 1989, p10.
81. *id*.
82. NSW Health Department, *Planning for HIV/AIDS Care and Treatment Services in New South Wales 1990-1994*, prepared by the AIDS Bureau of NSW, September 1990, p8.
83. N Buhrich, D Cooper, and E Freed, 'HIV infection associated with symptoms indistinguishable from functional psychosis', *British Journal of Psychiatry* v152, 1988, p652.
84. *id*.
85. Buhrich, op cit, (submission), p1.
86. *id*.
87. *ibid*, p3.
88. *ibid*, p4.
89. This suggestion is consistent with recommendations made by the NSW Health Department, which noted: 'It is desirable for people with AIDS-related dementia and other neurological impairments to be managed in the least restrictive environment possible, taking into account the level of their impairment, available health and community resources and the need to ensure the safety of the individual.' NSW Department of Health, op cit, p8.
90. Eg G Prigatano 'Psychiatric aspects of head injury: Problem areas and suggested guidelines for research', in H S Levin, J Grafman and H Eisenberg (eds), *Neurobehavioural Recovery from Head Injury*, Oxford University Press, NY 1987, pp224-229; I Grant and W Alves, 'Psychiatric and psychosocial disturbances in head injury', in Levin et al, op cit, pp234-237; A H Van Zomeren and R J Saan, 'Psychological and social sequelae of severe head injury', in R Braakman ed, *Handbook of Clinical Neurology*, v13, Elsevier Science Publishers, 1990; P Storey, 'Some psychological and emotional problems after head injury', paper provided to the Inquiry by HEADWAY, the National Head Injuries Association, Nottingham, England.
91. Information obtained by the Inquiry from Margaret Santiago, Executive Director of the Head Injury Association of Victoria (HEADWAY).
92. *id*.
93. See Storey, op cit, p10.
94. Santiago, op cit.

## Chapter 22

### PEOPLE IN RURAL AND ISOLATED AREAS

The irony is that in many of the areas where the need is greatest the services are fewest. This is particularly the point in small country communities where mental health services — and certainly mental health services for children and adolescents — are almost entirely non-existent.<sup>1</sup>

More than 5 million Australians live outside our major urban centres and more than half of these live in small rural towns or remote areas.<sup>2</sup> These people have a number of special needs in relation to mental health. Isolation, social factors associated with small scale communities and the effects of recent, severe rural recession can all exacerbate mental health problems.<sup>3</sup> Psychiatric services, however, as the Inquiry heard from witnesses all over Australia, are even more inadequate than other health services in rural areas. There appears to be a particular tension between effective recognition of the needs and rights of rural Australians affected by mental illness and the pressures of economic rationalism.

#### Distribution of Services

One of the major difficulties confronting country people was put clearly to the Inquiry by a representative of the Country Women's Association:

Those who decide...mental health policies are city based administrators who make adverse comparisons between city and rural hospitals, trying to make rural admissions conform to those of city hospitals. When services in the country do not get utilised to the required level because there is not the general population to sustain them and the population is decreasing, it is immediately questioned whether those services are needed and they are sometimes withdrawn.<sup>4</sup>

In some States the reality of this perception was confirmed by witnesses representing the health administration:

The population of the region that I 'look after' is around about 17,000. It is very sparsely spread over approximately 65 percent of the area of South Australia [including Oodnadatta, Coober Pedy, Roxby Downs and Woomera]. This of course means that...the incidence of mental illness is extremely sparsely spread over that area. This in itself causes a major problem when people require a given service. It is simply regarded as uneconomic to provide specialist services to those areas.<sup>5</sup>

We are particularly poorly serviced in the country. A model that locks up resources in the hospitals means, because of economies of scale, in a place like South Australia where there

are no cities of more than 30,000 outside of Adelaide, that [country people] are particularly disadvantaged...because none of them have the economies of scale even to have an inpatient unit.<sup>6</sup>

'Regionalisation' of health administration has been implemented in most States and Territories. In theory, this policy promotes consideration of localised factors and places services in closer contact with communities. In practice, however, the policy often becomes the vehicle or rationale for excessive 'economies of scale' — so that services are less likely to be provided, particularly in sub-specialty areas. The Inquiry repeatedly heard of the acute shortage or complete absence of services such as child or adolescent psychiatry,<sup>7</sup> multicultural mental health<sup>8</sup> and forensic psychiatry.<sup>9</sup>

The contrast between rural and metropolitan mental health services was illustrated in a submission from the Queensland Country Psychiatrists' Association, comparing the actual staffing and resources at Toowoomba General Hospital (serving a population of 234,000) with recommendations made by the Royal Australian and New Zealand College of Psychiatrists:<sup>10</sup>

It is considered appropriate that the General Hospital be staffed with:

- five full-time psychiatrists — in the present service there is one;
- six visiting psychiatrists — at present there are two;
- ten full-time registrars — at present there is one;
- five full-time residents — at present there is one;
- five psychologists — at present there is one;
- five psychologists — at present there is one;
- three occupational therapists — at present there is one;
- five social workers — at present there are none.

The recommendation is for 80 beds. Space has been provided for 24 but the financial constraints only permit the staff allocations sufficient to provide 15 bed places. The nursing and organisational limitations are comparable. The unit itself, although better than the one it replaces, is far below the standard of that provided in metropolitan areas.<sup>11</sup>

Similarly, a NSW witness described the sparse distribution of psychiatrists in major country health regions of our Premier State:

In the Central West Health Region there are approximately three full-time equivalent psychiatrists in the public health system and less than one full-time equivalent in private practice. In Orana Region [north-west] there is one psychiatrist in private practice. In the Far West I believe there is one at Broken Hill. I also contacted South West New England and South Eastern Regions, each of which have about four psychiatrists, some in private practice and some in the general health system. Needless to say, most of these are based in the major cities and services in the more remote areas are generally conducted by psychiatric nurses who are embattled.<sup>12</sup>

Outside the capital cities and a few regional centres in our three most populous States (NSW, Victoria and Queensland), services are limited to local hospitals, general practitioners and periodic visits (often monthly or less frequently) from mental health professionals. In most cases these hospitals have no dedicated beds for country people affected by mental illness and no psychiatrists or nurses with psychiatric training. The general practitioners, who seldom have much expertise in mental health, service much larger and more dispersed populations than general practitioners in the city.<sup>13</sup>

The undesirable effects of this pattern of 'service delivery' were repeatedly drawn to the Inquiry's attention. Typical of the problems identified were those at one large regional centre in South Australia:

There is no resident psychiatrist in Whyalla. Services are provided by four visiting psychiatrists who come on a monthly basis... Mentally ill patients have to wait several months to see a psychiatrist... There are incidents of clients being admitted to hospital in an attempt to obtain psychiatric services as visiting psychiatrists will try to see inpatients if their load permits. These attempts to access services mean that hospital beds can be occupied unnecessarily and at enormous expense to the hospital.<sup>14</sup>

The Inquiry also heard that there is a serious lack of non-government rehabilitation and support services outside the metropolitan and provincial cities. (This issue is addressed in Chapter 5 — Mental Health Services.)

### **Inpatient Treatment**

Few local hospitals serving rural areas have the resources to deal with people in acute phases of mental illness. Admission to a local hospital may nevertheless sometimes be preferred to the limited alternatives. One rural community health worker summarised the advantages and disadvantages of local hospital admission as follows:

It doesn't have the stigmatisation of someone being admitted to a psychiatric hospital and, in some cases, it can be quite beneficial. But sometimes the hospital environment isn't suitable for someone who's not physically ill but rather depressed or agitated. For example, we don't have a secure area and staff are unable to spend the many hours demanded by someone who's anxious and depressed.<sup>15</sup>

However, the inappropriateness of admitting people with mental illnesses to local hospitals, and the absence of facilities for such patients, was emphasised by witnesses in all States and the Northern Territory.

- At Albany Hospital, there are no currently qualified nursing staff dedicated to nursing the psychiatrically ill. This creates difficulty for the young inexperienced general trained nurse who may be anxious or even afraid in the presence of a behaviourally disturbed

patient, or a patient who is at risk of self harm. The patient may be disadvantaged by lack of special psychiatric nursing skills.<sup>16</sup>

- There is no major country facility in the mid north of this State [South Australia] that can adequately hospitalise a mentally ill person. Local hospitals are forced to admit a patient with a mental problem, are not equipped to handle these problems, and staff are not trained to care for such people. Because of ignorance, the patient becomes the brunt of jokes, is treated with derision and often victimised, a situation that would not be tolerated had the patient had a socially acceptable illness.<sup>17</sup>

- The type of care and attention we get after hours [in the Alice Springs Hospital] is very much dependent on individual doctors. Some doctors have had experience in psychiatric wards in other hospitals in the country and are quite keen to respond to a crisis... Others clearly have had no experience, and were not aware that there was an expectation that they would provide services to us — which means we fluctuate from having a more or less immediate response from a medical officer to no response whatsoever for many hours.<sup>18</sup>

Admission of individuals affected by mental illness to local hospitals not only creates immediate problems for patients and staff but also carries the risk of fostering prejudice in small local communities. A representative of GROW in South Australia depicted the problem from the consumer's perspective:

It has been disconcerting at times when GROWers have been put into the local hospital and they have had to go into the geriatric ward and that's a bit hard for them...because when they're in a manic episode... They're too disturbing in the ordinary ward... I think there's more stigma with them being put into ordinary hospitals, in a small town...because if they do go off or cause a disturbance... People never forget that in a little town. It's really hard to live it down.<sup>19</sup>

Sometimes, the shortage of appropriate facilities means that a person in an acute phase of mental illness is detained in the local jail or police cells. Evidence that this occurs as a regular practice in parts of rural Queensland was given to the Inquiry by several witnesses.<sup>20</sup>

The other option for treating those with acute conditions is hospitalisation in the city. This has many disadvantages. Forcible removal and transportation to the city, often over long distances, are likely to be traumatic and stigmatising — particularly where this is done by the police, as is frequently the case in several States.<sup>21</sup>

If a person had a compound fracture in one of our outback centres they would be evacuated by a retrieval team. A team of experts would come up from a metropolitan area in a safe, comfortable aircraft; they would be stabilised and put into a safe condition before they were transported and then they would be transported under the care of professionals. It does seem somewhat unjust that because you happen to have a mental illness rather than a physical illness you are treated to a ride in the paddy wagon rather than being stabilised and given the care of a professional.<sup>22</sup>

The stigma never goes away when someone is taken off in the back of a police paddy wagon in this way.<sup>23</sup>

Often no provision is made for the return journey — as illustrated by a case cited by the Medical Superintendent of Bloomfield Hospital in Orange:

The Ambulance [service]...limit their responsibility to getting them here. So that we have recently had the distressing experience of a 15 year old Aboriginal boy coming from Brewarrina, left by the ambulance, discharged the next morning to find his way back to Brewarrina.<sup>24</sup>

For a person from a rural or remote community, admission to a facility in the city means isolation from family, friends and other support networks.<sup>25</sup> This may be devastating at a time when the individual is particularly vulnerable. Many witnesses referred to difficulties experienced by relatives and friends visiting those admitted to hospitals that are many hours drive from the patients' homes.

To drop everything and drive four hours, find accommodation and then to return home can be out of the question for some people.<sup>26</sup>

Depending on circumstances, there is sometimes also an element of 'culture shock' for rural patients transported to an alien urban environment.<sup>27</sup> This dislocation has significant costs in both human and economic terms.<sup>28</sup> Nevertheless, if a patient requires involuntary treatment, the mental health legislation in every jurisdiction limits the availability of such treatment to specifically designated facilities that have been approved for this purpose — and these exist only in a very small number of centres, particularly in Western Australia, South Australia and the Northern Territory.

However, once a person is discharged from hospital there are further difficulties associated with obtaining appropriate follow-up treatment and support on their return home. The initial problems were summarised by one witness:

Are they going to have continuity of care at some metropolitan hospital or where? There is limited information coming from the metropolitan area to the country, to GPs, mental health nurses and families of the patient re management plans, medications and after-care.<sup>29</sup>

In South Australia, patients returning to the country from inpatient units in Adelaide, unlike those in the city, are not able to receive free of charge the regular maintenance medication they require to remain in the community.<sup>30</sup> They do not even have access to the hospital by way of a toll free telephone number.<sup>31</sup> The Coordinator of the Port Augusta Mental Health Service told the



Inquiry that there was no system for regular blood testing of clients on Lithium or Modecate.<sup>32</sup> The same witness also drew attention to the lack of day care or drop-in centres and the absence of supported accommodation.<sup>33</sup>

These specific examples were indicative of widespread inadequacies in aftercare services in rural areas. The point was conceded, in general terms, by the Queensland Government in its submission to the Inquiry:

Difficulties are experienced in providing adequate follow-up when people return to their home communities.<sup>34</sup>

A recent report by the Health Department of Western Australia also emphasised these problems and conceded the need for change at both legislative and practical levels.<sup>35</sup>

The recent concerns about the quality of care at Wilson's Patch<sup>36</sup> raise the question of the adequacy of supervision for all patients on aftercare within the provisions of the current *Mental Health Act*... In recognition of the different arrangements required by people on aftercare, measures need to be implemented to ensure that roles and responsibilities are understood and accepted by all persons involved in the care of these patients. In addition, supervision arrangements with a nominated medical practitioner must be formalised before discharge and remain in place throughout the period of aftercare.<sup>37</sup>

As is apparent from the evidence concerning the distribution of services in rural and remote areas, appropriate supervision by a medical practitioner can be extremely difficult to arrange in the country. In many cases, aftercare and follow up, like primary services, rely on visiting services — which are, at best, sporadic.

### Visiting Services

In all States the Inquiry heard evidence concerning the outreach services to many rural areas conducted from hospital or community based services in major population centres. At best, these may involve multi-disciplinary teams with psychiatrists (including sub-specialists such as child or adolescent psychiatrists and psychogeriatricians), psychologists, mental health nurses and social workers.<sup>38</sup> However, such a range of expertise is available in very few places — and never at the same time or full-time. Team members visit country locations on a rotational basis (if at all), according to the availability of resources. A large number of towns in rural areas receive no services of this nature at all.<sup>39</sup> Services in South Australian regional cities and towns again typified the problems.

Of the four psychiatrists servicing Whyalla, one is in town for only half a day per month and works primarily, although not exclusively, as a psychogeriatrician. Of the remaining three, one offers two days per month and the others one day per month.<sup>40</sup>

While the situation varies from town to town, the basic problems are the same. In Port Pirie:

We have two psychiatrists who visit one day each, once a month. We have no psychologist. There is a long waiting list to see the psychiatrist. The psychiatrist is usually exhausted and doesn't finish until sometimes 10pm in an attempt to fit all patients in. Needless to say, psychiatrists do not extend their visiting rights when their time is up. There is no family counselling, there is no one to do it.<sup>41</sup>

In these circumstances sick individuals may have to wait several months before they are able to see a psychiatrist.<sup>42</sup> Cancellation of visits not only extends these delays<sup>43</sup> but may jeopardise the therapeutic relationship or lead to the failure of a referral.<sup>44</sup>

Lack of continuity in the relationship of care-giver to client and the sporadic nature inherent in visiting services are also significant in terms of the need for mental health workers to have — and to be accepted as having — an understanding of the lifestyle and environment of their rural clients.<sup>45</sup> Awareness of and sensitivity to local values and concerns are important in the development of trust, particularly with clients in the mental health field. The feelings of one resident of a remote area in the Northern Territory about health workers from the city were expressed succinctly:

Do not send me any more glib, smart talking young health workers.<sup>46</sup>

These problems are not insurmountable. The issues have been addressed by those responsible for the operation of one successful outreach program, the NSW Far West Mental Health Team. This Team, based in Broken Hill, services a population of approximately 33,000 (spread over a region of 150,000 square kilometres) by car and with the help of the Royal Flying Doctor Service.

We have certainly found that integrating members of the mental health team into local communities increases the likelihood of their being contacted for assistance. We therefore have a firm practice and belief in individual team members taking responsibility for particular isolated communities in which, over time, they become well known and accepted. It takes a considerable amount of time and energy to build trust in isolated communities: all our primary therapists who visit the outlying towns in our region, routinely spend time at both the local hospital and school, to help support and listen to the nurses and teachers who bear the brunt of the psychosocial problems in the community.<sup>47</sup>

However, in terms of the evidence presented to the Inquiry this program is exceptional — if not unique.

## **Strains on Health Professionals**

At times we ply a fine line between exhaustion and unpopularity, and it's very difficult.<sup>48</sup>

The demands on services in country areas far exceed supply — with the result that recruitment to such positions is notoriously difficult, vacancies remain unfilled for long periods and the strain on the small number of mental health professionals is enormous.<sup>49</sup>

Evidence to the Inquiry from the Royal Australian and New Zealand College of Psychiatrists emphasised that this problem is compounded by the effects of isolation itself.

Working in remote areas entails being professionally isolated, with greater demands placed on psychiatrists and lack of access to appropriate support services. Hence practising in remote areas is unattractive to psychiatrists and results in these areas being under-serviced.<sup>50</sup>

This isolation may take various forms. A psychiatrist practising at a regional hospital is most unlikely to have the support of a registrar or relief by way of a locum.<sup>51</sup> In the more remote areas, there may be a complete lack of contact with professional colleagues and information networks for extended periods. The most extreme example of this brought to the Inquiry's attention was a psychiatrist providing an outreach service in the Kimberley region of Western Australia from Derby Regional Hospital. He described his position as follows:

To my knowledge, I am the most isolated psychiatrist in the world... When I arrived in 1987, I arranged to be on the circulating list for several journals, the first of which arrived in June 1989. It was accompanied by a letter saying that due to high costs, journals would no longer be circulated... Once or twice a year I can attend a conference somewhere but these trips are very expensive.<sup>52</sup>

A subtler form of isolation can sometimes occur with regionalisation, a point illustrated by another Western Australian witness:

Workers are [potentially placed] in very isolated positions in regionalised services which neither appreciate nor understand some of the issues associated with mental illness... We have a social worker in a region in WA who made a complaint, as she should have, about treatment that was being given to a person who was mentally ill... She took it up with the director of the service unit who told her to keep quiet. She brought it to the Ethics Committee of the AASW who said 'you have no right to keep it quiet...' It was then taken

to the administrator in the region whose preference was for the social worker not to stir the pot — there were enough troubles in the region as it was. Now her statement to me, and I am on the Ethics Committee of the AASW, was 'What the hell am I to do? I want my job but I also value the [client's] rights and I want to see these policies in place.' She ended up with spiders being put through her front door by other workers in the unit.<sup>53</sup>

Evidence from other witnesses indicated that the problems of professional isolation could be alleviated by networking among professionals. In the area serviced by outreach workers from Whyalla, South Australia, the Inquiry was told:

Basically there is no networking at all...even amongst professionals. We feel that [networking] should be encouraged so that the professional working in these areas would not feel too isolated or uncared for by their colleagues working in the suburban areas. And through networking we feel they will be able to access professional help and advice... Now, of course, there are attempts being made in this area but the cost factors and distances required to travel make professional networking quite difficult to establish.<sup>54</sup>

However, a more optimistic picture was given in areas where professional networking did occur. For example, in Kalgoorlie, as a result of visits by specialists from Perth:

I think those of us who go to the country, just from the process of referrals, build up a sort of network of general practitioners that we get on well with and who know us... I find that GPs will ring me up just to chat about something and ask whether a referral is warranted or not... But there is not actually a formal structure...and of course there are a number of large country areas which do not have that resource.<sup>55</sup>

## **Strains on Consumers and Families**

Factors such as inadequate services for acute treatment, follow-up or respite, distance from services and transport problems compound the pressures which are increasingly a part of rural life. Small scale communities are less likely to generate self help groups or other consumer or carer networks because of the relatively small number of people involved, concerns about confidentiality,<sup>56</sup> and because of financial and geographic limitations.<sup>57</sup> Many witnesses pointed to the effects of the rural recession<sup>58</sup> which has both reduced household incomes and further eroded limited employment opportunities, increasing existing strains and exacerbating stresses. Many country witnesses referred to a particular lack of understanding of mental illness in rural areas, lack of information about services, and need for education about mental health issues.<sup>59</sup> These factors add to the strains on country consumers and their families or other carers.

One of the most serious and prevalent problems in country areas is that the combination of lack of awareness on the part of carers and professionals or para-professionals, combined with the difficulties in accessing services, means that mental illness often goes untreated until it reaches the acute stage. As a psychiatrist in northern Queensland pointed out:

Usually the people out there have little or no experience in the treatment of mental illness and they are often battling quite hard to deal with this situation adequately. Often times the person has to be ill enough to be regulatable [ie fit to be detained] before they can be brought into the hospital and adequately assessed and treatment started.<sup>60</sup>

## **Pressures on Young People**

In the context of such disadvantage and deprivation, the disturbingly high rate of suicide in rural areas is, perhaps, not surprising.<sup>61</sup> But the extent of this phenomenon is alarming — and it must be addressed. (The increased rates and possible causes of youth suicide in country areas are dealt with in more detail in Chapter 20 — Children and Adolescents.)

The point that must be noted in this chapter is the evidence that adolescent males in larger country towns appear to be at substantially greater risk than those in our cities. Even more alarming is the fact that the suicide rate of young males in small country communities has increased by 600 percent in the space of one generation.<sup>62</sup>

## **Possible Solutions**

Despite the enormity of the problems in rural areas, it is clear there are a number of possible solutions. At one level these involve incentives to general practitioners, psychiatric registrars, psychiatrists, psychiatric nurses and other mental health professionals to encourage them to practise or to continue practising in the country.<sup>63</sup> As discussed in Chapter 5, the critical need for rehabilitation and support services also suggests that initiatives should be taken to encourage the establishment of non-government services for rural and isolated communities.

There is also a model for provision of mental health services by one psychiatrist and several nurses trained in community psychiatry, acting in consultation with a network of other community nurses, GPs, schools, police and others. The founding psychiatrist of the Psychiatric Emergency Team (PET) in Perth outlined the possibility of adapting this concept to rural areas.

The Psychiatric Emergency Team was a community nursing service with psychiatric backup. My nurses...decided when a psychiatrist was needed. I or other psychiatrists would go in and do what we had to and then get out and the nurses would continue to manage the case which was quite revolutionary and quite threatening to senior members of my profession...that nurses should run a service...

For the country regions one does not have to have psychiatrists in every region. I had a model in mind of community psychiatric nurses being trained by a minimum of six months placement with the PET and then to be placed as community nurse in each of the country regions... As one nurse covering a huge area she could not possibly attend to every patient's concerns but what she could do is make herself a valuable resource person who works with all other people involved in health care...other community nurses...local GPs, families, schools. So if someone were to become mentally ill she could make an assessment, get information over the phone perhaps from relatives and others involved, liaise with police, justices of the peace, the local country doctor to put in place referral, if indicated, to hospital.<sup>64</sup>

For our most remote regions, there are also responses using recent advances in science and technology which could be used to offset the shortage of services. Some of these involve the use of 'Tele-medicine' or two-way interactive computers that allow client assessment and consultation from remote locations. This technique has been found to have features making it particularly applicable for psychiatric use<sup>65</sup> and the Queensland Health Department has already pioneered a network of facilities in remote areas linked with major urban hospitals through Aussat.<sup>66</sup> While this will clearly not replace face-to-face interaction entirely, it does provide another significant mechanism to address the widespread disadvantages of rural isolation.

Whatever programs or practices are implemented, however, it is clear that the basic rights of rural Australians necessitate urgent action by governments — including initiatives in resource allocation which acknowledge the extent of increased vulnerability and disadvantage in many rural areas.

1. Prof Brent Waters, Professor of Child and Adolescent Psychiatry, University of NSW. Oral evidence, Sydney 17.6.91, p22.
2. From statistics compiled in 1990 by the Department of Community Services and Health, quoted in Appendix 1 of National Health Strategy Background Paper No11: *Improving Australia's Rural Health and Aged Care Services*, Sept 1992.
3. Evidence of the effects of such factors was given to the Inquiry by a number of witnesses, including Dr Michael Dudley, psychiatrist, Avoca Clinic, Prince of Wales Hospital. Oral evidence, Sydney 18.6.91, p198; and M Brewster, GROW. Oral evidence, Port Lincoln 18.10.91, p31. Also see A Fahey, 'Just Like Us', Report of a consultation on psychiatric services in rural areas to the Lodden District Health Council, March 1991, given to the Inquiry by David Pugh, Coordinator, Community Support Scheme, Bendigo; and P Yellowlees, 'Rural mental health', *Medical Journal of Australia*, v157, Aug 1992, pp152-153.
4. Elva Hansen, Country Women's Association. Oral evidence, Perth 11.2.92, p242.
5. Lindsay Cheers, Director, Outback Services, Port Augusta Hospital. Oral evidence, Adelaide 23.10.91, p345.
6. David Meldrum, Acting Chief Executive Officer, South Australian Mental Health Service. Oral evidence, Adelaide 21.10.91, p80.
7. Cheers, op cit, p345; Patricia Mead, Southern Child and Adolescent Mental Health Service. Oral evidence, Adelaide 21.10.91, p30; Dr J Dingle, Assistant Director, Department of Psychiatry, Princess Margaret Hospital for Children and Secretary, Faculty of Child Psychiatry, RANZCP. Oral evidence, Perth 10.2.92, p21; Prof Bruce Tonge, Centre for Developmental Psychiatry, Monash University. Oral evidence, Melbourne 9.4.91, p244; Dr Ian Shochet, clinical psychologist, Australian Psychological Society. Oral evidence, Orange 12.7.91, p944.
8. Mead, op cit, p31. Also Marie Gibson, Coordinator, Migrant Resource Centre. Oral evidence, Townsville 12.8.91, p1137.
9. Vince O'Donnell, Roma and District Community Support Association, Queensland. Submission, p1.
10. The recommendations originated with the Queensland Branch of the Royal Australian and New Zealand College of Psychiatrists.
11. Dr Fabian Bryant, Chairman, Queensland Country Psychiatrists' Association. Submission, p1.
12. Norman Rowlands, clinical psychologist. Oral evidence, Orange 12.7.91, p945.
13. National Health Strategy Background Paper No11, op cit, Table 2, p19.
14. Siva Pearce and others, South Australia. Submission, p18.
15. Ruth Kinslow, social worker, Central Clinic, Port Augusta. Oral evidence, Adelaide 18.10.91, p108.
16. Dr J A Lister, psychiatrist, Western Australia. Submission, p2.
17. Judith Sherry, South Australia. Submission, p2.
18. Sue Jefford, Director of Psychiatric Nursing, Mental Health Services, Alice Springs. Oral evidence, Alice Springs 23.7.92, p221.
19. Brewster, op cit, p31.
20. See for example V O'Donnell, Roma and District Community Support Association, Queensland. Submission, p2. P O'Brien, Brisbane Psychiatric Social Workers Group, Queensland. Submission, p2.

21. See for example Brewster, op cit, p31; Pearce, op cit, p14; M Parsons, community mental health nurse, Colbrook House. Oral evidence, Port Lincoln 18.10.91, p42; M E Kilpatrick, Queensland. Submission, p1; D Wright, Central Clinic, Port Augusta, South Australia. Submission, p1; Sister Trainer, chaplain, Bloomfield Hospital. Oral evidence, Orange 12.7.91, p935.
22. Cheers, op cit, p358.
23. Sherry, op cit, p4.
24. Dr John Hoskin, medical superintendent, Bloomfield Hospital. Oral evidence, Orange 12.7.91, p887.
25. J Ross, consumer. Oral evidence, Melbourne 10.4.91, p445. O'Donnell, op cit, p1.
26. O'Donnell, op cit, p1. Also see Queensland Government, submission, p38; Joyce Lawrence, carer, Queensland. Submission, p1; Private hearing, carer. Oral evidence, Newcastle 9.7.91, p776.
27. Indeed, the Inquiry was told that for this reason, as well as the great difference in distances (45 minutes by plane, compared to more than three and a half hours by road), it would be preferable to transfer patients from the remote Kimberley region to Darwin rather than to Perth — but this was not possible because of the need to abide by State boundaries. Christine O'Farrell, Regional Director, Kimberley Health Region, Western Australia. Submission, p2.
28. id. Also see O'Brien, op cit, p2.
29. Sherry, op cit, p3.
30. Kinslow, op cit, pp107-108. Parsons, op cit, p67.
31. Sherry, op cit, pp1-2.
32. Wright, op cit, p1.
33. id.
34. Queensland Government, op cit, p38.
35. WA Department of Health, *Report to the Minister for Health into Investigation of Allegations Concerning Aboriginal People Discharged from Graylands to Wilson's Patch*, Dec 1992.
36. These concerns, reported in the media in December 1992, related to the appropriateness of care provided to four former patients of Graylands Hospital at a private property in a bush setting. See Chapter 23 — Aboriginal and Torres Strait Islander People.
37. id.
38. For example, outreach services from the Central Clinic, a community mental health service based at Port Augusta Hospital: Kinslow, op cit, pp101-103.
39. id. Also Queensland Government, op cit, p38.
40. Pearce, op cit, p18.
41. Sherry, op cit, p4.
42. id.
43. O'Donnell, op cit, p1.
44. Cheers, op cit, p354.
45. Hoskins, op cit, p889.
46. Quoted in D Clarke, *A Study of the Health and Welfare Needs of Women Living in Remote Areas of the Northern Territory*, NT Women's Advisory Council, Aug 1991, p32.



47. Yellowlees, 'Rural mental health', *op cit*, p153.
48. Kinslow, *op cit*, p104.
49. Sherry, *op cit*, p4. Also see Bryant, *op cit*, pp5-6; Caust, *op cit*, p16.
50. Dr Barrie Kenny, Honorary Secretary, RANZCP, Victoria. Submission, p8.
51. Bryant, *op cit*, pp3-6; Dr C Alroe, psychiatrist. Oral evidence, Brisbane 15.8.91, p1642.
52. Dr N McLaren, part of submission from RANZCP, WA Branch, p1.
53. Maria Harries, President, WA Branch, Australian Association of Social Workers. Oral evidence, Perth 11.2.92, p263.
54. Parsons, *op cit*, p48.
55. Dingle, *op cit*, p29.
56. Hansen, *op cit*, pp243-4; Fahey, *op cit*, pp32-3. These and other witnesses stressed the negative consequences of being labelled 'mentally unstable' in a small community.
57. Pearce, *op cit*, p14.
58. Dudley, *op cit*, p198; Mead, *op cit*, p31; Pearce, *op cit*, pp6-9.
59. Wright, *op cit*, p1; Sherry, *op cit*, p1; Ross, *op cit*, p445.
60. Dr James Woolridge, consultant psychiatrist, Cairns Community Health Services. Oral evidence, Cairns 9.8.91, p1044.
61. Mead, *op cit*, p31; Dudley, *op cit*, pp197-198; B Melvin, Director, Mental Health Services, Orana and Far West Region. Oral evidence, Orange 12.7.91, p910.
62. Waters, *op cit*, p27.
63. Bryant, *op cit*, pp5-6. Kenny, *op cit*, pp8-9. National Health Strategy Background Paper, *op cit*, p24.
64. Dr Malcolm Roberts, psychiatrist. Oral evidence, Perth 12.2.92, p334.
65. Jane Preston, 'Using telemedicine to improve health care in distant areas', *Hospital and Community Psychiatry* v43 No1, 1992, pp5,25-27.
66. David Watson, 'Telemedicine', *Medical Journal of Australia* v151, July 1989, pp62-68.

## Chapter 23

# ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE

## Introduction

Mental health services are designed and controlled by the dominant society. The health system does not recognise or adapt programs to Aboriginal beliefs and law, causing a huge gap between service provider and user. As a result, mental distress in the Aboriginal community goes unnoticed, undiagnosed and untreated.<sup>1</sup>

The Inquiry received evidence from Aboriginal and Torres Strait Islander people from urban, rural and remote communities throughout Australia. Aboriginal witnesses emphasised that mental illness among Australia's indigenous people cannot be understood in the same terms as mental illness among non-Aboriginal Australians, because of their unique culture and their experience as a dispossessed people. A complex range of social and cultural issues were presented to the Inquiry which were not directly related to mental illness. However, the Inquiry recognises the complexity and breadth of issues which contribute to the psychological wellbeing and mental ill-health of Aboriginal people and their significance in the development of culturally appropriate and effective treatment models and programs. In this context, the evidence discussed in this chapter reflects the needs and issues identified by Aboriginal people as being significant.

## The Historical Experience

The underlying causes of the physical and emotional ill-health prevalent in Aboriginal communities lie in the continuing social, political and economic disadvantage that Aboriginal people experience.<sup>2</sup>

Traditional Aboriginal societies were not homogeneous. Prior to white settlement the diversity of the physical environment led to the development of a variety of indigenous cultures and societies throughout the Australian continent. In traditional societies, Aboriginal people were totally dependent on the land. As a result, complex social systems evolved in which the land and the people were not only physically, but spiritually linked.

The dominant non-Aboriginal cultures have very little understanding of Aboriginal culture as a rich and enduring culture which extends back over 40,000 years to the beginning of time. Aboriginal culture and society have their origin in the dreaming, when the Ancestral

Beings created Aboriginal people and the earth simultaneously, breathing life and shape into the land, its life forms and the cyclic processes of nature... Aboriginal culture has been perpetuated by the Elders who have passed on the knowledge through stories, dance, song, rules for living, ceremonies and paintings [which] ensure the spiritual bond between the land, the Ancestral Beings, spirits and Aboriginal people in the cycle of life... Aboriginal culture still combines beliefs and law in relation to spiritual obligations, rituals and customs, men's and women's business, family obligations, kinship rules, various taboos and communication.<sup>3</sup>

These traditional customs and life cycles were irrevocably affected by colonisation. As white settlement spread, Aboriginal people were forcibly removed from their traditional lands and their families. The Central Australian Aboriginal Congress told the Inquiry that for Aboriginal people, colonisation left a legacy of grief and loss that is still profoundly felt today:

Our people were forced from their country, and into mission or government settlements. This loss involved economic, spiritual, and cultural disruption. There were massacres of our people as recently as the 1930s. Forced settlement came with handouts of food — white flour, sugar and tea. We were denied access to our natural sources of food. Then a policy of assimilation was imposed on us and our children were taken away and families split up.<sup>4</sup>

Every Aboriginal witness discussed the long-term psychological effects that colonisation has had on Aboriginal people since 1788. As one witness said, 'the pain and bitterness of these memories are passed on from generation to generation and results in feelings of hate, anger, frustration, grief, depression and alienation'.<sup>5</sup> These memories are reinforced by the continuing economic and social disadvantage experienced by Aboriginal people.

For Aboriginal people, contact with European culture has been characterised by the denial of access to public facilities, to adequate housing, to education, to economic power or the resources needed to play a meaningful role in the new culture.<sup>6</sup>

The Inquiry was told the denial of Aboriginal peoples' human rights has had a profound effect — not only on the mental health of individuals, but on the collective psyche of Aboriginal communities.

The underlying causes of Aboriginal mental ill health flow from generations of cultural genocide, a dislocation and destruction of Aboriginal cultural ways of survival and a denial of the right to self-determination. This has its psychological [consequences]... Aboriginal people are subjected to blatant and subtle racism, and inevitably this racism is internalised and people feel bad about themselves and each other...<sup>7</sup>

## Cross-Cultural Perspectives on Mental Illness

Evidence from Aboriginal people and non-Aboriginal psychiatrists indicated a lack of knowledge and appreciation of Aboriginal society and culture by mental health professionals. Aboriginal witnesses expressed concern that the definitions of mental health which have been applied to Aboriginal people are ethnocentric and perpetuate stereotypes of Aborigines as deviant, rather than providing ways of understanding mental health from an Aboriginal point of view.

An Aboriginal [perception] of mental health is holistic, there is no need to compartmentalise... Aboriginal mental health should not be viewed from a medical model of abnormality.<sup>8</sup>

This is in direct contrast to the western psychiatric tradition which conceives the mind and its illnesses as generally distinct from those of the body or the spirit. Aboriginal culture sees the health of the mind, the body and the spirit as inextricably linked. In some traditional societies:

The word most commonly applied to the 'behaviourally disturbed' is translated both as madness and deafness... The seat of reason is affected... Individuals with disturbed behaviour are often seen as not responsible for their actions. This perception of disturbed behaviour also implies a certain acceptance and lack of moral judgement about the actions of a 'mad' person.<sup>9</sup>

Western psychiatry's emphasis on symptomatology often fails to appreciate the cultural and sociological framework in which the symptoms and the diagnosis take place. This is an issue of major concern to Aborigines, who perceive non-Aboriginal diagnostic techniques as simplistic and frequently inaccurate in defining their experiences.<sup>10</sup>

Aboriginal people view mental health in a very different way to non-Aboriginal people. Their traditional ways of dealing with mental illness would appear not to compartmentalise it to the same extent as modern western psychiatry.<sup>11</sup>

For Aboriginal people, traditional concepts concerning the meaning of 'illness' and 'health' are quite unlike western ones. Health is not a purely physical state, it is related to the wellbeing and harmony of groups of people with their spiritual and physical universe. For Aboriginal people, perceptions of health were, and continue to be, closely related to quality of life.

In Aboriginal society there was no word, term or expression for 'health' as it is understood in Western society. It would be difficult from the Aboriginal perception to conceptualise 'health' as one aspect of life. The word as it is used in Western society almost defies translation but the nearest translation in an Aboriginal context would probably be a term such as 'life is health is life'.

Health to Aboriginal peoples is a matter of determining all aspects of their life, including control over their physical environment, of dignity, of community self esteem, and of justice. It is not merely a matter of the provision of doctors, hospitals, medicines or the absence of disease and incapacity.<sup>12</sup>

## **Prevalence of Mental Illness**

The Inquiry was informed that 'hard data on the incidence of mental ill health within Aboriginal communities is scarce'.<sup>13</sup> This makes any accurate estimation of psychiatric morbidity rates and the occurrence of specific psychiatric diseases extremely difficult.

There [is no] adequate or comprehensive epidemiological survey of Aboriginal psychiatric morbidity in Australia. There has never been such a survey. Even if one looked at what information is available, for example in institutional catchments, [and] Aboriginal versus non-Aboriginal psychiatric morbidity with respect to hospital inpatients, it tells you very little because the whole question of how Aboriginality is [taken into account] is dubious.<sup>14</sup>

Despite the absence of epidemiological data, evidence presented to the Inquiry by Aboriginal people indicated that 'mental illness amongst Aboriginal and Torres Strait Islander people is a common and crippling problem which goes undiagnosed, unnoticed and untreated'.<sup>15</sup>

The Inquiry was told that there are two dimensions to Aboriginal mental illness: what was frequently referred to in the evidence as the 'mental distress' and poor self image caused by colonisation and perpetuated by the poor socio-economic circumstances in which Aboriginal people live; and the range of diagnosable psychiatric disorders which are also prevalent in the non-Aboriginal community. Although these phenomena are frequently linked, they are not the same.

It is important in looking at mental health problems affecting the Aboriginal population to recognise that there are two overlapping areas of difficulty. One is a group of people who have mental disorders as we would usually understand them and then there is another very large group of people presenting with symptoms of distress, which really reflect in social issues [such as] depressive symptoms, substance abuse problems and suicidal behaviour. I think this clearly represents mental distress, but it has to be understood in a social context.<sup>16</sup>

## **Social Context of Aboriginal Mental Illness**

Evidence from Aboriginal people demonstrated that environmental and social factors have had a lasting and significant impact on their psychological wellbeing.

If you talk to Aboriginal people, the themes [that] will come up again and again are the kidnapping of children, dispossession, economic discrimination, political discrimination. I have no doubt that these factors together have eroded the wellbeing of most Aboriginal individuals...such that they are more vulnerable to a variety of stresses and that would probably lead to high psychiatric morbidity.<sup>17</sup>

A number of studies of Aboriginal mental health problems throughout Australia have identified factors associated with lifestyle stress as contributing significantly to emotional and psychological ill health. One study undertaken by the Tharawal Aboriginal Co-operative in New South Wales, found that 29 percent of the Aboriginal men and 38 percent of the Aboriginal women surveyed were suffering from stress levels which impaired their ability to cope with day-to-day problems and caused physical or social problems in their lives. These figures are more than double those cited in similar studies of non-Aboriginal men and women undertaken by the Heart Foundation.<sup>18</sup>

In 1991, the *New South Wales Aboriginal Mental Health Report* found that 'the particular disadvantage that characterises Aboriginal people's position in Australian society today leads to an increased vulnerability to the development of some categories of mental health problems'. It also found that the likelihood of a person experiencing a mental health problem and/or a mental disorder was exacerbated by a childhood history of separation from biological parents, neglect or institutionalisation.<sup>19</sup>

Similar findings have also been made in other States. A study conducted by the Victorian Aboriginal Health Service found that 54 percent of all respondents had a psychiatric disorder. Of these respondents, over 50 percent had been separated from both their parents and more than 25 percent had been brought up outside their Aboriginal communities in foster homes and institutions.<sup>20</sup>

The Inquiry was told by many witnesses that the forced removal of Aboriginal children is a major factor in the mental distress experienced by Aboriginal people.<sup>21</sup> This issue was also raised by psychiatrists:

We are seeing trans-generational patterns occurring in Aboriginal society, in terms of the impact on people raised in institutions who then have to confront dilemmas of parenting down the line... [Clinical] interventions need to take account of that long-term cycle.<sup>22</sup>

However, the grief, poor self-image and emotional distress experienced by Aboriginal people are rarely dealt with in a clinical setting:

Aboriginal people grow up in communities and experience family dying around them all the time. There is no grief or crisis counselling available...<sup>23</sup>

It was suggested by several witnesses that one of the phenomena which may obscure the extent of mental illness in Aboriginal communities is the fact that many individuals act out their behavioural and psychological problems through anti-social and self-destructive behaviour.

[There is] a link between the socioeconomic conditions of Aboriginal people and their mental health... In many circumstances the links are [demonstrated] in domestic violence, alcohol abuse, child neglect and abuse and other forms of 'anti-social behaviour', and these problems have their roots in the powerlessness of Aboriginal communities and the subsequent high levels of stress and tensions within them.<sup>24</sup>

Many Aboriginal people told the Inquiry that much of this behaviour either goes undiagnosed or is treated as a police problem. This leads to contact with the criminal justice system, where Aboriginal people are labelled as socially deviant — and their psychological problems are exacerbated.

Jails and children's institutions are full of Aborigines who have been branded anti-social and many have been diagnosed as having a behaviour disorder. So, since the coming of Cook we have been led to believe that Aborigines are a nation of sociopaths.<sup>25</sup>

Many Aboriginal people have seen their brothers and sisters labelled as mentally ill (and hospitalised and incarcerated as a result) when they understand and know the problem as a social and political one. The diagnoses are always 'white' non-Aboriginal ones and the solutions are seen as another form of oppression.<sup>26</sup>

Dr Ernest Hunter, a psychiatrist with the NSW Aboriginal Medical Service, told the Inquiry that non-Aboriginal professionals tend to treat symptoms of social distress as medical disorders.<sup>27</sup>

The significance of these issues was also addressed in the report of the Royal Commission into Aboriginal Deaths in Custody, which found that there had been an extraordinary level of state intervention in the lives of all the Aboriginal people who had died in custody. In his final report, Commissioner Johnston observed:

The most fundamental causes of the over-representation of Aboriginal people in custody are not to be found in the criminal justice system but in those factors which bring Aboriginal people into conflict with the criminal justice system in the first place... The most significant contributing factor is the disadvantaged and unequal position in which Aboriginal people find themselves in the society — socially, economically, and culturally.<sup>28</sup>

As one Aboriginal mental health worker told the Inquiry:

We know that people that have a lot of mental health problems are picked up by the police and they usually end up in jail... We feel that's not good enough.<sup>29</sup>

The Royal Commission concluded that the overwhelming majority of deaths in custody resulted from suicide. Evidence to this Inquiry indicated that Aboriginal offenders who are incarcerated often experience depressive symptoms and unresolved anger which sometimes leads them to attempt or commit suicide whilst in custody. Many young Aboriginal men and juveniles are in custody during their formative years. As a result they are permanently alienated from their communities.

Alienation from the outside culture increases and the ability to cope normally — that is within Aboriginal culture or within mainstream culture — decreases. [When they are released from prison] the mental health consequences of this cycle [are] an accumulation of unresolved anger and the inwardly turning self-destructive behaviour... [such as] alcohol abuse. The high incidence on release of domestic and community violence and re-offending reflects this mental state.<sup>30</sup>

## Diagnosing Mental Illness

While most academic surveys of hospitalisation rates and the extent of mental illness in Aboriginal communities have used data from urban populations, most of the evidence provided to the Inquiry about the experiences of Aboriginal people with a mental illness was given by individuals and community representatives from rural and remote areas.

Although there is little epidemiological information available concerning Aboriginal people, the Inquiry received several statistical estimates of morbidity rates based on research studies and hospital separation figures in different Australian States. These statistics generally indicate that Aboriginal people who are hospitalised with a mental illness are most commonly diagnosed as having either an affective disorder, a mental disorder associated with alcohol abuse or some form of psychosis.

The Western Australian Branch of the Royal Australian and New Zealand College of Psychiatrists presented evidence that Aboriginal people are massively over-represented in involuntary admissions to State psychiatric hospitals and within the corrective services system:

Being Aboriginal carries a three-fold increase of involuntary psychiatric admission to State hospitals and being a metropolitan Aborigine carries a five-fold increased risk of compulsory admission. In comparison with non-Aboriginal patients, Aboriginal patients have a seven-fold greater chance of an alcohol and organic brain syndrome diagnosis being made.<sup>31</sup>



Another Western Australian witness indicated that:

47 percent of Aboriginal males suffer with mental disorders associated with alcohol dependence... 19 percent of Aboriginal women have depressive disorders and 21 percent of Aboriginal women have neurotic disorders.<sup>32</sup>

In Queensland, a survey conducted in 1991 found that 70 percent of Aboriginal and Torres Strait Islander inpatients were diagnosed as having schizophrenia or substance abuse disorders, in comparison to 42 percent of non-Aboriginal patients. These apparent disparities between diagnoses may reflect culturally inappropriate methods of assessment.

You could not confidently generalise about the [Aboriginal] population by looking at who is in an institution because...the validity of the diagnostic assessments that have been made with those people are problematic... At best you are catching one part of major psychiatric illness in terms of various psychoses; you would not be catching any sort of less debilitating symptoms of psychological distress and you certainly wouldn't be tapping widespread poor mental health...<sup>33</sup>

One of the additional difficulties associated with determining the rate of mental illness among Aboriginal communities is that people who may be mentally ill are often cared for within their community and do not come into contact with mental health professionals. The Inquiry was told that unlike non-Aboriginal society, Aboriginal people are often very tolerant and supportive of people who are behaving anti-socially as a result of mental illness. One researcher working with the Aboriginal community in Western Australia observed that:

The Aboriginal community has the capacity to hold its ranks and support someone who displays patterns of strange behaviour. And, though they are not described as mentally ill, they [may exhibit symptoms of mental illness]. [However], the community, rather than isolate that individual or sending them off to [a psychiatric institution], maintains them in the community with protection from their peers and families.<sup>34</sup>

Witnesses to the Inquiry also emphasised the fact that disturbed people are often kept within their communities because their illness is perceived as a normal reaction to spiritual forces or a curse such as being 'sung'.<sup>35</sup> Rather than being physically ill, the person is considered to be spiritually ill.

Signs from the Ancestral Beings and the power of the spirits are still culturally relevant for a significant number of Aboriginal people... For those who have retained their cultural ties and lifestyles...[hallucinations and other phenomena associated with disorders] may not be fantasy but a reality within their cultural context.<sup>36</sup>

In these cases, specific traditional treatments may be employed.

The sorts of traditional treatments which people still use today include the skills of *ngangkari*. *Ngangkari* can help when someone has something in their head. There are other Aboriginal ways of treating problems caused if someone has been sung, or if they walk into a special place or intrude on secret singing when they are not supposed to. These sort of problems can be cured by the person who sent someone mad in the first place. There are also bush medicines which help if someone has a headache, if they cannot hear properly, if they are angry, or their thoughts are confused.<sup>37</sup>

There are, however, some situations where people who are ill pose problems which the community cannot manage.

The important message communities gave us was that in traditional times they would have cared for slightly 'mad' people and that is what families still try to do today. However, for really bad problems in the past, people said that they would have had to leave the person behind or punish them. These are another sort of problem which communities now need help to deal with.<sup>38</sup>

Looking after community members with mental illness can also be difficult because of an implicit assumption that the community is able to care for its own:

There's a lot of mental health problems in the community and they're just mostly left for community people because everyone thinks that because you're Aboriginal that you can look after your own. But there's a lot of other illnesses to look after and often mental illnesses are just not understood and people are just left.<sup>39</sup>

## **Substance Abuse and Mental Illness**

While not always related to the issue of mental illness, a number of witnesses emphasised that the physical and psychological effects of substance abuse are particularly worrying for Aboriginal people. These effects may be caused by the action of the drug itself or result from brain damage or other psychological deficits directly related to substance abuse. Whatever the cause, violent and disturbed behaviour creates extreme distress in communities.

The Central Australian Aboriginal Congress told the Inquiry that 'alcohol abuse is a reflection of mental health problems in the community, and also in many ways exacerbates these problems':<sup>40</sup>

It is hard for people to control drunks or [petrol] sniffers, and traditional ways of treating disturbed people often do not work with these modern problems. In addition, people told us about other cases where grog makes it harder for disturbed people. Maybe their families do not look after them if the family starts drinking; drunks are often least tolerant of disturbed people, and may beat them up or take their money.<sup>41</sup>

However, there are few services to deal with this problem<sup>42</sup> and inappropriate assessment and treatment is common.<sup>43</sup>

Drug and alcohol consumption, when excessive, often accompany mental illness, and consideration of the one generally involves an assessment of the other. However, when the patient is Aboriginal, a proper evaluation and diagnosis may be impaired because medical information about Aboriginal drug and alcohol consumption can be [inappropriate, resulting in] poor doctor/patient communication and adverse treatment outcomes.<sup>44</sup>

### **Misdiagnosis**

Evidence to the Inquiry highlighted two major issues associated with the misdiagnosis of mental illness in Aboriginal people: the diagnosis of a mental illness when the patient is exhibiting 'unusual' behaviour which is appropriate in Aboriginal terms; and making an inaccurate diagnosis when a patient is in fact mentally ill.

The Inquiry was told that many psychiatrists are ill-equipped to distinguish between these phenomena.

While it is now accepted that Aboriginal people do suffer from the same psychiatric afflictions as [non-Aboriginal] Australians, recognition, assessment and management of these illnesses in Aboriginal people is different because of their [social disadvantage] and the idiosyncratic and non-European styles in which psychiatric illnesses sometimes present.<sup>45</sup>

The lack of special psychiatric services and professional expertise in cross-cultural psychiatry makes Aboriginal people particularly vulnerable. Because most of the mental health workers responsible for assessing Aboriginal people are not Aboriginal themselves, the importance of cultural beliefs and practices and their relevance to the patient's symptomatology are often overlooked. This was particularly apparent in evidence presented to the Inquiry concerning people from remote Aboriginal communities where traditional cultures are strong.

In Darwin, the Inquiry heard evidence concerning an Aboriginal man who was killed by police following a confrontation on Elcho Island in 1990. The Inquiry was told that the man had a long-standing psychiatric disorder.

The person killed had suffered bouts of psychiatric illness for ten years. He had been generally managed by his own community. At the times when the episodes became acute and violent, given members of the community would restrain him and arrange for his medication and occasional hospitalisation... Taking him into custody was always done with patience and kindness.<sup>46</sup>

In 1990 the mentally ill man speared another Aboriginal man on Elcho Island. Following the spearing a search party was mounted by the police. The man was confronted and ran towards police with a broken fishing knife. The police called on him to stop and the man, who was disturbed and spoke little English, kept running. He was shot dead.<sup>47</sup>

The Inquiry was told that the man had been misdiagnosed as having alcohol-related brain damage when in fact he did not drink, and that one doctor had regarded him as being intellectually disabled because he could not speak English. Although these aspects of the patient's case history were not specifically related to the incident during which he was shot, it was alleged that if the man's case had been dealt with more carefully, and accurate diagnosis and appropriate case management had been undertaken, the fatal confrontation with the police may not have occurred.<sup>48</sup>

Evidence to the Inquiry suggested that it can be extremely difficult to accurately diagnose mental illness in an Aboriginal person because of factors such as the person's traditional language and spiritual beliefs:

The diversity of Aboriginal cultures creates a dilemma for psychiatrists and psychologists alike because what applies for a particular set of overt conditions (symptoms) in the case of a specific patient and the corresponding appropriate treatment may not be appropriate for an individual with similar problems from a different location and community because of differing cultural beliefs and practices.<sup>49</sup>

Because of the geographical isolation of many Aboriginal and Torres Strait Islander communities, particularly in the Northern Territory, Western Australia and Queensland, people who are mentally ill are often sent to cities and large towns for assessment and treatment. This physical dislocation of individuals from their communities can be extremely destructive to their mental wellbeing.

As an Aboriginal witness told the Inquiry in Queensland, mental health service providers need to be aware of the particular cultural needs of Aboriginal people who are mentally ill:

Everything in the environment gives us cues as to our standing and place in the universe, our standing within the community, and within our own family groups. The situations and structures we've got today in our society, whether they be mental institutions...or wards attached to hospitals, they are a totally alien environment [from what] we need to make us sane... Those people who have been diagnosed or actually put into a situation like that are not getting the necessary cues [so that they can] behave in the right manner — so that there can be some meaningful dialogue with...the people that are actually doing the therapeutic work...<sup>50</sup>

These observations were reaffirmed from a clinical perspective by a psychiatrist who has worked with Aboriginal people:

Most Aboriginal people of my acquaintance are very concerned with the quality of their relationships with other people [and] the quality of the relationships with their immediate country. The quality of the relationships are very important barometers of their individual wellbeing. If you have a western psychiatric intervention that just looks at an individual out of context — indeed you might be assessing an individual who is several thousand miles from their home without any of their family there and under heavy medication — I'm not sure that you would get much sense out of them in terms of their experience of distress because you have taken the individual out of their context and for them context is everything.<sup>51</sup>

## **Cultural Bias in Psychological Tests**

The Inquiry was told that the psychological tests administered by non-Aboriginal mental health workers to assess psychiatric illness can also contribute to misdiagnosis.<sup>52</sup> Psychological tests are based on asking questions which are formulated to give a standard response. However, the standard is derived from a sample of the general population — a population which is not Aboriginal. Evidence indicated that there are no known Aboriginal norms for these tests and that they are based on concepts alien to Aboriginal culture.

An example in the field of personality clinical testing and mental health is the CAQ, which is a well known personality test. This measures normality of functioning in different areas of personality as psychometrically derived from the mainstream population. So, they have already determined a number of traits and they measure people against that, so even the concept of [types of] personality such as extrovert and introvert are culturally biased. So, an abnormal score for a person from a very different culture may well be indicating cultural difference rather than abnormality. Attributing abnormality to cultural difference is an institutionalised abuse of human rights just as is the assumption that the concepts used in the field of mental health can be fairly assessed cross-culturally.<sup>53</sup>

## **Aboriginal People with Special Needs**

Two particular groups within the Aboriginal community were identified by a number of witnesses as requiring special attention — the elderly and young people.

### **Elderly People**

In Alice Springs the Inquiry heard disturbing evidence concerning misdiagnosis and inappropriate treatment of elderly Aboriginal people with mental illness. Evidence suggested that elderly people have been incorrectly diagnosed as having dementia, and removed from their traditional communities in remote

areas (often several hundred kilometres from any other settlement) to nursing homes in Alice Springs where they become isolated and institutionalised.

The Inquiry was told that the use of the term 'elderly' when talking about Aboriginal people does not always relate to old age in chronological terms. Aboriginal people's greatly reduced life expectancy means that those regarded as elderly may be in their forties or fifties, an age not considered old in the non-Aboriginal community.<sup>54</sup>

According to the evidence, two major reasons are advanced for removing elderly Aboriginal people to nursing homes: physical frailty and confusion; and the lack of facilities in remote areas to enable families and communities to care for old people who are physically or mentally ill.<sup>55</sup>

[Not being able to cope] results in families and carers sending old people away to nursing homes. The lack of options for support for carers continues to go largely unaddressed by health clinics in the bush which assist in the process of removal of old people. The lack of respite care [is also a factor]. Support services which would provide basic physical and mental health assistance are either limited or basically they are just non-existent.<sup>56</sup>

The Inquiry was told that while many of the old people resident in nursing homes may be deemed by health professionals to be mentally ill or suffering from dementia, it is difficult to determine whether this is in fact the case. The Central Australian Advocacy Service (CAAS) contended that the tests developed to assess dementia are inappropriate for Aboriginal people. In addition to practical difficulties in assessing dementia, it was suggested that most of the Aboriginal people in nursing homes exhibit symptoms of confusion and distress similar to dementia:

Many residents have been genuinely, justifiably confused and fearful about their whereabouts and their future. Some residents of nursing homes have told us that, after years had passed, they were still in hospital waiting to go home. Other residents have, in the words of relatives, 'talked silly' during visits — including forgetting that certain relatives have passed away and must not be named. When away from the [nursing home], in the company of family and their country, however, these same residents have been clear headed and lucid... This is an indication of the anxiety which people are experiencing at separation from their own kin and country.<sup>57</sup>

Many Aboriginal people living in nursing homes are unaware of their rights as patients. Their powerlessness is compounded by the fact that most staff in the homes are non-Aboriginal and do not speak Aboriginal languages.

As people get older they tend to revert to their first language. This has sometimes been interpreted as a sign of dementia. Becoming non-communicative and withdrawn due to

depression has also been interpreted as dementia. Of course once old people are diagnosed as demented, they can have guardians appointed, with resultant loss of rights.<sup>58</sup>

Many Aboriginal nursing home residents have expressed despair at what they perceive to be a 'life sentence' in a nursing home. The mental illness and anxiety experienced by Aboriginal old people has been described as severe homesickness by Aboriginal healers. The Inquiry was told that 'the prospect of dying away from one's country and family causes old people a level of distress which is seriously unjust'.<sup>59</sup> Reintegration with their communities would be a more effective treatment for many elderly people with depression than anti-depressants and other medical therapies.

[These old people] are miserable and lonely. They have no focus and are cut off from their dreaming because they are separated from their community, away from their country and not continuing the ceremonial business which is their responsibility. The community too is cut off from its dreaming because the old people are not there to sing the songs, maintain the sacred sites and direct the business.<sup>60</sup>

The maintenance of these rituals is essential to Aboriginal spirituality and the cycle of life.

The living person's spirit comes from the dreaming and is returned to the dreaming and country after death. Death and burial on country represents a continuation of relationships between people and places.<sup>61</sup>

The CAAS and the Central Australian Aboriginal Congress told the Inquiry that it is important to ensure, where possible, that Aboriginal old people are able to end their lives in their traditional communities. However, community workers have found this extremely difficult to organise. Problems include the physical difficulties of caring for the frail elderly in isolated and remote areas, particularly without adequate support services<sup>62</sup>; families being unable to cope because of poverty; and a reluctance on the part of health workers in community clinics to welcome old people back because of the general lack of facilities and resources with which they have to work.

Aboriginal community workers and organisations in Alice Springs have adopted a range of strategies to address this situation. Attempts have been made to ensure better and more regular communication between local service providers and Aboriginal groups and more effective assessment and placement of old people in nursing homes. Evidence indicated that while the adoption of these strategies has led to more effective advocacy on the part of the Aboriginal elderly, they have also posed some threat to the operation of nursing homes in Alice Springs:

In Central Australia there is an obvious contradiction between attractive notions of consumer rights or social justice policies of government and a funding system for nursing homes which continues to encourage the residential care industry to fill its beds. In Central Australia these beds are now usually filled by Aboriginal people, despite nursing homes being built with non-Aboriginal people in mind... The rights and mental wellbeing of a proportion of the aged population cannot be guaranteed, simply because they are elderly and Aboriginal. This flies in the face of current grandiose government claims about equity and equality in aged care.<sup>63</sup>

The Inquiry was told there is an urgent need for the development of services to enable Aboriginal old people to remain in their communities and 'die with dignity where they choose'. The range of services would include respite care for carers and culturally appropriate residential care for those who require it.<sup>64</sup> Appropriate responses could also include the development of protocols for minimum standards of care for people remaining in remote areas and the provision of financial support to a nominated carer who would be responsible for ensuring that basic standards are met.

A recent study undertaken by the Central Australian Aboriginal Congress found that most Aboriginal people caring for the frail and elderly were not accessing the home and community care services available to them because they were largely inappropriate to meet their needs. 'Some had preferred to go without these services rather than change their life to fit the needs of service providers. Most had not had the opportunity to use them at all'.<sup>65</sup> Clearly, further consultation and research need to be undertaken to ensure that appropriate services are developed in consultation with Aboriginal people and provision is made for Aboriginal control of culturally appropriate services.

### **Young People**

It is difficult to determine how many Aboriginal young people are affected by a mental illness. The Inquiry was told by several child and adolescent psychiatrists that they believed psychiatric problems were widespread among Aboriginal youth, particularly among adolescent boys and young men — but that little epidemiological data is available.<sup>66</sup>

One child psychiatrist told the Inquiry's Cairns hearing that the 1986 census showed there were over 10,000 Aboriginal young people under the age of 19 living in the region — yet he had never had a client who was Aboriginal.<sup>67</sup>

Presumably there must be a need for an Aboriginal child and adolescent service. We don't see anybody at all unless they have some concomitant medical problem [for example, deafness] and are referred to the Health Department. So its really a bit of a mystery to me why people aren't detecting disturbance among children or why they're not referring.<sup>68</sup>



However, an Aboriginal worker from the same region told the Inquiry that serious problems exist, including problems related to mental health, and there is a desperate need for services in regional communities.

There are no services to counsel parents or juveniles, even though there's an extremely high rate of juvenile offending, and I believe that the communities are certainly in crisis when it comes to physical and mental health issues and law and order issues.<sup>69</sup>

Similarly, in Victoria, the Inquiry was told by one of Australia's leading child psychiatrists, that

the number of Koori [Aboriginal] children who present or receive assistance from child psychiatric services in Victoria you could count on one hand. They are not getting through to services and there are complex reasons for this...<sup>70</sup>

The coordinator of the Victorian Aboriginal Mental Health Network noted that while very few Aboriginal young people are coming into contact with psychiatric services, access to them is 'vital to the survival of [Aboriginal] communities'.<sup>71</sup> She suggested that one of the major reasons for the under-utilisation of child psychiatric services is the reluctance to deal with child welfare agencies which had previously been instrumental in taking children away from their families and communities. Experience of government intervention in community affairs has undoubtedly led to justifiable reticence and suspicion on the part of many Aboriginal people.

As the evidence cited above indicates, many Aboriginal juveniles come into contact with the juvenile justice system. The Inquiry was told that there are clear links between behavioural and mental health problems such as low self esteem, alienation and substance abuse, and the high incidence of juvenile offending in Aboriginal communities. A study undertaken in Campbelltown, NSW, found that 76 percent of the young people going before courts were charged with drug and alcohol related crimes.<sup>72</sup>

Many young Aboriginal people who come into contact with the juvenile justice system also have a serious learning disability.

Large numbers of Aboriginal children from early childhood through to adolescence have a significant hearing disability — hearing loss due to chronic otitis media. [Eighty] percent of children tested in [inner Western Sydney] had some degree of hearing disability. These are the beginnings of major problems with regard to the ultimate lifestyle of significant numbers of these young people. Because they can't hear, together with the social disadvantage of their families, they're at risk and often drop out of school early. They are then subject, of course, to racial and social prejudice. So the steps from there into drug taking and low self esteem going on to delinquency and then to the juvenile justice system are not difficult to follow.<sup>73</sup>

The Inquiry was told there is a potent legacy of mental health problems resulting from the high rates of incarceration of young Aboriginal men, many of whom spend their formative years (between 15 and 19) in prison.

Research undertaken in Western Australia indicates that a very strong, dysfunctional subculture has evolved in Aboriginal communities as a result of the lengthy periods of time that young and adult men spend in jail. In some communities, young men see contact with the criminal justice system as a rite of passage which is to be expected as part of the transition to manhood. Many Aboriginal juveniles who are in institutions have fathers who are or have been in jail.

The absence of the adult male becomes particularly critical as the male children reach adolescence. As in all cultures, this makes the establishment of boundaries, self-discipline and social responsibility difficult to achieve and it also makes it difficult for the growing male child to see and learn positive and meaningful personal, family, social, educational, and cultural roles. The moral and ethical standards become those of a reactive counter-culture.<sup>74</sup>

One particularly disturbing manifestation of behavioural and mental health problems among Aboriginal juveniles is the increasing incidence of suicide and other forms of self-directed violence. One psychiatrist who has undertaken considerable research with Aboriginal people in the remote Kimberley region of WA has identified a substantial increase in youth suicide since the 1970s:

For instance, in the Kimberleys in the 1960s there was one suicide; in the 1970's there were three, and in the 1980s there were 21. This is a substantial increase. We also see an increase in violence [against] women, and we see an increase in self-mutilation. Now, this is occurring amongst a group of people who are getting younger. If we look at the suicides up to 1988, two of 17 were aged 20 or less. In 1988 and 1989 there were eight suicides, and six of those were aged 20 or less.<sup>75</sup>

Those committing suicide are the children of a generation of people who were taken away from their families and suffered extreme social and economic discrimination.<sup>76</sup> These experiences have a long-term psychological impact that can only be addressed through the involvement of Aboriginal people in the development of psychiatric and other services. Organisations like the Koori Mental Health Network in Victoria must have appropriate government support to extend their activities to Aboriginal young people. All over Australia, the development of programs to divert juvenile offenders from custody and prevent their 'criminalisation' is an urgent priority.<sup>77</sup>

## **Women**

Although little direct evidence was received, it is also recognised that the experiences of Aboriginal women in caring for people affected by mental illness are particularly important. As is the case in the non-Aboriginal community, Aboriginal women frequently provide the primary care and emotional support for those in their communities who suffer from behavioural problems and mental illness. A number of witnesses emphasised the particular psychological stresses experienced by Aboriginal women and the important role they play in maintaining the mental and emotional health of Aboriginal communities.

## **Servicing Rural and Remote Areas**

Many Aboriginal people in Australia are denied the right to adequate mental health services because they live in geographically isolated areas. The Town Clerk of one Aboriginal community in the Northern Territory told the Inquiry:

*We feel that our community and other Aboriginal communities are severely disadvantaged in mental health care. If we lived in other centres of Australia we would have the use of a broad range of services... At present we only have one trained nurse, and one Aboriginal mental health worker visiting approximately two times a year.<sup>78</sup>*

This severe lack of services is widespread in remote areas of WA, the Northern Territory and Queensland — all regions with a comparatively large Aboriginal population. Several witnesses observed that the rate of suicide, domestic violence and self mutilation in remote Aboriginal communities is high because of the high levels of psychological stress associated with daily life.<sup>79</sup> However, as one Aboriginal community representative told the Inquiry in Queensland, there are no primary prevention or other mental health services available.

*As far as I am aware, there is no psychiatrist that ever visits Aboriginal communities. Certainly there is no psychologist, or social worker employed on any of the Aboriginal communities...<sup>80</sup>*

Visiting health workers or resident nursing staff generally bear the responsibility for caring for the mentally ill in isolated communities. However, these workers are usually untrained in psychiatric treatment or diagnosis and are also responsible for providing primary health care to a whole community. This lack of resources combined with limited training necessitates a committed but somewhat unfocussed approach to mental health care.

*We have mainly concentrated, not on mental illness, but on mental health and wellbeing. The area we cover would be 300 miles to the East and 200 miles to the West and the islands off the coast. We are the only two workers in mental health in this area. There are*

16 major communities, some of them over 1000 people, with probably 30 minor communities. We mainly concentrate on primary health care because of the size of the area and the job that we have, and we deal with biological, psychological and social issues... We actually look after everybody, we do not knock anybody back no matter what the problem.<sup>81</sup>

The Inquiry recognises the importance of the primary health care work undertaken by nurses and Aboriginal health workers in remote areas. However, the very basic services provided are clearly inadequate. Aboriginal communities are denied effective diagnosis and treatment because of the lack of trained professionals available.

The strain placed on individual health workers is immense. One Aboriginal mental health worker told the Inquiry that health authorities often assume that because she is Aboriginal, she is automatically able to relate to and care for all Aboriginal people regardless of their medical needs; that government service providers feel that by employing one Aboriginal worker, they are adequately addressing the needs of Aboriginal people in isolated areas.

Sometimes you must do the reverse and put in place money and resources for Aboriginal communities to explore the mental health needs of their community with government workers in association with the President of the community or in association with health workers.<sup>82</sup>

This is not easily done, however. The Inquiry was told that when psychiatrists do visit remote communities (usually because someone has suffered an acute episode and is being evacuated to a regional hospital to be treated) they are not perceived as having 'credibility'.<sup>83</sup>

A psychiatrist has to be accepted in those [traditional and remote] communities. I feel very strongly that Aboriginal people on those communities should be treated, if possible, on those communities if practicable. It is very important not to alienate them from their own people. [When people are taken to regional centres for treatment and returned home] it is very difficult for people on communities to accept them back on the community... Now, I do accept that there are times when people have to [be sent away for treatment] but I would like to see that only as a last resort.<sup>84</sup>

As indicated earlier, many Aboriginal people living in geographically isolated areas are taken away from their communities to receive psychiatric treatment. Rather than improving their mental health, this frequently heightens their sense of alienation and mental distress. It is crucial for government service providers to recognise the rights of Aboriginal people to receive adequate mental health care — and that this requires adaptation of services, including in relation to their geographic location. There must be a clear recognition of the particular cultural needs of Aboriginal people and the efficacy of providing appropriate

mental health care to those living in remote areas — before their needs become acute.

## **The Need for Culturally Appropriate Services**

Witnesses presenting evidence to the Inquiry were in general agreement that existing services for Aboriginal and Torres Strait Islander people are seriously inadequate and culturally inappropriate. Many factors have contributed to this situation. They include: a lack of knowledge and understanding of Aboriginal and Torres Strait Islander perspectives and cultures; the way people conceptualise and define illness and health; a limited understanding of the nature and scope of mental health needs within Aboriginal and Torres Strait Islander communities; a lack of consultation by Governments and medical professionals with indigenous Australians; and a lack of education and training.

The network of psychiatric services in Australia is designed to meet the needs of the mentally ill who present in the European manner. Consequently, there are no special psychiatric services...[or] specific policies for the diagnosis and treatment of Aboriginal people with mental illness.<sup>85</sup>

The particular historical and social context in which mental illness among Aboriginal people occurs has already been described. It is clear that mainstream service providers must be cognisant of these issues in the development and delivery of mental health services to Aboriginal communities. As the *New South Wales Aboriginal Mental Health Report* found:

Disturbances of psychological and emotional functioning are common in the Aboriginal community and mental health services are needed and wanted. Mainstream community mental health services are neither functionally accessible nor appropriate to the social and cultural needs of the Aboriginal community.<sup>86</sup>

The inappropriateness of mainstream services for Aboriginal people was summarised by one Queensland witness:

The current psychiatric system has a basic underlying cultural difference which creates for Murris [Aborigines] increased difficulties in dealing with mental health problems. Any form of incarceration, isolation, removal from family, friends, and the Murri community, is fundamentally alien to culturally appropriate methods of dealing with any Murri cultural problem. [For example] one person I spoke to related to me how her family would pack up and move to each town that she was moved to. They followed her from one hospital to another to give her the support that she needed... Removing Murri people from the Murri community and placing them within an alien psychiatric system is like trying to force a square peg into a round hole. We do not fit.<sup>87</sup>

While Aboriginal people recognise that there will always be a need for the provision of acute care in facilities like hospitals, the Inquiry was told that major reforms are needed to ensure that they are able to utilise mainstream facilities, without feeling alienated and suspicious of them.

Many Aboriginal and Torres Strait Islander people do not trust non-Aboriginal people or their systems, including psychiatric systems. In most cases it would be a great deal easier for an Aboriginal worker to develop a trusting relationship with an Aboriginal patient... It is our belief that existing services are not utilised because a trusting relationship has not been developed. This means that therapy is not effective and treatment is based totally on medication. Without culturally aware psychiatric support as well as the appropriate medication (when needed), the people admitted to hospital are not being provided with the same equality of opportunity in terms of service provision. Indeed, when trust has not been developed, the mistrust only exacerbates stress and hence the illness.<sup>88</sup>

The report of the *National Aboriginal Health Strategy* recommended important ways of facilitating more culturally appropriate and accessible mental health services: employment of Aboriginal liaison officers to communicate between psychiatric ward staff and Aboriginal Health Service staff and the community; and employment of specialist psychiatric Aboriginal health workers in Aboriginal communities.<sup>89</sup> Unfortunately, despite the fact that these recommendations were made early in 1989, evidence to this Inquiry confirmed that effective implementation has not been achieved.

While the involvement of Aboriginal people in service provision is crucial, non-Aboriginal service providers have responsibilities too. Psychiatrists and other mental health workers must develop strategies for extending mainstream services to Aboriginal people and ensuring that diagnosis and treatment are culturally appropriate.

Because Aborigines constitute less than two percent of the population, it is very easy to avoid ever being involved with them at all... Consequently, if the psychiatrist is to be of assistance, it will be necessary for each and every one of us to adopt a positive sense of awareness of the issues concerned and to demonstrate a willingness and availability for this psychiatrically neglected section of the...community.<sup>90</sup>

The WA Branch of the RANZCP suggested several practical ways psychiatrists could more effectively service their Aboriginal patients.

Psychiatrists should be encouraged to develop an awareness of and a concern about the present deficiencies in the prevention, recognition and treatment of psychiatric illness in Aboriginal people [through] educational programs. We also suggest that the psychiatrists' role should be to facilitate psychiatric care amongst health workers in the field with rural practitioners, the Royal Flying Doctor Service etc. Psychiatrists should also be encouraged to participate in the administration of existing services and to visit rural centres regularly.<sup>91</sup>

Many witnesses referred to the need to train Aboriginal and Torres Strait Islander mental health workers to work both in mainstream programs and community controlled services.

While the need for culturally appropriate services is clear, the evidence suggested that Aboriginal communities face major financial and philosophical barriers in their attempts to become more involved in service provision.

Obtaining the resources and placements for training Aboriginal mental health workers has been identified as an important area of need, particularly in remote areas such as those in WA, the Northern Territory and Queensland. The Inquiry was told that although Aboriginal health services often employ specialists, they are usually non-Aboriginal people who do not have the cultural knowledge necessary to make accurate diagnoses or communicate well with patients. In this context, considerable responsibility is often placed on Aboriginal health workers.

Our medical officers find it very difficult at times to [diagnose] and need to work very closely with our health workers...but it is very difficult with our health workers as well, because none of the information of the western medicine or western mental health has come over to our side... We do not have any modules at Batchelor College, where health worker training goes on, in mental health. Medical professions...have fixed ideas on illnesses and Aboriginal people are feeling that a lot of organisations actually guard against [wanting] to give information over to us. It is very difficult to acquire this knowledge.<sup>92</sup>

One psychiatric nurse who works closely with Aboriginal health workers in remote communities emphasised the importance of training — not only because of the need for additional expertise within communities but also because of the high ‘burn out’ rate among health workers:

Aboriginal health workers do a lot of mental health work but they actually do not know how to look after themselves, because they get tangled up with a lot of emotional issues on the communities... They certainly give advice to other Aborigines in communities but they do not know much about mental illness. There are people with major illnesses on the communities that are given psychotropic drugs... These people have been given treatment without people looking after them who have any idea about the drugs they have and the side effects. So I feel that it is very important that Aboriginal health workers get some kind of grounding. I was talking to a couple of teachers from Batchelor College yesterday and I said, ‘we should be doing something about mental health education for Aborigines’ and they said ‘we do not feel that Aboriginal health workers are able to handle it’, so there is certainly a lot of educating to be done with the educators.<sup>93</sup>

There is no one particular service or philosophy which can be identified as a model for service provision for indigenous people. While Aboriginal people throughout Australia suffer similar difficulties concerning mental health, the heterogeneous nature of Aboriginal communities and the differences between

those in urban, rural and remote areas make it important for individual communities to work with mental health professionals to identify areas of need and strategies for reform. One instructive case study in this regard is Wilson's Patch in Western Australia.

### **Wilson's Patch**

The Aboriginal community at Wilson's Patch, about 280km north of Kalgoorlie, received considerable media coverage in December 1992 when allegations were made that three mentally ill Aboriginal people being cared for in the community were being mistreated.

The allegations concerned three former patients of Graylands psychiatric hospital in Perth who had been released into the care of the community.<sup>94</sup> It was claimed that they had been detained in 'cages' and 'tethered' to trees. The Inquiry's attention was drawn to the matter following representations from Aboriginal people involved with the community at Wilson's Patch, politicians and journalists.

The Wilson's Patch community was established by Mr Victor Isaacs to provide an alcohol-free community where Aboriginal people with substance abuse problems could live in a supportive and healthy environment with their own people. The community began caring for former psychiatric patients in 1988, following the discharge of one of several Aboriginal people from Graylands into Mr Isaacs' care. The WA Health Department supported the initiative as a positive attempt to deinstitutionalise Aboriginal people with psychiatric disabilities.<sup>95</sup>

In its report to the Health Minister in December 1992, the Health Department observed:

When the arrangements were established, the community appeared to be well run... Routine medical and health supervision has been provided by weekly, and more recently, fortnightly visits by community nursing staff. The present community nurse is a qualified mental health nurse and is responsible for administering medication and providing general health supervision. The previous doctor in Leonora was also a regular visitor. However, under the current doctor patients are transported to Leonora for medical care.<sup>96</sup>

In November 1992, one of the mentally ill community members 'absconded' from the community and made a number of allegations to police, claiming that she had been starved and locked up in a 'cage'.<sup>97</sup>

Following this incident an unprecedented level of attention was focussed on the community. Media reports about Wilson's Patch highlighted allegations of



mistreatment. They included claims that the mentally ill were being subjected to physical abuse and neglect; that supervision was inadequate; that pension checks received by the community for the mentally ill members were being misspent and that several people with mental illness had been held in cages.<sup>98</sup> The ensuing public controversy caused the Minister to order an investigation.

Information made available to the Inquiry indicated that the fundamental difficulty concerning Wilson's Patch was the uncertain relationship between the care givers in the community and the Health Department; and the inadequate resources made available to the community in caring for their people with mental illness.

Members of the Anglican Social Responsibilities Commission visited the community and found that the allegations were unfounded. Rather than neglect, they found a small group of people attempting to provide the best care they could with extremely limited financial and physical resources:

The community has only its own resources to care [for people with mental illness]. It has received no funding to improve the facilities, nor to provide the infrastructure normally associated with the care of people with special needs. The buildings have been constructed by the community, without financial or material assistance from local, State or Federal government. There is a clear need for additional buildings more suited to the community and its work...<sup>99</sup>

The Health Department made similar observations in its review of Wilson's Patch. While it found that the use of a bough shed (the alleged 'cage') to prevent people from wandering during certain times of the day was not 'the usual accommodation for people with mental illness in the community', it was occasioned by the real need to prevent people from wandering; the need for respite time for carers; and the lack of resources to build a more secure area.<sup>100</sup> The Department concluded:

The use of these facilities does not appear to have been associated with any observable harm. Indeed, the harm they seek to prevent, from wandering patients, is very real. However, the secure areas provided fall well below community standards and alternatives need to be devised.<sup>101</sup>

This case study raises important issues concerning the care and provision of support services to Aboriginal people with mental illness. Although the Health Department was aware of the initiatives undertaken at Wilson's Patch, the Aboriginal carers were basically isolated and completely under-resourced in their attempts to provide a secure and comfortable environment for those in their care.

Each of the people under care has very serious and difficult behavioural problems associated with their brain damage, retardation and dementia which causes substantial difficulties for carers even in Graylands Hospital. The challenge of providing security in a humane way at Wilson's Patch is very great. Equally, while all attention in this inquiry has focussed on the care of patients, much greater attention needs to be given to the needs of carers. In none of the [Health Department] correspondence relating to Wilson's Patch does there seem to be the least concern expressed about their needs, although in the general society, considerable attention is paid to the importance of providing respite and support for the carers of disabled people.<sup>102</sup>

The Wilson's Patch case illustrates the immense practical and attitudinal difficulties which Aboriginal people face in attempting to provide culturally appropriate services for their own people. It is quite irresponsible for governments to purport to meet their obligations by supporting community initiatives in principle — but failing to provide the financial and other resources necessary to provide humane and adequate care. The Health Department's own investigation found that:

Wilson's Patch has provided a generally effective, stable, and caring environment in which persons with mental illness can reside... Intemperate allegations about the behaviour of carers can only result in an injustice to them, particularly when their general quality of care and concern is taken into account.<sup>103</sup>

Many Aboriginal people in remote communities throughout Australia manage to provide care for the mentally ill under extremely deprived circumstances. One of the major results of this incident was a review of the supervision provisions for all persons currently subject to the aftercare provisions of the West Australian *Mental Health Act* (see Chapter 4 — The Legal Framework) and the development of a State policy on Aftercare which includes guidelines on the coordination and monitoring of patients and the responsibilities of mental health professionals, including psychiatrists and case-managers.

### **Respite Care and Relief**

In Chapter 15 of this report specific attention is focussed on the critical role played by family members as carers for those affected by mental illness. It is clear from the previous sections of this chapter, and in particular the case-study just cited, that adequate recognition of the need for appropriate respite and relief for carers is just as important for Aboriginal people.<sup>104</sup>

### **The Importance of Self-Determination**

We support the practice of cross-cultural psychiatry in the short term, but long-term strategies must be developed to enable our people to develop the skills and resources needed to develop and run our own mental health services.<sup>105</sup>

Aboriginal and Torres Strait Islander people told the Inquiry that solutions to the mental health problems of indigenous peoples are contingent upon the recognition of their human right to self-determination. All Aboriginal and Torres Strait Islander witnesses identified the provision of self-determined, culturally appropriate services as a key strategy in improving their communities' mental health.

The most fundamental principle is that of self-determination. This means that problems affecting Aboriginal people can only be effectively dealt with if Aboriginal people are in control of the process.<sup>106</sup>

Self determination, in this context, involves providing Aboriginal people with the training, power and resources to determine their own mental health strategies within their own terms of reference. In addition to the provision of services run by and for indigenous people, it is essential that mainstream services are delivered in a culturally appropriate manner and are geographically accessible. As many witnesses pointed out, it is useless providing 'appropriate' services if the professionals responsible for delivering them are several thousand kilometres away from the communities which need them.

The Royal Commission into Aboriginal Deaths in Custody concluded that:

Mental health service provision for Aboriginal people constitutes, for the most part, mainstream services. As a result, Aboriginal people are particularly disadvantaged. Not only are they disadvantaged by their socioeconomic status and cultural background, but proportionately more Aboriginal people than non-Aboriginal people are disadvantaged by their geographic location, in the sense that many live in the rural or remote regions of Australia where mental health services are lacking.<sup>107</sup>

Aborigines and Torres Strait Islanders are among the most powerless and socially and economically disadvantaged groups in Australian society. Despite their continuing disadvantage, many Aboriginal communities have developed innovative and effective strategies for addressing their problems. As the Central Australian Aboriginal Congress told the Inquiry:

Our strength is that we have survived. We are strong, or we would not have survived. Our culture is alive, and is central to our strength. The colonisation process of dispossession made us strong. We depend on each other, we understand and support each other.<sup>108</sup>

The challenge for Australian governments, the non-Aboriginal community and mental health professionals is to build on this strength by providing the training and resources necessary to ensure culturally appropriate mental health care.

In terms of human rights the solutions are not to be found simply...in improved access to mainstream services; provision of culturally appropriate services; and culturally self-

determined services. Although progress in each of these directions is of extreme importance, the bald fact is that the symptoms will not go away even with the best service provision until there is real progress on the fundamental cause, which is to ensure access to Aboriginal mental health through Aboriginal self-determination in all aspects of life — to make possible a dignified Aboriginal life which is viable and meaningful as seen and experienced and constructed by Aboriginal people themselves.<sup>109</sup>

1. Pat Swan, *200 Years of Unfinished Business*, Aboriginal Medical Service, Redfern. Paper provided to the Inquiry, p7.
2. Aboriginal Medical Service Co-operative Ltd, *NSW Aboriginal Mental Health Report*, May 1991, p9.
3. Ken Wyatt and Richard Wilkes, *Fantasy or Reality: Aboriginal Mental Health*. Paper presented as a submission to the Inquiry, pp9-12.
4. Central Australian Aboriginal Congress and Anyinginyi Congress Aboriginal Corporation. Joint submission, p1.
5. Barbara Miller, *A Socio-Historical Perspective on Aboriginal Intra-Cultural Aggression*, Aboriginal Coordinating Council, Queensland. Paper provided to the Inquiry, p24.
6. *200 Years of Unfinished Business*, op cit, p2.
7. Pat Dudgeon, Head, Centre for Aboriginal Studies, Curtin University. Oral evidence, Perth 12.2.92, p306.
8. Wyatt and Wilkes, op cit, p10.
9. Sarah Dunlop, *All that Rama Rama Mob: Aboriginal Disturbed Behaviour in Central Australia*, Central Australian Aboriginal Congress 1988, p9.
10. *ibid*, p7.
11. Wyatt and Wilkes, op cit, p10.
12. National Aboriginal Health Strategy Working Party, *A National Aboriginal Health Strategy*, AGPS, Canberra, 1989, pix.
13. Shane Houston, Coordinator, Tharawal Aboriginal Corporation. Oral evidence, Sydney 21.6.91, p603.
14. Prof J Reser, Department of Psychology, James Cook University. Oral evidence, Townsville 13.8.91, p1274.
15. National Aboriginal Health Strategy Working Party, op cit, p286.
16. Dr Ernest Hunter, psychiatrist, Aboriginal Medical Service, and Fellow, National Drug and Alcohol Research Centre. Oral evidence, Sydney 21.6.91, p535.
17. Reser, op cit, p1279.
18. Houston, op cit, p604.
19. Aboriginal Medical Service Co-operative Ltd, op cit, p11.
20. Dr Jane McKendrick, Koori Mental Health Network. Oral evidence, Melbourne 9.4.91, p249.
21. Carol Kendall, Coordinator, LINK-UP, New South Wales. Submission, p2.
22. Hunter, op cit, p546.
23. Barbara Miller, research officer, Aboriginal Coordinating Council. Oral evidence, Cairns 9.8.91, p1010.
24. Houston, op cit, p604.
25. *200 Years of Unfinished Business*, op cit, pp3-4.
26. *ibid*, p2.
27. Hunter, op cit, p535.
28. Commissioner Elliott Johnston QC, *Royal Commission into Aboriginal Deaths in Custody: National Report Overview*, AGPS, Canberra, 1991, p15.

29. Pat Swan, psychiatric nurse, Redfern Aboriginal Medical Service. Oral evidence, Sydney 21.6.91, p534.
30. Harry Pickett, psychologist and counsellor, Centre for Aboriginal Studies, Curtin University. Oral evidence, Perth 12.2.92, pp311-312.
31. Dr John Spencer et al, Social and Cultural Issues Committee, RANZCP (WA), *Branch Statement on Psychiatric Services for Aboriginal People*, p1. Included with submission presented to the Inquiry by Dr David Lord.
32. Ken Wyatt, Senior Policy Officer, Aboriginal Health Policy Unit, Health Department of Western Australia. Oral evidence, Perth 12.2.92, p287.
33. Reser, op cit, p1275.
34. Liz Hayden, Aboriginal community representative. Oral evidence, Albany 14.2.92, p453.
35. See, for example, the submission by Ken Wyatt, Aboriginal Health Policy Unit, Health Department of WA, who discussed the influence of spiritual forces on psychological wellbeing.
36. ibid, p20.
37. Dunlop, op cit, p12.
38. id.
39. Swan, op cit (oral evidence), p534.
40. Central Australian Aboriginal Congress, op cit, p9.
41. ibid, p10.
42. These issues came to the fore in Queensland recently, where it was alleged that the civil liberties of an adolescent Aboriginal boy had been infringed. A report prepared by the Barambah Aboriginal Child Care Agency into youth problems at Cherbourg alleged that a young boy was taken into custody by police without the knowledge of his parents and taken to the government medical officer. He was then allegedly taken to Brisbane, where attempts were made to have him admitted to a psychiatric hospital. 1993.
43. John Hopkins, Coordinator, Disability Services, Central Australia. Oral evidence, Alice Springs 23.7.92, p165.
44. These concerns were raised in a letter to the Inquiry from Dr Pamela Watson and Maggie Brady, research fellow, Australian Institute of Aboriginal and Torres Strait Islander Studies. In it they provided a critique of three academic papers on Aboriginal substance abuse in which, they suggested: 'uncorroborated claims are used as important elements in the construction of argument, relevant information is omitted or misrepresented, there are factual mistakes, and perceived negative attitudes or behaviours which are common to most, if not all, human groups are presented as being specific to Aboriginal society. As a result of these errors, the articles present accounts of drug/alcohol use which are extremely derogatory to Aboriginal people.'
45. Spencer et al, op cit, p1.
46. John Lawrence, solicitor, North Australian Aboriginal Legal Aid Service Inc. Submission, p3.
47. ibid, pp3-4.
48. id.
49. Wyatt, op cit, p5.
50. Watson, op cit, p1511.
51. Reser, op cit, p1277.

52. Dudgeon, op cit, pp305-308.
53. Pickett, op cit, p307.
54. Margaret Collins, administrator, Central Australian Advocacy Service. Oral evidence, Alice Springs 23.7.92, p175.
55. Jo Harrison, project officer, Central Australian Advocacy Service (CAAS). Oral evidence, Alice Springs 23.7.92, p175.
56. ibid, pp175-176.
57. Central Australian Advocacy Service. Submission, pp5-6.
58. Central Australian Aboriginal Congress, op cit, p7.
59. Central Australian Advocacy Service, op cit, p6.
60. Extract from explanation of a painting by Mantatjara Wilson, included with Central Australian Advocacy Service submission, op cit.
61. Anthropologist Jane Lloyd, quoted in Central Australian Advocacy Service submission op cit, p4.
62. Central Australian Advocacy Service, op cit, p7.
63. ibid, p9.
64. Central Australian Aboriginal Congress, op cit, p8.
65. id.
66. Dr Michael Dudley, psychiatrist, Avoca Clinic, Prince of Wales Hospital, Sydney. Oral evidence, Sydney 18.6.91, pp197-198.
67. Dr John Rigano, child psychiatrist. Oral evidence, Cairns 9.8.91, p1026.
68. ibid, p1027.
69. Miller, oral evidence, op cit, p1011.
70. Professor Bruce Tonge, Head, Monash University Centre for Developmental Psychiatry. Oral evidence, Melbourne 9.4.91, p244.
71. Marjorie Thorpe, coordinator, Victorian Aboriginal Mental Health Network. Oral evidence, Melbourne 9.4.91, p246.
72. Houston, op cit, p604.
73. Dr Maree Bashir, Director, Community Health Services for Central Sydney. Oral evidence, Sydney 20.6.91, p499.
74. Dudgeon, op cit, p313.
75. Hunter, op cit, pp536-537.
76. id.
77. E Hunter, *Problems of Aboriginal Youth in Remote Australia*. Information provided to the Inquiry. One innovative program to divert young Aboriginal offenders and those 'at risk' from remand and detention facilities has recently been instituted in WA. It is jointly funded by the Australian Youth Foundation. (Details of the program can be obtained from the Executive Director of the Foundation at Suite 302/134 William St, East Sydney, NSW. 2011.)
78. Kevin Doolan, Town Clerk, and Mathew Woneaemirri, President, Milikapiti Community Government Council, Melville Island. Submission, p1.
79. Miller, op cit, pp1010-1014.
80. ibid, p1010.

81. Glen Norris, psychiatric nurse. Oral evidence, Darwin 21.7.92, p82.
82. Chickie Darling, Aboriginal mental health worker. Oral evidence, Darwin 21.7.92, p86.
83. Norris, op cit, pp82-83.
84. *ibid*, p83.
85. Spencer et al, op cit, p1.
86. Aboriginal Medical Service Co-operative Ltd, op cit, p11.
87. Alex Goulash, voluntary worker, Aboriginal and Islander Community Welfare Service. Oral evidence, Brisbane 15.8.91, p1504.
88. Wilkie, Thorpe, et al. Submission of the Aboriginal and Islander Community Health Service, Brisbane, p2.
89. National Aboriginal Health Strategy Working Party, op cit, p173.
90. Spencer et al, op cit, p3.
91. *ibid*, p1.
92. Sally Ross, Director, Danila Dilba Aboriginal Medical Service. Oral evidence, Darwin 21.7.92, p71.
93. Norris, op cit, p83.
94. 'Black Mental Patients Held in Desert Cages', *Melbourne Age*, 10 December 1992.
95. Stephen Hall et al, *Report of Visit to Wilson's Patch*, Anglican Social Responsibilities Commission, 22 December 1992, p6.
96. Health Department of Western Australia, *Investigation Concerning Aboriginal People Discharged from Graylands Hospital to Wilson's Patch: Report to the Minister for Health*, Perth, December 1992, p2.
97. *ibid*, p3.
98. *ibid*, p4.
99. Stephen Hall et al, op cit, p5.
100. Western Australian Health Department, op cit, p16.
101. *ibid*, p17.
102. *id*.
103. *ibid*, pp21-22.
104. Health Department of Western Australia Mental Health Policy Unit, *Draft Policy on Aftercare*, February, 1993, p10.
105. Central Australian Aboriginal Congress submission, op cit, p3.
106. *ibid*, p6.
107. Commissioner Elliott Johnston QC, *Royal Commission into Aboriginal Deaths in Custody: National Report v4*, p224.
108. Central Australian Aboriginal Congress, op cit, p3.
109. Dudgeon, op cit, p315.



## Chapter 24

### PEOPLE FROM NON-ENGLISH SPEAKING BACKGROUNDS

There is a pattern of systematic disadvantage for the migrant group. The health care system has its own culture... Most workers take this culture for granted. We don't appreciate that health care is practised in very different ways in different countries and it depends largely on culture.<sup>1</sup>

Approximately 3.2 million Australians, or 20 percent of the population, are migrants from non-English speaking countries or the children of migrants from such countries. That is, they are from a non-English speaking background.<sup>2</sup> Evidence to the Inquiry from consumers, consumer advocates and service providers clearly established that although Australian society is becoming increasingly culturally diverse, the current mental health 'system' is failing to meet the needs of a large number of people with mental illness from non-English speaking backgrounds.

The Inquiry heard that while the Commonwealth Government and most State and Territory Governments emphasise access, equity and social justice in their health policy statements, these objectives are yet to be realised in the form of culturally appropriate services and community education. The provision of effective early intervention and treatment services for people from non-English speaking backgrounds is also essential if the implementation of the National Mental Health Policy is to address the needs of one in every five Australians.

#### The Migration Experience

Since most people from non-English speaking backgrounds have come to Australia as migrants, the migration process itself has become a significant focus in considering the prevalence, diagnosis and treatment of mental illness among different ethnic groups.

The question most consistently asked in the research literature on migration and mental illness has been: Is migration associated with an increased prevalence of mental illness?<sup>3</sup>

Studies on the connection between migration and mental illness have concentrated on two issues. First, the migration experience as a causal factor in the development of mental illness, and second, the prevalence of mental illness among people who choose to migrate. The research on the causes of mental

illness is generally inconclusive — because ‘Very few adequately controlled community-based studies of the prevalence of psychiatric disorder in immigrant communities have been carried out, and results have been quite variable’.<sup>4</sup>

Recent studies in Australia and overseas suggest that the emotional and physical trauma and disruption sometimes associated with migration to and settlement in a new country may create psychological distress or exacerbate existing vulnerability to mental illness.<sup>5</sup>

However, it is difficult to isolate definitive causal factors in the development of mental illness among migrant groups. Dr Elsa Bernardi, a bilingual psychiatrist who works with patients from non-English speaking backgrounds, presented evidence that the diverse cultural origins and individual experiences of many migrants pre and post migration make generalisation very difficult.<sup>6</sup> Other witnesses agreed that a wide variety of factors may affect a migrant’s mental health and predisposition to mental illness:

Research tells us that the stress associated with the migration process is a factor in relation to the risk of the development of mental illness. We know that issues such as the reception and ease of settlement in the host country, the size of the ethnic community and its capacity to provide support, accessibility and availability of services, discrimination and racism, underemployment and employment of migrants are all crucial issues with respect to the impact of migration on the mental health of individuals.<sup>7</sup>

This view is supported by a recent review of Australian research on ethnicity, migration and mental illness which found that there is no conclusive evidence on the incidence of mental illness among migrants. The researchers concluded that ‘it is not the culture of one’s ethnicity per se, but the interaction between culture and societal forces and the immigrants’ status and experience in society that accounts for a given profile of immigrant mental health’.<sup>8</sup>

## **Groups Particularly at Risk**

The Inquiry heard evidence that several groups within the non-English speaking background community are more susceptible to mental illness. Refugees are particularly vulnerable. Others at risk include the elderly and women.

### **Refugees**

Refugees, particularly those who have experienced torture and trauma, face a high risk of developing a mental disorder. Australia receives between 10,000 and 15,000 refugees and displaced persons each year under its refugee and special humanitarian immigration programs. The Inquiry was told that a significant number of these migrants are ‘experiencing physical and mental

health problems as a result of their torture experience'.<sup>9</sup> No figures are available to establish how many refugees have been victims of such treatment. However, some witnesses suggested that at least 10 percent and possibly as many as 15 percent of refugees are suffering mental illness as a result of maltreatment prior to their migration.<sup>10</sup>

Professor Derek Silove, a psychiatrist who has worked with many refugees, gave evidence that those who have come to Australia under the humanitarian program are particularly at risk because of the human rights violations they have suffered.

They are dispossessed, dislocated, they suffer psychological disintegration and they arrive in a country where they become disempowered. Ten to twenty percent of these people have been subject to formal torture and that's probably an underestimate, but almost all of them have been subjected to what we call 'organised violence' which is a World Health Organisation term to cover a wide range of trauma to do with civil unrest, dispossession, persecution by authorities, famine, war and other forms of violence carried out in societies that are disintegrating.<sup>11</sup>

Professor Silove told the Inquiry that torture survivors could, on the basis of their psychiatric needs, be divided into two groups: those suffering from the more traditionally recognised psychiatric disorders such as schizophrenia and manic depressive disorder, and those suffering from other psychiatric disorders which were the direct consequences of torture and 'refugee trauma'. The most common psychiatric condition associated with this second group is 'post traumatic stress disorder', a term used to describe a range of psychological and psychiatric phenomena which manifest themselves in individuals who have suffered extraordinary physical and emotional trauma. Post traumatic stress disorder (PTSD) results from 'a terrifying calamity involving threatened or actual loss of life or severe bodily harm. The syndrome lasts for at least six months and can be distinguished from the usual period of distress that would be expected to follow the catastrophe.'<sup>12</sup>

The Clinical Coordinator of the Rehabilitation Unit for Survivors of Torture and Trauma in Brisbane described the symptoms associated with PTSD:

The effects of torture can be conceptualised as physical, psychological, social and spiritual. The physical effects are the easiest to treat. The other three effects are much more difficult because the aim of torture is to destroy without actually killing. A torture survivor is typically quite disabled socially and suffers serious disruption to mental health. Physiologically there is upset in terms of sleep, appetite and energy level. Cognition is usually disturbed with memory problems, concentration and orientation problems, and stress symptoms [such as] hallucinations, panic attacks, and flashbacks [are common]. Values and beliefs may be shattered and identity and integrity destroyed... These symptoms can make the initial settlement tasks almost impossible for the torture survivor and their family.<sup>13</sup>

Mental illness among refugees can sometimes be difficult to diagnose. The NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors (STARTTS) said that in addition to the kinds of symptoms described above, mental health problems associated with torture and trauma can also manifest themselves somatically in conditions such as ‘...chronic pain, arthritic conditions, broken bones, brain damage, and cardio-pulmonary disorders’.<sup>14</sup>

It is not uncommon for torture survivors to visit general practitioners for treatment of these physical symptoms. However, general practitioners often fail to make a diagnosis of PTSD because they are not trained to recognise it. As a result, there are refugees in our community in need of professional assistance whose problems remain undiagnosed or incorrectly diagnosed. In either case they are not receiving appropriate treatment.

Evidence presented to the Inquiry indicated that the identification of PTSD among refugees and the provision of specific psychiatric services are comparatively recent developments in Australia. The Inquiry was told that although specialist services are available in Melbourne, Sydney and Brisbane for treating torture and trauma survivors, they are unable to meet demand because of their limited financial and professional resources.<sup>15</sup> Professor Silove spoke of the urgent need for a coherent and sustained approach to the psychological problems faced by refugees:

Policy in this country in dealing with the psychiatric and psychosocial problems of refugees...is somewhat piecemeal [and] ad hoc. [For example] there is no coherent screening program for psychiatric and psychological problems. There are screening programs for physical disorders when refugees come, which are partially effective — but none to screen for family problems, psychosocial problems, and no coherent, nationwide policy and set of procedures for dealing with this vast problem across the country.<sup>16</sup>

At the time of writing it appears clear, tragically, that this need will not diminish — assuming our policies on humanitarian and refugee intake and family reunion continue. The atrocities perpetrated in the former Yugoslavia will, for example, mean a significantly increased number of PTSD victims requiring assistance. Indeed, the level of savagery recently inflicted on tens of thousands of civilians appears to be posing new challenges to those who seek to care for its victims.<sup>17</sup>

### **The Elderly**

The Australian population is ageing rapidly. Projections suggest that by the year 2001, more than 20 percent of individuals aged 60 and over will be from non-English speaking backgrounds.<sup>18</sup> The Inquiry received expert evidence

concerning the effect the changing demographics of our ageing population is having and will continue to have on service provision:

Migration to Australia has followed a wave pattern, with the sequence from World War II being firstly East European refugees... Secondly, migrants from Western Europe, then migrants from the Mediterranean: the Italians, the Greeks, the Yugoslavs, then [more recently] the Asian migrants and the refugees from Indo-China... The wave pattern of immigration has resulted in...an increase in the proportion of older [migrants]... We're now seeing more elderly with depression and dementia and the shortfall of services to provide for those problems in the elderly migrant who doesn't speak English.<sup>19</sup>

As the evidence analysed in Chapter 17 indicates, personal networks and support systems are extremely important in maintaining mental health as people age and become more dependent on those around them for physical and emotional care. For many elderly people from non-English speaking backgrounds the situation becomes particularly complicated. Many older migrants who came to Australia from non-anglophone countries may have learnt English comparatively late in life. As a result of dementia and other illnesses, they lose their linguistic abilities in English and, sometimes, their native tongue. One expert specialising in transcultural psychiatry told the Inquiry:

It is well known that with age [people] have reduced resources, both cognitive, emotional and physical, to look after themselves. The question is much more complicated for the person from non-English speaking background. His even meagre knowledge of the English language is further reduced, completely disappears, and when he is put in institutions where he all of a sudden after many years of particular life experience finds himself in a completely new situation ranging from not having people with whom he could communicate to having food which has never been part of his diet — I think this could be seen, in a way, as significant discrimination against these people.<sup>20</sup>

For elderly people from non-English speaking backgrounds, the loss of language can lead to social isolation and very real difficulties in accessing aged care and psychiatric services. Several witnesses told the Inquiry that a significant proportion of elderly people from non-English speaking backgrounds are affected by mental illness. However, they have not been diagnosed or received professional support for their illness because they are so isolated:

The recognition of mental illness happens much later with non-English speaking background people than among the Australian population... The result of this is that we are meeting these people in the total crisis situation... I am often sent or referred to people who might be lonely — and several sentences exchanged with these people make me realise they are extremely disturbed; disturbed to the point that if somebody will virtually speak a sentence to them, they will realise that.<sup>21</sup>

This lack of early diagnosis and intervention can precipitate chronicity and institutionalisation. One witness described a number of situations in which she

had encountered elderly people from non-English speaking backgrounds who were highly disturbed.<sup>22</sup> The Inquiry was told of several cases where elderly people had contact with police and psychiatric services as a result of their mental illness, but were still living in the community unassisted. One example involved an Eastern European man in his seventies with a severe psychosis:

He believes that he is Jesus; he talks about [his] war experience and has an extremely violent imagination. He wants to kill everybody around him... [On] referring his case to Mental Health, I find out that there was an example, five years ago, when he threatened the neighbours with a firearm...then the police were called. The gentleman was taken to Royal Derwent Hospital... He was discharged to the community... The tension which is building there is just incredible. I contact Mental Health and they say, 'well, we'll visit'. They visit; they never contact me back. The gentleman is still in the community.<sup>23</sup>

Elderly women from non-English speaking backgrounds are particularly at risk of having an undiagnosed mental illness because they are one of the most isolated groups in the community.

The ageing women of non-English speaking backgrounds are particularly disadvantaged... Many never learnt English. Most of them had poor schooling in their country of origin. They were employed (if they were employed at all in Australia), in poorly paid, unskilled jobs which put them at increased risk of danger to their health. Unfortunately this group, the group that needs a lot of assistance, is forgotten by the services and tends to under-utilise the services and thus doesn't show up in the statistics.<sup>24</sup>

Another witness described the case of an elderly woman living in public housing who had been behaving erratically over a long period of time and eventually became psychotic. She did not receive any assistance until an incident of self mutilation which resulted in the police being called:

The lady is placed in [hospital] in [a] total crisis situation. She is properly assessed as suffering from deep psychosis, and now the search begins for a place for her... [The nursing home will not take her [because] although she is over 65 she can cook and clean and look after herself. She is not demented, so she is not a candidate [for an institution]... She is placed [back] in the Housing Commission... The community worker and myself are already receiving very worrying sounds from community nurses and all possible Departments who are in contact with her... We all know that she needs help, it is just we cannot do anything about it.<sup>25</sup>

## Women

In addition to elderly women and those who are refugees, women from non-English speaking backgrounds may generally be at increased risk of developing a mental illness. The Inquiry was told that in addition to the emotional and psychological pressures affecting women who are mothers and carers, those

from non-English speaking backgrounds face difficulties related to their ethnicity and their disadvantaged position in Australian society.

A women's agency from our most populous State, NSW, presented the Inquiry with the results of a mental health survey of women from non-English speaking backgrounds conducted in June 1990.<sup>26</sup> The main concerns identified were depression and the subsequent over-use of tranquillisers, social isolation resulting from migration and social dislocation, the stigma associated with mental illness, culture conflict and feelings of powerlessness, and the lack of culturally appropriate treatment services. All of these factors were also identified in evidence in other States.

Many women from non-English speaking backgrounds experience loneliness and isolation as a consequence of migration:

[Adjusting to life in a new culture] is a painful process; women often lose the support of the traditional women's cultural group. Simultaneously, they are often subjected to rejection and criticism if they move towards accepting the new culture's norms. This conflict increases psychological pressure on women from other cultures.<sup>27</sup>

Not only do women from non-English speaking backgrounds face the personal difficulties of adjusting to a new society, but they must often be a major source of emotional support for their families and extended families. They often provide additional economic support to the family, frequently working in unskilled, poorly paid jobs. Evidence to the Inquiry suggested that these psychological pressures are exacerbated by cultural differences and linguistic problems which further isolate women from support networks.

The Inquiry was told that these pressures make women from non-English speaking backgrounds one of the groups most at risk of developing a mental illness.<sup>28</sup> A recent study found that the largest client group presenting at the Multicultural Psychiatric Centre in Perth were immigrant and refugee women. These women suffered from 'a lack of interaction with partners because of their long working hours, lack of contact outside the home, coping with a job as well as family commitments, the pressure of tedious jobs, and the possibility of retrenchment, or being housebound with young children'.<sup>29</sup>

These findings were also reflected in submissions to the Inquiry from advocacy and support groups. One witness noted that social isolation and the pressures of caring for a family often culminate in the development of depression and other serious illnesses:

Exposure to constant mental and physical stress, with no outlets for verbalising the various problems these women face as mothers, carers, nurturers, employees, in unstimulating,

unskilled, impoverished environments, forces them to internalise these problems [which] unconsciously manifest themselves into somatic pains and complaints which have no physical aetiology. They seek medical advice [from predominantly male, English speaking doctors] who usually prescribe pain relief drugs or, if the woman is depressed or hyperactive, anti-depressants and tranquillisers.<sup>30</sup>

While alleviating the immediate symptoms of distress, drug treatment in these circumstances does little to address the fundamental cause of the problem. If the patient is not an English speaker misdiagnosis can occur — as exemplified in the case of a Southern European woman brought to Australia as a proxy bride:

[Her husband] kept her in isolation. She became subject to panic attacks, and could not leave the house. Her husband left work to 'care for her'. However the attacks became so severe that she was periodically institutionalised. The mental health service relied on the husband to interpret, and decided [that she was] depressed and mildly schizophrenic. This revolving door syndrome continued until a Grant-in-Aid Worker and proper interpreter became involved. It was then established that the woman had panic attacks because she did not have a word of English, did not know how to use public transport, and could not be autonomous. All she needed was English classes and information to resolve her situation.<sup>31</sup>

## Accessing Services

They seek quality, relevant and accessible services, and often encounter similar difficulties when trying to obtain services. However...by virtue of their differing language, culture, and subcultural backgrounds [they] often require a differing approach to the provision of psychiatric services if they are to obtain accessible, relevant, quality services, which also uphold their fundamental human rights.<sup>32</sup>

Members of cultural minority groups are often disadvantaged in terms of access to appropriate mental health services and preventive care.<sup>33</sup> Evidence submitted to the Inquiry by community workers, service providers and consumer advocates indicated that mainstream services are under-utilised by people from non-English speaking backgrounds. Witnesses suggested that this is not because mental illness is any less prevalent in these communities, but relates to three factors: reluctance by members of ethnic communities to use the services available; barriers to accessing services once a decision has been made to seek help; and the overall lack of culturally appropriate services staffed by appropriately trained mental health professionals to treat people from non-English speaking backgrounds.

### Reluctance to Use Services

As discussed in Chapter 3, other cultures perceive the behaviours and phenomena which Western societies define as 'mental illness' in a variety of



ways. Evidence presented to the Inquiry suggested these differing perceptions of mental illness can have a significant impact on how the onset of an illness is conceptualised and, subsequently, whether assistance is sought from a psychiatrist or general practitioner.

The personal cultural history and tradition of the individual as they are reflected in the mental health and illness are actually an integral part of the presentation of both the individual and of the illness, and not only some phenomenon, something on top of universal, biological reality.<sup>34</sup>

People from non-English speaking backgrounds are often reluctant to seek medical intervention because of their 'cultural history'. Mental illness is stigmatised in many cultures — either because of the perceived influence of malevolent forces or because it involves behaviour that deviates from what is considered to be normal.

There is a degree of ignorance and stigma within certain migrant groups which lead them to care for their mentally ill at home for the longest time possible. [Because] there's a lack of extended family in Australia...this puts an incredible burden on the family to try to manage and they often only come to attention when there's a major crisis... They may come to treatment too late.<sup>35</sup>

In some cultures the unusual behaviour associated with mental illness is not perceived as being a manifestation of a psychological problem but a spiritual one. Medical intervention may not be sought because it is not seen as offering a solution to the problem. In these circumstances people from particular cultural backgrounds who believe that mentally ill people have been 'cursed' may prefer to obtain assistance from practitioners of folk medicine and 'magicians'.<sup>36</sup>

A social worker presented evidence to the Inquiry based on her study of two Italian and two Vietnamese families in Perth with relatives suffering from schizophrenic illness.<sup>37</sup> In each of these families the development of mental illness was attributed to an external physical event. For example, one family attributed their child's schizophrenia to a beating inflicted some years earlier by a school teacher.<sup>38</sup> The witness noted that:

It is interesting that all four families 'somatised'<sup>39</sup> the onset of mental illness to explain what was otherwise unexplainable... Three of the families seemed to feel no stigma because they had been able to link the ensuing illness to a causal factor. This is a feature of families from traditional backgrounds.<sup>40</sup>

The Inquiry was also told that people from non-English speaking backgrounds may be reluctant to seek early intervention because of a fear of government services. In particular, refugees and survivors of torture may regard

government with suspicion because agencies of the state have been instrumental in perpetrating human rights abuses against them in their country of origin.

To many people coming from a country with an oppressive regime, any service provided by the government is often not trusted. Our Western model of a benevolent and safe government is one we are very fortunate to have, and one which is not shared by a majority of the world's countries. We must ensure that services are introduced to each culture appropriately and encourage people to use them — not just expect them to, simply because they are there.<sup>41</sup>

## **Barriers to Obtaining Referrals and Services**

People from non-English speaking backgrounds face particular barriers in obtaining referrals and accessing mainstream treatment services. The under-utilisation of services frequently reflects the attitudes of both the ethnic communities and the service providers themselves:

To put it bluntly, mental health theory and services are geared in every way to our English speaking Anglo-Saxon majority and members of ethnic minority groups simply must fit in or miss out.<sup>42</sup>

In Victoria the Inquiry heard that government health agencies have failed to make the mental health services accessible to migrant communities — and that this failure is compounded by the lack of data on utilisation rates by people from non-English speaking backgrounds. The lack of effective needs analyses and focussed service delivery can further disadvantage the very groups already deprived of adequate access to care.<sup>43</sup>

In NSW the Inquiry was told people from non-English speaking backgrounds have less access than the rest of the population to information about mental illness and advocacy services. They are doubly disadvantaged because of the stigma attached to mental illness and by having to deal with services which are not designed for their use. It has been suggested that this is due, at least in part, to the lack of consideration given by mainstream services to identifying and targeting the needs of the ethnic communities in local health areas:

Services are either unaware of the needs of their local ethnic population or they put into place systems that only pay lip-service to the problems of access and equity.<sup>44</sup>

While the translation of material into community languages is often seen by health authorities as ensuring better access to services, evidence received by the Inquiry indicates that this is frequently not the case:

NESB communities do not have equitable access to information essential for the maintenance of health and early and effective treatment of illness. There is a paucity o

information which is available to NESB communities concerning available services, what they offer, how to gain access to them, and so on. Translation of a few pamphlets into the major community languages is a wholly inadequate response to this issue, particularly for elderly members of such communities (and others) who may be illiterate in their own language.<sup>45</sup>

Clearly, the provision of appropriate written material is only one of the strategies needed to make preventive treatment more accessible:

Information is a vital part in any service establishment and delivery. The effectiveness, utilisation and access of the service by the consumer depends on appropriate, accurate...promotion and prevention education...and [the use of] appropriate avenues to reach vulnerable groups in the community.<sup>46</sup>

For people not fluent in English, or unfamiliar with the Australian health system, it can be extremely difficult to obtain medical treatment or intervention before an illness becomes acute:

The two major points of contact for information seem to be Migrant Resource Centres (MRCs) and local general practitioners. If MRCs are unaware of the services in mental health available in their area, or unfamiliar with mental illness and the mental health system, then there will be no, or inappropriate, referrals from them. Similarly, if GPs do not link up with local services who can provide for a NESB client, then there will be difficulties.<sup>47</sup>

In Tasmania the Inquiry was told that many people from non-English speaking backgrounds use Migrant Resource Centres as a 'last resort'.<sup>48</sup> In Victoria these issues were also addressed by the Ethnic Communities and Mental Health Issues Group of the Victorian Community Managed Mental Health Services agency (VICSERV) in its submission:

Often NESB psychiatrically ill and their families are referred to ethno-specific services in the community... Often staff in these ethno-specific services lack information and expertise in psychiatry and find they are unable to assist. The result for the individuals and their families is an ethno-specific service which is culturally relevant and linguistically accessible but which does not meet psychiatric needs, while public run or funded psychiatric services may offer psychiatric knowledge, but are inaccessible.<sup>49</sup>

## **Lack of Culturally Appropriate Services**

There was unanimity among experts in transcultural and general psychiatry, community advocates, ethnic community workers and families directly affected that the mainstream psychiatric system is not effectively servicing the needs of people from non-English speaking backgrounds. Two major difficulties were continually raised in evidence. First, the essentially monocultural nature of the Australian medical system and the consequent provision of culturally inappro-

priate services to people from non-English speaking backgrounds; and second, the use and misuse of interpreters.

The Inquiry received a great deal of evidence about the standard of treatment received once a mentally ill person is referred to public inpatient psychiatric services — but much less about utilisation rates prior to referral. There has been limited research concerning the frequency with which people from non-English speaking backgrounds visit general practitioners and community mental health centres and whether this is similar to the rest of the Australian population. However, evidence and secondary research made available to the Inquiry indicates it is not.<sup>50</sup>

The few studies that have been undertaken suggest significant differences between immigrant and native born Australians in relation to utilisation of primary health care and outpatient services.

In one survey of Turkish people living in Melbourne, researchers found a high rate of psychological stress among respondents, but a significant under-utilisation of the psychiatric services available, including community psychiatric clinics,<sup>51</sup> and ‘...admissions of Turkish-born people to state psychiatric hospitals occur at two thirds the rate of that for the Australian-born [and] contact with community psychiatric clinics occurs at one third the rate of that for the Australian born’.<sup>52</sup>

Expert evidence in NSW indicated that ‘crisis services are utilised more often than preventive services’;<sup>53</sup> and in Victoria:

It is clear that in general it is primarily the very disabled who come to the attention of psychiatric services... This observation highlights the question of what happens to those members of the [NESB] community who may have less severe disability but have significant psychiatric illness. Are they receiving treatment? If so, by whom are they being treated and how effectively? If not, it is likely...that suffering and morbidity for which there may be effective treatment goes undetected.<sup>54</sup>

This may be linked to the comparatively high rates of hospitalisation and inpatient care among people from non-English speaking backgrounds. The Mental Health Coordinating Council of NSW expressed concern that people from non-English speaking backgrounds experience ‘significantly longer periods of hospitalisation [which is] possibly due to clients being admitted to hospital later in the illness’ and the disturbing and significant fact that the ‘majority of admissions are involuntary and/or escorted by police’.<sup>55</sup>

## **Diagnostic Issues**

There are few assessment and treatment programs designed to meet the particular needs of ethnic minority groups. The importance of cross-cultural awareness on the part of psychiatrists and other mental health professionals was emphasised by the Federation of Ethnic Communities Councils of Australia in its submission to the Inquiry:

The ethnic background of consumers must be considered in the...diagnosis and management of mental disorder... [In] the absence of this consideration, diagnostic error occurs which leads to inappropriate treatment, prolongation of illness and development of chronicity and disability.<sup>56</sup>

Evidence to the Inquiry indicated that diagnostic error and inappropriate treatment frequently occur. The most common diagnostic errors made by psychiatrists treating people from non-English speaking backgrounds relate to misdiagnosis of the nature of the illness and diagnosis of psychopathology when it is not present.

Dr Bernardi told the Inquiry that overassessment and inaccurate assessment of symptoms often occur because of a clinician's lack of understanding of other cultures. She recounted, as one example, the history of an Italian man who had sustained a head injury in a car accident. The man was suffering from concussion and was brought into casualty. When he recovered consciousness he was disoriented and believed that the sedative he was being given was poison. The medical staff took this to indicate paranoid behaviour and certified the man. However:

He happened to catch an Italian speaking psychiatrist... [an] interview in his own language [resulted in diagnosis of] an organic condition... He received some medication and was immediately discharged... [He recovered fully] within a few weeks.<sup>57</sup>

The ethnocentricity of psychiatrists was raised by several interpreters who gave evidence to the Inquiry. One interpreter and welfare worker told the Inquiry of several cases where patients' rights were infringed as a result of a misdiagnosis resulting from poor communication:

A person presented at the hospital behaving strangely... No interpreter was called [and] no cultural background information was sought... The patient was there for six months until [an ethnic community worker contacted the family]... Communication was improved and things were clarified... The person was discharged because it was recognised that he did not have a mental illness but an alcohol problem.<sup>58</sup>

The Inquiry also heard that the diagnostic tools used by psychiatrists to evaluate the psychological state of patients can, because of their inherent cultural bias, be entirely inappropriate for people from non-English speaking backgrounds.

In tests and diagnostic concepts such as the DSM-III-R<sup>59</sup>...concepts are devised and questions formulated to gauge a standard response... These standards are derived from the normal response of the population sample [which is frequently Anglo-Celtic].<sup>60</sup>

A number of witnesses said they were concerned about the application of culturally inappropriate tests. One example concerned a psychiatrist who was administering a test to determine the cognitive ability of a newly arrived migrant. One of the questions was, 'Who is the Prime Minister of Australia ?' In this witness's view, 'this test had no cultural sensitivity at all'.<sup>61</sup> In another case, an interpreter had to help administer a word association test to a Southern European woman who became increasingly agitated:

She said to me in her own language, 'What is he doing? Is he mocking me?' She [was very] distressed... The woman said she was not a child and she was not going to do this test. [Afterwards]...I explained to the doctor that some tests are unknown to people from different cultural backgrounds and they may view them with suspicion... [The doctor] was not interested.<sup>62</sup>

The validity of standard diagnostic tools such as the DSM-III-R was also questioned by expert witnesses. There is considerable debate in professional circles about whether it is appropriate for psychiatrists to use Western based, biological models to diagnose mental illness in people from non-Western cultures:

The therapist, according to this view, is expected to 'deculturalise' the presenting symptoms in order to arrive at an objective diagnosis in which a biological base is implicit... Such an orientation makes it difficult to diagnose [people from non-Western cultures]...who necessarily perceive stress from the perspective of their own cultures... The rationale behind DSM-III-R assumes that indicators of dysfunction are uniform and universal. It fails to take into account illness behaviour which is imbued with cultural symbols, values and beliefs.<sup>63</sup>

The Inquiry was told that very few Australian psychiatrists have the necessary expertise to take account of cross-cultural values and beliefs when making a diagnosis. They often rely on bio-medical models of illness and misdiagnoses are consequently made. For example, many people from non-English speaking backgrounds refer to 'hearing voices' and 'talking to God'.<sup>64</sup> While some individuals experience auditory hallucinations as a result of psychosis, it should also be recognised that many people from Southern European cultures are extremely devout and would certainly find solace in times of stress by communicating (sometimes audibly) with God. A psychiatrist failing to take

adequate account of these cultural 'nuances' could find it difficult to differentiate between normal and psychotic behaviour.

The Inquiry also heard evidence that individuals from particular cultural backgrounds are more likely to exhibit physical symptoms as a result of psychiatric disorder or psychological distress.<sup>65</sup> This process, known as somatisation, can complicate diagnosis:

Applying the DSM-III-R classification to non-Western patients in a textbook fashion may not only produce misleading diagnoses but may also neglect other valuable behavioural and situational variables and observations that might shed light on the patient's emotional condition.<sup>66</sup>

Lack of awareness by clinicians can lead to inappropriate diagnosis and the infringement of patients' rights. For example, women from non-English speaking backgrounds are sometimes misdiagnosed as suffering from a mental illness when overmedication or family problems may be the real problem:

Many migrant women come to see me with a long history of depression which has been treated with benzodiazepines. They are now dependent on drugs...[and have come to expect] that this is their lot in life... They may be victims of domestic abuse, but because of cultural factors will not tell a male practitioner... They are treated as being a sick person rather than the family being the problem... [As a result] they are admitted to hospital inappropriately.<sup>67</sup>

### **Use of Interpreters in Hospitals**

The failure of psychiatric services to adequately provide for the linguistic and cultural needs [of NESB patients] affects the ability of individuals and their families to...participate in decision making about their own psychiatric treatment. They are effectively disenfranchised.<sup>68</sup>

These problems are most apparent when people from non-English speaking background are admitted to hospital. Here, the medical model may exclude any consideration of the individual's 'values, aspirations, needs and personal experiences' and the cultural context in which they have developed.<sup>69</sup> As a result, hospitalisation can exacerbate the trauma experienced by non-English speaking patients because it increases the sense of alienation and distress associated with their illness.<sup>70</sup>

It is impossible to ensure that non-English speaking patients are aware of their rights and understand the nature of their treatment when psychiatrists and other hospital staff do not know when or how to use interpreters:

The failure to provide practice guidelines for professionals across services indicating how to use [interpreter services] and when it is necessary or appropriate results in the onus for

requesting [them] being placed on the NESB individual and/or family, or an interested staff member. The result may be that an individual who requires interpreter services to understand the psychiatric illness and the service system does not receive this information.<sup>71</sup>

Leaving the decision of whether and when to use an interpreter to the discretion of medical staff can lead to difficulties. For example, a person may be admitted in an emergency situation, making it difficult for hospital staff to obtain a detailed case history or to assess their proficiency in English. As a result, it may not be until treatment has commenced that it becomes apparent the patient does not understand what is happening.

One witness told the Inquiry of an individual who had been in hospital for four months without seeing an interpreter. Medication was prescribed and the patient developed an allergic reaction which he could have foreshadowed if staff had used an interpreter to communicate with him. In another case, a patient received ECT:

[No prior explanation was given]... This person did not speak any English, had no interpreter and was totally terrified [about] the whole situation.<sup>72</sup>

The Inquiry frequently heard evidence that psychiatrists and nurses use other inpatients, family members and cleaners to interpret.<sup>73</sup> Not only does this violate principles of privacy and confidentiality, but it may also mean that important decisions are based on inaccurate information — sometimes with life-threatening results.

Interpreters clearly have a crucial role to play in the treatment process by bridging the communication gap between patient and clinician. However, the issue is complex and needs to be carefully handled. While qualified interpreters are proficient in translation and communication, their skills may not include familiarity with mental health terminology and other specialised psychiatric issues. One expert told the Inquiry that clinicians tend to oversimplify the issues involved in treating people from non-English speaking backgrounds:

All the efforts in providing services for people from non-English speaking backgrounds have been directed towards language... Nobody denies the need to understand the [patient] on a verbal level... But it has been repeatedly pointed out in the international psychiatric literature that with the use of interpreters... numbers of phenomena which could be relevant for understanding the mental illness [are not picked up].<sup>74</sup>

Clearly, interpreters need special training to work effectively with people affected by mental illness.



The presence of an inappropriate interpreter — no matter how proficient their linguistic skills — can actually inhibit the development of a trusting client-patient relationship. The Inquiry was told that patients from non-English speaking backgrounds will sometimes refuse to have an interpreter present during consultations because they know the individual concerned:

When it comes to very small communities it's almost impossible to get an anonymous interpreter, almost inevitably the interpreter will know the patient and vice versa... The patients perceive that there will be talk in the community about their case.<sup>75</sup>

## **Treatment Issues**

The evidence indicated that although many non-English speaking consumers receive drug treatment, many do not understand the nature of their illness and why a particular course of treatment is being prescribed. The Mental Health Coordinating Council of NSW documented the case of a person who had been receiving treatment for schizophrenia for several years but was unaware of his condition until a doctor who spoke his language explained what schizophrenia was. As the Council noted (perhaps optimistically):

It is virtually inconceivable that an English speaking person would receive treatment for a long period of time without fully understanding the illness.<sup>76</sup>

The Inquiry conducted a telephone survey to obtain additional information about the experiences of consumers from non-English speaking backgrounds.<sup>77</sup> Responses revealed that many people who had received drug treatment had not been adequately informed about the nature of their mental illness and the type and side effects of the drugs prescribed. One consumer told the Inquiry he had been seeing private psychiatrists and taking medication for several years, but only discovered that he was being treated for schizophrenia when he saw his chart during a period in hospital. Others expressed concern that they had never been offered alternatives to drug based treatment or information about community support services.

This evidence is supported by recent research which indicates that people from non-English speaking backgrounds are more likely to receive treatment with drugs and ECT, and less likely to receive psychotherapy, group therapy and occupational therapy — even where these may be more appropriate for their particular conditions.<sup>78</sup>

Another recent study of the case records of 185 Turkish patients referred to a bilingual psychiatric service, revealed that a significant proportion had been receiving inappropriate drug treatment. The patients were suffering from

situational reaction, neurotic disorder, schizophrenia and paranoid psychosis, psychotic depression and mania. The researchers concluded that

...drug treatment was common, regardless of diagnosis and there was a poor match between diagnostic category and the classes of drugs which patients were receiving, suggesting that treatment with inappropriate classes of drugs was not uncommon.<sup>79</sup>

Community organisations also expressed concern about the over-reliance on drug-based treatment programs:

Many of the NESB psychiatrically ill are effectively shut out from receiving many non-pharmacological rehabilitation and treatment services both in institutional and community settings.<sup>80</sup>

The Inquiry heard several explanations for this over-emphasis on drug treatment. First, people from non-English speaking backgrounds are more likely to receive treatment in the chronic stage of an illness when medication is necessary. Second, language differences between patient and clinician make misdiagnosis and inappropriate treatment more likely. Finally, people from non-English speaking backgrounds may be unwilling to participate in psychosocial therapies because they are culturally unfamiliar.

However, expert evidence to the Inquiry indicated that people from non-English speaking backgrounds are often forced to comply with treatment approaches and therapies that are anathema to their cultural background and values.<sup>81</sup> It was suggested that the only way to meet these needs is to develop more holistic treatment strategies which are closely linked into local communities:

The psychiatric hospital is something extremely important. However, I believe that the accent on the distribution of resources and organisation of services has to be on community oriented psychiatry... The non-English speaking background patient has to have the support of their community.<sup>82</sup>

## **Continuity of Care**

People from non-English speaking backgrounds experience particular problems in obtaining continuity of care. Ethnic organisations and communities generally do not have the resources to provide community support to people with psychiatric illness and their families once they have been discharged from hospital.<sup>83</sup>

A matter for particular concern, given the major shift to community-based psychiatric services, is that community-based services are particularly under-used by immigrant communities. In this case, a shift to community-based services, which may be expected to lead to considerable benefits for the general community, may, paradoxically, lead to a

further reduction in service use by immigrant communities, who may have a greater need for services. It is not possible to predict such difficulties and to prevent unintended consequences of service change without information such as can be derived from service utilisation data.<sup>84</sup>

In Victoria, the Inquiry was told that 'there is a significant population making use of psychiatric inpatient and outpatient facilities, but is receiving very little in terms of other [community based] services'.<sup>85</sup> In the 1989-90 financial year, 20 percent of the individuals discharged from psychiatric inpatient services in Victoria were from non-English speaking backgrounds.<sup>86</sup> While discharge data reflects a high utilisation rate of inpatient services, there is no information available about the extent to which people from non-English speaking backgrounds use community based programs and community managed services once they leave hospital.<sup>87</sup>

The under-utilisation of community based psychiatric services is often a function of poor or non-existent discharge planning. The Inquiry was told by an organisation representing the large Greek community in Melbourne that patients are often discharged into the community with no support networks or structured plans for continuing care.<sup>88</sup> This was echoed by other Victorian witnesses:

Unfortunately NESB communities have not had information and have not participated in the debate or the processes involved in deinstitutionalisation. This has meant a generally poor understanding of the psychiatric service system...and the support and rehabilitation options available.<sup>89</sup>

In the absence of information about alternatives to hospital based care, many consumers from non-English speaking backgrounds and their families are unable to lobby for services and initiate change. Instead, they continue to care for the mentally ill at home, and utilise inpatient facilities sporadically.

In many respects people of NESB [non-English speaking background] who are mentally ill share similar objectives to people of ESB [English speaking background] in their use of psychiatric services.

## **What is Required?**

NESB issues have been addressed by governments at all levels over the last ten years — the Federal program of 'Access and Equity' has been in place for some time, and its title is synonymous with the major problems facing people of NESB... Equal opportunity practices and anti-discrimination legislation have gone a long way to removing visible barriers to employment, accessing services and quality of life. What is left now, however, is the task of remodelling services in the community at the grass roots level, in order to make them appropriate and accessible.<sup>90</sup>

## **The Need for Culturally Appropriate Services**

Fundamental problems contributing to inadequate mental health care models include a lack of easily accessible translating services, lack of cross-cultural education in psychiatry for mental health workers and poor working relationships with ethno-specific non-government organisations resulting in inappropriate referrals, and poor collaboration and consultation.<sup>91</sup>

Evidence to the Inquiry established that people from non-English speaking backgrounds often experience infringements of their human rights as a result of culturally inappropriate services and insensitivity or ignorance on the part of psychiatrists and other mental health professionals. There appears to be a mistaken perception on the part of some policy planners and service providers that the particular needs of non-English speaking consumers can be adequately met by the mainstream services currently available. This is clearly not the case.

Many of the inadequacies in services currently available relate to the fact that diagnosis and treatment of psychiatric disorders are firmly based on Western definitions of mental illness and the medical model. Service providers must develop a more comprehensive approach to these issues and to examine ways in which cross-cultural perspectives can be introduced into the clinical setting.

A major area of concern for many groups representing non-English speaking people is the absence of consumer participation in decision-making and planning. It was suggested to the Inquiry that simple but important strategies for overcoming the ethnocentric nature of mainstream services include the employment of bilingual and bicultural psychiatrists and mental health workers and the development of language skills among health professionals treating NESB people with psychiatric disabilities. Related to this is the demonstrated requirement for more stringent guidelines for the use of interpreters.

The evidence presented clearly established that misdiagnosis and inappropriate treatment of non-English speaking consumers could have been prevented in many circumstances by better communication with clients. Training in the role of interpreters in the clinical process and the use of interpreters and ethno-specific agencies would be valuable for many mental health professionals. In addition, the introduction of standard procedures in public psychiatric hospitals could include the use of interpreters at key stages, including admission, the period following admission when decisions about treatment are being made, during pre-discharge planning (of which there is currently precious little) and at the point of discharge.

The evidence also demonstrated that mainstream services are often unaware of the demographics of their client groups. Understanding the demographic profile

of the ethnic groups living within an area would allow local service providers to target their resources and outreach strategies to particular communities. Similarly, improved liaison and information-sharing with ethno-specific non-Government agencies would facilitate client involvement in policy development and planning and encourage a more informed understanding of the needs of particular client groups. It would also encourage the use of community-based mental health centres and other alternatives to hospital treatment.

The Inquiry heard that one of the main impediments to successful service provision is the lack of coordination between government, non-government and ethno-specific agencies in relation to the planning, implementation and evaluation of services:

[The failure to coordinate policy development]...only increases the probability that services relevant to NESB people and their families will be developed in an ad hoc manner and not integrated within all service delivery areas. The result is uncertainty of access to relevant services for NESB people, fragmented and generally inadequate delivery.<sup>92</sup>

The provision of adequate funding is obviously a significant element in the development of culturally appropriate mental health services. Several psychiatrists told the Inquiry that they acknowledged the need for specialist services, but simply could not provide for them from existing resources:

We are under-resourced [and that] means that we have even more difficulty in trying to provide for the niche requirements for the different NESB groups. I think this is a problem.<sup>93</sup>

Several specialist services are currently operating in Australia for migrants suffering psychiatric illness as a result of torture and trauma. However, their activities are also threatened by insufficient funding.

A number of witnesses suggested that one positive way of addressing these problems was to fund more joint projects between the community and government sectors:

[One problem has been] the difficulty in initiating collaborative pilot projects between government and non-government organisations... A key area of concern is looking at the collaboration between government and non-government organisations regarding new innovations, [to] target people from non-English speaking backgrounds.<sup>94</sup>

## **Transcultural Psychiatric Models**

While there are few services designed to meet the special needs of people from non-English speaking backgrounds in Australia, the Inquiry did receive

evidence concerning two specialist facilities: the Multicultural Psychiatric Centre in Perth, and the Transcultural Psychiatry Unit in Melbourne.

Both centres operate along the following lines:

In essence, [transcultural psychiatry] challenges the Western frame of reference within which disease is understood and treated. It basically questions the view that signs and symptoms of behaviour are logically of the same order in different cultures. As a result of this new thinking we have begun to question the taken-for-granted assumptions of psychiatric theorising such as those relating to the normal/abnormal, validity of diagnostic categories, assumptions about modes of treatment...<sup>95</sup>

### *The Multicultural Psychiatric Centre*

The Multicultural Psychiatric Centre was established by the Health Department of Western Australia in 1983. The Centre's underlying philosophy is holistic:

The individual with psychological/psychiatric problems, from whatever background, should be seen and understood as a total human being and not as an admixture only of symptoms or social problems or cultural peculiarities.<sup>96</sup>

The Centre is community-based, and provides specific clinical psychiatric services as well as a range of psychosocial therapies. It employs a multidisciplinary team of psychiatrists, psychiatric nurses, psychologists and social workers. At the time of writing 13-15 permanent staff were employed.

The Centre strives to care for patients in the community wherever possible. It runs a comprehensive outpatient service for people from non-English speaking backgrounds, providing consultations at the Centre itself, as well as consultations in patients' homes, hospital wards and nursing homes as necessary. Community psychiatric nurses make home visits, monitor medication use and provide crisis intervention services.

The Centre is concerned with better understanding the relationship between culture and mental illness, and the delivery of psychiatric services in a multicultural society. Clinical services are supplemented by a range of educational and therapeutic activities, including welfare services and living skills for clients, and practical advice and assistance in relation to accommodation, employment and financial and legal issues. In addition to these services, the centre is involved in providing professional education in transcultural psychiatry for psychiatrists and other mental health workers — including assistance with clinical advice on a case by case basis.

While the Centre has been the subject of criticism because it does not provide a 'mainstream' service, the Inquiry was told that:

Services like the Multicultural Centre are mainstreaming. First, because they respond to the needs of the society; secondly, they provide people with the opportunity to receive services and assistance from people who know their culture... Thirdly, they are in the mainstream because through their activities...they spread their ideas to other services. Finally, they are in the mainstream because they do not work in isolation.<sup>97</sup>

From this perspective, services like the Centre can be seen as supplementing and broadening the mainstream psychiatric system by providing a cross-cultural approach which is not yet generally available. NESB consumers are able to obtain integrated care within the community which incorporates preventive education and information, as well as appropriate medical treatment when necessary.

### *The Transcultural Psychiatry Unit*

Victoria's Transcultural Psychiatry Unit acts as an adviser to the Office of Psychiatric Services. It attempts to ensure that psychiatric services become more accessible and effective in catering to the needs of people from non-English speaking backgrounds. It undertakes work in four areas: research, education, clinical services and policy development.

The Unit provides a bilingual clinical service, using interpreters specialised in psychiatric and medical terminology who are able to assist medical staff when assessing non-English speaking patients. It is also responsible for providing interpreter services for the State psychiatric service and for conducting continuing education for medical undergraduates, psychiatric registrars, nurses and other health workers on cross-cultural issues.

In order to improve the effectiveness of mainstream services, the Unit has undertaken a number of research projects to assess the prevalence of psychiatric disorder in ethnic communities, patterns of service utilisation, and the role of culture in the conception of mental health and the treatment of mental illness. The research agenda is primarily concerned with obtaining the information needed to inform mental health policy development and implementation for immigrant communities.

### **The Need For Further Research**

One of the major obstacles to improving services to people from non-English speaking backgrounds is the lack of information available on the prevalence of

mental illness generally, and the particular kinds of psychiatric disorder which occur in different non-English speaking communities. As one expert put it:

Any attempt to understand and to rectify disadvantage based on language and culture must attend to relevant factors in the NESB communities and in mental health services and practices. Of particular importance is the grossly inadequate level of research in the area of defining mental health needs of NESB communities, in the investigation of the appropriateness and effectiveness of educational service systems, and in the development of service models and treatment approaches which are responsive to identified mental health care needs.<sup>98</sup>

Consumer groups and community workers expressed similar concerns. The Ethnic Issues Group of VICSERV recommended that:

Both the State and non-government sector agencies become more active in the collection and analysis of data regarding psychiatric services requirements and current service utilisation by NESB communities, and that this information be actively utilised in the development and provision of psychiatric services.<sup>99</sup>

The Inquiry supports this recommendation. The evidence summarised in this chapter clearly demonstrates the need for basic data collection on the ethnicity of client groups and rates of service utilisation — data which can be used to undertake needs analysis and assessment. It also illustrates the value of research on the incidence of mental illness in particular ethnic communities, as well as broader studies of issues relating to mental health and illness among the NESB population generally.

### **The Need for Education**

The Inquiry was told there is a critical need for professional education of psychiatrists and other mental health professionals in cross-cultural issues. Several expert witnesses emphasised that cross-cultural awareness is often treated superficially by medical professionals and that this lack of commitment has to be addressed to ensure effective service provision:<sup>100</sup>

I want to make a special point about education. Education...particularly regarding ethnic services...[is often reduced to] folkloristic [stereotypes]... The Italians like spaghetti...and the Chinese are afraid of spirits... Education...has to be meaningful...[not only] at the level of services but as part and parcel of the university curricula for people who work in the field of mental health, be those people social workers, sociologists or doctors... We cannot go off and claim that we have met our responsibilities regarding the education of people with a couple of lectures on how [a particular ethnic group] behaves or a couple of lectures on migrants and mental health.<sup>101</sup>

Other evidence to the Inquiry supported these observations. Consumer organisations stressed the provision of continuing education for government and



non-government mental health workers as essential. Training for non-medical staff working in ethno-specific agencies in psychiatric issues and medical terminology was seen as a simple and effective way of reducing inappropriate referrals and increasing general awareness of mental health issues.

Consumer education also needs to be given higher priority:

Basically...a lot of people from non-English speaking backgrounds don't have a very good understanding of their rights as consumers... The care-givers of those people don't really know what the rights of their relatives are either.<sup>102</sup>

Community education must also be complemented by effective outreach programs which target non-English speaking communities:

The outreach model...is much more satisfactory in meeting the needs of non-English speaking communities because in a sense you're reaching the whole community as well as the individual.<sup>103</sup>

Many public awareness campaigns and preventive strategies never reach non-English speaking communities because they are inappropriately targeted. Coordination with ethno-specific agencies and the media when planning activities (for example, Mental Health Week and other national public events) would help to address this problem — as would the active involvement of peak consumer organisations in bilingual and cross-cultural groups to support people from non-English speaking backgrounds with mental illness.

1. Dr Elsa Bernardi, representative, RANZCP, NSW Branch. Oral evidence, Sydney 17.6.91, p111.
2. Bureau of Immigration Research, *Community Profiles: Non-English Speaking Born*, AGPS, Canberra 1991. These figures are derived from 1986 Census statistics.
3. H Minas, *Transcultural Psychiatry Papers*, Victorian Transcultural Psychiatry Unit, v1, Dec 1991, p31.
4. *ibid*, p32.
5. See, for example, L Jayasuriya, D Sang, and A Fielding, *Ethnicity, Immigration and Mental Illness: A Critical Review of Australian Research*, Bureau of Immigration Research, AGPS, Canberra 1992, pp10-11.
6. Bernardi, *op cit*, p109.
7. O'Brien, *op cit*, pp277-278.
8. Jayasuriya et al, *op cit*, p47.
9. Margaret Cunningham, NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors (STARTTS). Oral evidence, Sydney 20.6.91, p438.
10. Margaret Cunningham and Rise Becker, STARTTS. Submission, p1. Recent research supports this estimate, suggesting that the figure may be significantly higher: Patrick McGorry, 'The significance of torture: Theoretical and therapeutic aspects', in H Minas (ed), *Cultural Diversity and Mental Health*, Proceedings of the 14th Annual Symposium of the Section of Social and Cultural Psychiatry, RANZCP, Melbourne 1991, p165.
11. Professor Derek Silove, Professor of Psychiatry, University of NSW and Director, Mental Health Services, South Western Sydney Area Health Service and Macquarie Clinic, Liverpool Hospital. Oral evidence, Sydney 21.6.91, p572.
12. G Andrews, 'The Anxiety Disorders', in P Beumont and R Hampshire (eds), *Textbook of Psychiatry*, Blackwell Scientific Publications, Melbourne 1989, p101.
13. Dr Aidene Urquhart, Director of Child Psychiatry and Clinical Coordinator, Mater Children's Hospital, Brisbane. Oral evidence, Brisbane 16.8.91, p1685.
14. Cunningham and Becker, *op cit*, p1.
15. *id*.
16. Silove, *op cit*, pp574-575.
17. 'The four month siege of Sarajevo, with its daily mayhem and systematic destruction, has spawned a type of mental illness that psychiatrists are at a loss to treat... [Sufferers] show symptoms of severe depression. But they do not respond to standard treatment for depression'. Allen Nacheaman, 'A war-ravaged people willing themselves to die', *Weekend Australian*, 5-6 September 1992.
18. D Ames, 'Geriatric Psychiatry in a Culturally Diverse Society', in I H Minas (ed), *Cultural Diversity and Mental Health*, *op cit*, p119.
19. Bernardi, *op cit*, p110.
20. Dr Slav Kostov, senior consultant psychiatrist, Multicultural Psychiatric Centre. Oral evidence, Perth 11.2.92, p176.
21. Zophia Pakulski, HACC project worker, Migrant Resource Centre. Oral evidence, Hobart 13.11.91, p284.
22. *ibid*, pp282-286.
23. *ibid*, p285.
24. Bernardi, *op cit*, p110.

25. Pakulski, op cit, p286.
26. J Woodruff, Director, NSW Women's Coordination Unit. Submission, p1.
27. Robyn James, Western Region Women's Human Rights Commission Response, NSW. Submission p15.
28. Joint submission to the Inquiry Action on Disability within Ethnic Communities (ADEC) and the Greek Welfare Society, pp8-12. Also Kostov, op cit, p173.
29. Study quoted in Jayasuriya et al, op cit, p27.
30. Vivi Germanos-Koutsounadis, Director, NSW Ethnic Child Care Development Unit, *Response to the Report of the Mental Health Task Force to the Overarching Committee on Health and Aged Care and to the Australian Health Ministers Advisory Council*, p8. Also see joint ADEC/Greek Welfare Society submission, op cit, p3, which calls for the establishment of support groups for NESB carers, particularly women.
31. Eva-Kersti Holmes, Launceston Migrant Resource Centre, Tasmania. Submission, p1.
32. Vittoria Mancini, Ethnic Communities and Mental Health Issues Group of the Victorian Community Managed Mental Health Services Inc (VICSERV). Submission, p1.
33. See ADEC submission, op cit, and submission by Dr Harry Minas, Director of the Victorian Transcultural Psychiatry Unit, p2.
34. Kostov, op cit, p171.
35. Bernardi, op cit, p112.
36. *ibid*, pp111-112.
37. Anne Wearne, MA thesis, *Schizophrenia and the Family: Case Studies of Four Families Attending the Multicultural Psychiatric Clinic*. Submitted to the Inquiry.
38. *ibid*, p67.
39. The term 'somatisation' usually refers to the development of physical symptoms as a manifestation of psychological disturbance or mental illness.
40. Wearne, op cit, pp67-68.
41. L Cole-Edelstein, 'Mental Health Services and NESB', Mental Health Coordinating Council Inc, *Spotlight on Mental Health*, p1.
42. Eileen O'Brien, advocacy worker, Home and Community Care Funded Program, Migrant Resource Centre. Oral evidence, Hobart 13.11.91, p279.
43. Minas, op cit (submission), pp2-4.
44. Cole-Edelstein, op cit, p2.
45. Minas, op cit (submission), p10.
46. Germanos-Koutsounadis, op cit, p5.
47. Cole-Edelstein, op cit, p6.
48. Irene Mathews, social worker, Migrant Resource Centre. Oral evidence, Hobart 12.11.91, p288.
49. Mancini (VICSERV Ethnic Communities and Mental Health Issues Group), op cit, p7.
50. Gabriel Malageorgiou, Action on Disabilities within Ethnic Communities. Oral evidence, Melbourne 9.4.91, pp317-319.
51. Cited in H Minas, *Transcultural Psychiatry Papers*, op cit, vI, p45.
52. *ibid*, p46.
53. Bernardi, op cit, p111.

54. H Minas, *Transcultural Psychiatry Papers*, op cit, VIII, p356.
  55. Cole-Edelstein, op cit, p3.
  56. C Harbaum, Federation of Ethnic Communities Councils of Australia. Submission, p1.
  57. Bernardi, op cit, p112.
  58. Maria Graham, welfare worker, Inala Community House. Oral evidence, Brisbane 14.8.91, p1762.
  59. *Diagnostic and Statistical Manual of Mental Disorders, Third Edition-Revised*. (As discussed in Chapter 3, this manual is one of the standard diagnostic texts for psychiatric disorders.)
  60. Pat Dudgeon, Head, Centre for Aboriginal Studies, Curtin University. Oral evidence, Perth 12.2.92, p307.
  61. Graham, op cit, p1762.
  62. Stella Goiser, Tasmania. Submission, pp1-2.
  63. A Nikelly, 'Can DSM-III-R be used in the diagnosis of non-Western patients?', *International Journal of Mental Health* v21 No1, p4.
  64. Bernardi, op cit, pp111-114. Wearne, op cit, also discusses these issues.
  65. For example, a study cited by Anne Wearne notes that 71 percent of clients attending a psychiatrist in Taiwan exhibited somatic symptoms.
  66. Nikelly, op cit, p16.
  67. Bernardi, op cit, p113.
  68. Mancini (VICSERV), op cit, p4. Similar concerns were also expressed by the Federation of Ethnic Communities Councils of Australia.
  69. Kostov, op cit, p171.
  70. *ibid*, pp171-173.
  71. Mancini (VICSERV), op cit, p9.
  72. Graham, op cit, p1761.
  73. Marie Gibson, Coordinator, Migrant Resource Centre, Townsville. Oral evidence, Townsville 12.8.91, p1137; Graham, op cit, p1764; and Mathews, op cit, p282.
  74. Kostov, op cit, p172.
  75. Lisbet Castro Lopo, Acting Area Coordinator, Migrant Health Services, Hunter Area Health Service. Oral evidence, Newcastle 9.7.91, p808.
  76. Cole-Edelstein, op cit.
  77. The telephone survey was conducted on 30-31 August 1991 with the assistance of the NSW Mental Health Coordinating Council. It aimed to obtain further evidence from individuals who believed that they, or someone known to them, had suffered discrimination or a violation of their rights due to mental illness. Flyers were distributed throughout NSW inviting people to call a toll-free number and provide their information anonymously.
- Over 200 calls were received. Of those, 32 calls were received from people of non-English speaking background. In addition to concerns relating to inappropriate drug treatment, callers raised the following issues: the lack of information available about community-based and other mental health services; inappropriate treatment and referrals made by GPs; and the lack of information regarding patient rights.
78. Minas, op cit (submission), p10.

79. H Minas, *Transcultural Psychiatry Papers* op cit, (v)i, p46.
80. Mancini (VICSERV), op cit, p6.
81. Kostov, op cit, pp172-173. See also submission by the Federation of Ethnic Communities Councils of Australia.
82. Kostov, op cit.
83. Mancini (VICSERV), op cit, p7.
84. Minas, op cit (submission), p9.
85. Malageorgiou, op cit, pp317-318.
86. *ibid*, p317.
87. *id*.
88. Action on Disabilities within Ethnic Communities (ADEC) and the Greek Welfare Council, Victoria, op cit, pp8-9.
89. Mancini (VICSERV), op cit, p7.
90. Cole-Edelstein, op cit, p1.
91. ADEC and the Greek Welfare Society, op cit, p12.
92. Mancini (VICSERV), op cit, p6.
93. Dr Roger Gurr, Clinical Director of Psychiatry, Blacktown Community Health Centre. Oral evidence, Sydney 17.6.91, p77.
94. Malageorgiou, op cit, p323.
95. L Jayasuriya, *Multicultural Australia: Towards the Twenty-First Century*, paper presented at the Twelfth Annual Conference of the Federation of Ethnic Communities Councils, August 1991.
96. Multicultural Psychiatric Centre, *Education Program 1990*, p2.
97. Kostov, op cit, p175.
98. Minas, op cit (submission), p3.
99. Mancini (VICSERV), op cit, p6.
100. Kostov, op cit, p179; Bernardi, op cit, pp114-115. Also Dr San Pedro, medical officer in charge, Migrant Mental Health, NT Department of Health and Community Services. Oral evidence, Darwin 21.7.92, pp95-98.
101. Kostov, op cit.
102. Malageourgiou, op cit, p322.
103. *ibid*, p324.

## Chapter 25

# FORENSIC PATIENTS AND PRISONERS

Untreated people are ending up in jail through either misunderstanding, non-recognition of their symptoms, or as a direct result of actions emanating from their treatable conditions going untreated. Once in jail, clearly, their opportunities to receive access to treatment and services are even more diminished.<sup>1</sup>

## Definitions

This chapter addresses issues affecting mentally ill people who commit criminal offences, and those who are or have been in the custody of police or prison services. The two criteria do not necessarily describe the same group of people. For example, some offenders serve their sentences in psychiatric wards; others receive a non-custodial sentence such as a community service order. Many inmates in jail are not actually serving a sentence; they are on remand, awaiting a court hearing. And former prisoners, whether released unconditionally or on parole, face an array of daunting obstacles in living with mental illness.

Prison conditions, police practices and the criminal justice process are all important areas to examine in assessing any society's attitude to human rights. As evidence already outlined has clearly established, people affected by mental illness are especially vulnerable to abuse or denial of their rights.

### 'Forensic Patients'

Legally, 'forensic patients' are people whose status in the penal system is determined by a mental illness<sup>2</sup> — eg offenders whom the court finds unfit to stand trial.

However, mental health professionals use the term 'forensic patient' to refer to any prisoner receiving psychiatric treatment, whether or not that fact has been legally acknowledged. 'Forensic psychiatrists' treat prisoners in jails and psychiatric wards, but may also provide some continuing care to ex-prisoners living in the community. They also provide psychiatric services to the courts — giving expert evidence during trials and preparing reports on particular offenders for sentencing judges to take into account.

## **Relevant Human Rights Instruments**

As described in Chapter 2, mentally ill people in the criminal justice system have rights prescribed in international treaties and other human rights instruments. These include the International Covenant on Civil and Political Rights (ICCPR); the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment; and the Body of Principles for the Protection of all Persons under any Form of Detention or Imprisonment.

The Principles for the Protection of Persons with Mental Illness specifically apply to prisoners. Principle 20 stipulates they are entitled to the best available mental health care, and to all the rights specified in the Principles, 'with only such limited modifications and exceptions as are necessary in the circumstances'.

In addition, the UN has developed the Standard Minimum Rules for the Treatment of Prisoners ('the Standard Minimum Rules'). Australia adopted these Rules in the form of the Australian Standard Guidelines for the Treatment of Prisoners in 1978.

## **Prevalence of Mental Illness Among Prisoners**

What is the prevalence of mental disorder within the prison system is a quite different question to the numbers of individuals being treated in the forensic psychiatric service.<sup>3</sup>

If the rate of mental illness in prison was measured by the number of individuals designated 'forensic patients', it would be deceptively low. According to the statistics most prison systems have only a small number. For example, NSW in October 1991 had 86 prisoners covered by the forensic review legislation.<sup>4</sup> This was just over 1 percent of the State's prisoners at the time.<sup>5</sup> Similarly, South Australia's prison psychiatric ward,

James Nash House, has usually 25 to 30 inmates from the criminal justice system being cared for within it. [However,] I suspect the prevalence of mental disorder within the prison system is very, very much higher than that.<sup>6</sup>

In the general prison population, the prevalence of mental illness is difficult to quantify. Most prison services do not routinely assess inmates for psychiatric problems, either on arrival or at any time — largely due to a chronic lack of funds for health services of any kind.<sup>7</sup>

Many people believe that the new approach to mental health since the 1950s has resulted in the 'criminalisation' of mental illness: instead of being detained in

hospitals, large numbers of mentally ill people are said to be ending up in prison:

If you decrease the number of mental health system beds, there will be an equivalent rise in prison system beds, as those with mental health problems will be channelled into the prisons.<sup>8</sup>

Empirical research on mental illness in prisoners has been scant and at times inconsistent.<sup>9</sup> The findings of the main Australian study on the topic indicate a high rate of mood disorders in jail, especially major depression: 12 percent of subjects had a current diagnosis. A startlingly high proportion of prisoners (82 percent) had suffered at least one 'mental disorder' at some point in their lives (including alcohol or drug abuse).<sup>10</sup> However, the findings do not support the perception of a large scale shift from hospitals to jails as the new repositories of people with severe psychotic illness.<sup>11</sup>

The general belief among witnesses to the Inquiry was that a great deal of mental illness goes undiagnosed in jails. This is not only caused by the lack of resources: the atmosphere of deprivation and despair which is normal in prisons leads staff and inmates to become desensitised to suffering.<sup>12</sup> The individuals affected may only come to the attention of prison authorities if their behaviour becomes severely disruptive.

Evidence to the Inquiry clearly indicated a higher rate of mental illness and disorder in prisons than among the general population.<sup>13</sup> A Tasmanian study found that approximately one-third of female prisoners admitted over the last ten years at Risdon Prison have had a psychiatric history;<sup>14</sup> but the absolute number with disorders has also steadily increased during that period.<sup>15</sup> An expert witness in Sydney estimated that 30-50 percent of young people in detention facilities have a mental health problem.<sup>16</sup> Another said 1-5 percent of prisoners have a 'classifiable psychiatric illness, meaning particularly psychotic states', while some 20 percent 'exhibit some form of psychological distress, symptoms which are troublesome or disabling and for which they require treatment or counselling'.<sup>17</sup>

NSW is estimated to have 300-400 prisoners who will require psychiatric follow-up after release, and another 500-600 currently on parole (but still under sentence) who require psychiatric management.<sup>18</sup> (300-400 prisoners represent 5-7 percent of the State's prison population.) The Schizophrenia Fellowship in Queensland estimates there are about 150 people with schizophrenia in that State's jails<sup>19</sup> (approximately 7 percent), while in the ACT's remand centre over half the inmates are 'believed to have a form of mental illness'.<sup>20</sup>



In Darwin the Inquiry was told that the population affected by mental illness in the Northern Territory includes a particularly high proportion of criminal offenders. This is because the NT population profile is young, with about 40 percent of Territorians under age 25, and offending is most common among young people.<sup>21</sup>

One obvious indicator of poor mental health is a high suicide rate. In 1990 and 1991 in Australia, 114 people died in prison or police custody, including at least 50 suicides.<sup>22</sup>

However, the lack of any systematic data on the mental health of prisoners is disturbing:<sup>23</sup>

We really don't know at the moment who is there because, to the best of my knowledge, there has not been an adequate census. I think one of the first things one ought to be doing is having some sort of census, because it really does matter whether we are talking about 1 percent or 5 percent.<sup>24</sup>

Despite the lack of statistical data, many witnesses told the Inquiry there are seriously ill or disordered people in our prisons who should not be there at all. Imprisonment damages them personally (by aggravating their condition); it is also an inappropriate use of the criminal justice system.<sup>25</sup> They basically need treatment — not punishment.

The mental illnesses found in jails include schizophrenia and other psychotic disorders (including drug-induced and other 'organic' psychoses), affective disorders such as depression, and adjustment disorders.<sup>26</sup> Two other disorders are not strictly mental illnesses, but nonetheless fall to mental health workers to treat: extreme 'personality disorders'<sup>27</sup> and substance abuse.<sup>28</sup> Many prisoners have more than one of these. A severe personality disorder often masks an underlying mental illness,<sup>29</sup> drug and alcohol abuse are rife.<sup>30</sup> The Tasmanian study of women prisoners found that, rather than chronic severe mental illness, the most common diagnoses are personality disorders and drug abuse.<sup>31</sup>

### **Who Are the Mentally Ill Prisoners?**

Evidence to the Inquiry established that mentally ill prisoners have several common characteristics which distinguish them from other prisoners:

[They are] less likely to be in a stable relationship; they are more likely to be unemployed; they have fewer children... they have more periods of imprisonment.<sup>32</sup>

Mentally ill inmates are more likely than other prisoners to be poorly educated; many also suffer from learning disabilities or difficulties (such as attention deficit disorder) which exacerbate their condition.<sup>33</sup>

As for the offences for which they are in prison:

The nature of their offences is generally minor, although there are major crimes committed by those suffering from mental illness. In many cases, mental illness has been an important factor in the commission of the offence or alleged offence.<sup>34</sup>

Witnesses in the Northern Territory said their forensic services deal with a large number of sexual offenders, especially those diagnosed with a personality disorder.<sup>35</sup>

### **Legal Recognition of Mental Illness**

Our criminal justice system recognises four ways in which mental illness can affect the disposition of offenders. A person charged with a criminal offence may be:

- found unfit to plead, and thus unfit to be tried;
- tried and acquitted on the grounds of mental illness;
- convicted, but mental illness is taken into account as relevant to sentencing;
- diagnosed while in custody — either while serving a sentence or on remand.<sup>36</sup>

People who fall into the first two of these categories are often detained ‘at the Governor’s pleasure’ — ie indefinitely — either in jail or in a psychiatric ward.

A fifth category comprises offenders who have a ‘personality disorder’ but not a mental illness. The most publicised prisoner in this category was the late Garry David, who was held for three years in preventive detention in Victoria after his sentence had expired, notwithstanding that he did not meet the legislative definition of ‘mental illness’.

### **Does Mental Illness Lead to Jail?**

He did hear a voice one morning — he said on the wireless — that told him if he could go to jail, he would be cured. So he went around to a used car lot, he threw a stone through a window and in sub-degree temperatures — there was ice on the ground — he went at 5 o’clock in the morning and sat and waited till 7am for the police to arrive, whilst we were driving the countryside looking for him.<sup>37</sup>

Many people are taken into custody — or have their detention prolonged — as a direct or indirect consequence of their mental illness or disorder going untreated. Untreated mental illness clearly causes some people to behave irresponsibly, irrationally and in a bizarre fashion. Sometimes this behaviour brings people to the attention of the police; in a small number of instances untreated mentally ill people commit violence against others.

The Inquiry heard several accounts of tragedy resulting from the actions of people who were known to be mentally ill, and in fact had been under some form of psychiatric care, but without sufficient continuity. One terrible example was a young man with long-term schizophrenia who owned firearms; he shot four young women dead. He was seeing a private psychiatrist, but was not considered critical enough for hospitalisation at the time of the offence:

The system didn't work then, and the results were the death of four young girls with the associated tragedy for their family — but also a tragedy for the young man himself... I suspect if he were under a system whereby committal had been easier and staying in hospital had been easier, and there had been a firmer and more detailed system of control once he was discharged, he would probably have had a life which consisted of admissions to hospital and then various discharges... whereas now he's likely to be incarcerated until the day he dies.<sup>38</sup>

The Inquiry heard many examples of untreated mental illness leading to jail:

- In [our son's] case the boredom which develops because of lack of activity (due to lack of motivation) leads to drug-taking and recently, for the first time, serious crime. [He] was arrested two months ago on a charge of armed robbery (\$150 from a shop). At the time he was under the influence of drugs and alcohol. The offence was typically bizarre in that he gave us pre-advice and we were able to alert the police beforehand. But they could not prevent the happening — in which there was no bodily harm. If [he] did not suffer from a depressive illness we feel sure this would not have happened.<sup>39</sup>

- One Cambodian woman who suffered from — well, she'd suffered all the appalling experiences that anyone from the Killing Fields could have suffered...and finally found herself in Australia and suffered then a very, very major psychotic illness — depressive — and during the course of this illness believed that the giant who had raped her, a brutal man in the refugee camp from which she fell pregnant, was coming to kill her now. And the voices in her head were telling her she deserved to die and she was going to be killed by this person, and this person was now embodied in her infant. So she attempted to kill this child. Subsequently, she was arrested and taken to the women's prison...<sup>40</sup>

- [An] example of someone with a fairly obvious psychiatric or psychological problem...but she's quite harmless: this particular woman self-medicates with cannabis, so therefore, she has been convicted on a number of occasions, and served short sentences; or if she's fined, it's impossible for her to pay a fine, and she ends up cutting out the fine in the watchhouse.<sup>41</sup>

Mentally ill people are especially likely to 'commit' certain offences such as drunkenness, offensive behaviour, disorderly conduct, loitering or vagrancy (which commonly coincides with homelessness).<sup>42</sup> Or it may be simply that they are more likely to get caught.<sup>43</sup> A Queensland witness described 'the case of an old man':

At the age of 76 his memory was shot. He was arrested in Cooktown for indecent exposure: he piddled on a tree in the main street. He didn't turn up in court because, amongst other things, he can't remember what day it is. So he was sentenced to 14 days for failing to appear.

He was transported, at great taxpayers' expense, from Cooktown to Cairns; put in the Cairns Watchhouse. When he'd served his 14 days out he was released; he didn't know where he was. He went across to the Esplanade just across from the police station, stood there for a while, had a drink of water, felt the call of nature, piddled on a tree again, as was his way when he lived in the bush — and straight back into the watchhouse.<sup>44</sup>

Non-payment of fines is another common avenue to prison for mentally ill people who are poorly organised financially,<sup>45</sup> or who do not comprehend that they owe money.<sup>46</sup>

One witness to the Inquiry described many of these minor offences as 'victimless' crimes:

A sentence to prison for essentially non-criminal behaviour adds another unshakeable label to those already ascribed to a mentally unwell person, and the process of alienation is an even greater burden.<sup>47</sup>

Mentally ill people may be at increased risk of being charged with offences they did not commit. Improbable confessions by people with psychiatric disabilities are fairly common. (One recent example concerned the death of a resident in a hostel for people with psychiatric disabilities. Six other residents reportedly confessed independently to having killed her.<sup>48</sup>)

People who do not have full control over their lives can also suffer the legal consequences of others' carelessness or misdeeds. The Inquiry was told of a mentally ill man whose financial affairs were in the hands of the NSW Protective Commissioner:

This man attempted to commit suicide by lying on the railway tracks. He was picked up by police who found that he had outstanding warrants, and he was brought to prison... He believed the warrants had been paid by the Protective Office. On checking, \$250 had been paid by the Protective Office; there was \$200 outstanding. But the court computer did not show any payments, [so] he served seven days in prison.<sup>49</sup>

Once arrested, mentally ill people may have trouble getting release on bail — because they are too poor to raise bail, because they have no fixed address, or because they do not comprehend or comply with bureaucratic requirements. For example, the Inquiry heard evidence about an offender whose bail was approved, but who refused (due to delusional beliefs) to sign any forms. The authorities felt they had no choice but to retain this individual in jail.<sup>50</sup>

Failing to obtain bail means people affected by mental illness are frequently remanded in custody — even on quite trivial charges. The same problem arises when they are tried, convicted and due to be sentenced. The policy of most court systems is to favour non-custodial sentences such as fines, bonds, home detention and community service orders. But these cannot be imposed on someone who has no money and no secure accommodation. Thus people with a mental illness, for whom prison is a particularly inappropriate and harmful penalty, often go to jail for minor offences which normally would attract a non-custodial sentence.<sup>51</sup>

Similarly, when an offender is due for parole or remission, the absence of secure accommodation can be reason for being kept in prison.<sup>52</sup> A NSW psychiatrist recounted the case of a prisoner with mental illness and an alcohol problem, who was found not guilty of an offence on the grounds of mental illness:

He has now made serious attempts to deal with the alcohol problem by having counselling and going to AA meetings in prison, has spent about four years in prison and could be released, providing there is ongoing supervision... But because of difficulties in arranging future management, the man in fact remains in prison.<sup>53</sup>

Mentally ill prisoners' inability to cope with the distressing living conditions may also make them more likely to commit disciplinary offences in jail. One example recounted to the Inquiry concerned a man who, due to mental illness, had moved in and out of jail and psychiatric wards all his life. At the time of the Inquiry he was in Alice Springs Prison, having committed several offences after his local mental health service lost its psychiatrist and discontinued his treatment. While in jail (still receiving no treatment) he was charged with assaulting prison officers:

He had been locked in his cell without access to water on the hottest day of the summer. When he was refused water, he became angry and caused damage to the cell. Two prison officers entered the cell to prevent further damage and it was alleged that [the prisoner], a man of 61, headbutted one of the officers... A further assault was alleged [later on].<sup>54</sup>

These assaults and similar incidents were used as a reason to deny the prisoner day leave or parole, which he applied for in order to undertake a rehabilitation

program arranged for him by the Disability Service of Central Australia.<sup>55</sup> Yet he obviously needs rehabilitation to help him 'unlearn' the institutional behaviour (including outbursts of aggression) which he has learned over years in prison.<sup>56</sup>

Evidence presented to the Inquiry also established that some people unnecessarily enter or remain in jail due to poor quality legal representation, or poor communication with their lawyers:

They have difficulty communicating with their legal representatives, particularly if they're Aboriginal; if their English isn't good; if their behaviour is bizarre; if they are aggressive, as people with some mental illnesses frequently are...<sup>57</sup>

Some lawyers may feel uncomfortable with a mentally ill client:

I first came across a solicitor, actually, in the courtroom when they were doing whatever it is they do. He refused to address me by name or to introduce himself, so I just made the statement that I refused to accept his assistance.<sup>58</sup>

Solicitors are prone to say when they have someone who has either an intellectual impairment or a psychological problem, that they find it impossible to take lucid instructions from them. But I think most people who are prepared to spend a little bit of time would be able to communicate with these people...<sup>59</sup>

### **Prison as an Avenue to Treatment**

There certainly are times when people who are known to be 'mad' are actually treated as 'bad', because it flows from that that at least they will get some psychiatric treatment.<sup>60</sup>

Paradoxically, some evidence to the Inquiry pointed to the use by the courts of prison sentences as a means of providing access to accommodation and treatment. For example, one Victorian submission referred to a report of a judge remarking that if a particular offender were released on a bond, he would have to wait at least 18 months for suitable accommodation and treatment; but in jail he would go to the top of the waiting list for a secure psychiatric unit within the prison system, where he would receive treatment at once. The judge described this state of affairs as 'totally obnoxious and deplorable.'<sup>61</sup> The Inquiry agrees.

### **Does Jail Lead to Mental Illness?**

We know, and the doctors know, that he will be unable to cope with jail and the result will be an even more traumatised human being with even less chance of future well-being.<sup>62</sup>

Contact with the criminal justice system is stressful for anyone. For a person with a mental illness the criminal process (being apprehended by police, arrested, bundled into a paddywagon, charged, tried and incarcerated) can be especially confusing and distressing. It can also be dangerous — because conditions in jail are likely to exacerbate mental illness. Mental health care is generally poor and at times non-existent. Living conditions in some detention facilities are disgusting. In addition, the procedures of our criminal justice and penal systems sometimes discourage people who are mentally ill from seeking treatment, by punishing them with longer sentences and even worse living conditions than usual.

### **Prison Living Conditions**

The environment we place them in is intellectually, socially, occupationally sterile, and it doesn't help their condition at all.<sup>63</sup>

The ordinary living conditions in prison are stressful and dehumanising — precisely the opposite of the therapeutic environment required by people with mental illness. Even for people who are not already mentally ill, the conditions are very conducive to depression:

Imagine a place without a tree; a high-walled place where sunsets and sunrises cannot be experienced; a place without a dog or other pet; a place without a child, or often a person of the other sex, without elderly people; a place where one is almost totally without an opportunity to make choices, where one is cut off from family and friends to the extent that partaking in a relative's funeral, or a visit to the hospital of a seriously ill one, is a privilege; a place where very few people have meaningful (or any) work; a place where you have no choice of companions — and you have some idea of the vast majority of, if not almost all, prisons.<sup>64</sup>

Conditions in Australian prisons, detention centres and police lock-ups have been condemned by numerous Royal Commissions, inquiries, reviews and even by Amnesty International.<sup>65</sup>

Witnesses to the Inquiry cited many aspects of prison conditions which are particularly detrimental for those with mental illness. NSW came in for especially severe condemnation; based on the evidence received, our 'Premier' State could claim the dubious distinction of having Australia's worst prison conditions.<sup>66</sup> One major problem is overcrowding.<sup>67</sup> In mid-1991 NSW had over 7000 people in prison<sup>68</sup> — nearly half of Australia's total, and three times as many as in the next most populous state, Victoria. Over the decade since 1981 the average prison population in NSW increased by 60 percent — compared with about 30 percent for other jurisdictions. (In Tasmania it actually declined.)<sup>69</sup>

Witnesses considered this overcrowding has been aggravated by the changes in prison policy introduced by the Coalition Government in NSW<sup>70</sup> — and that these changes have created a climate of increased hardship which damages the emotional wellbeing of all prisoners.<sup>71</sup> Simultaneously with the rapid increase in prison numbers came a cut in staffing levels:

And then because of the staffing cuts, the number of hours that the individuals are locked up in their cells was increased. So that they're now in maximum security locked into their cells at 3.30 in the afternoon and released again at about 8 o'clock in the morning.<sup>72</sup>

### *Personal possessions policy (NSW)*

Some crims have no family and are here for a long time. All they have are the things in their cells.<sup>73</sup>

Perhaps the most infamous policy change in NSW was the crackdown on personal possessions. Prisoners were told they had three days to dispose of all their possessions, including their clothes, books, letters, watches and address books; any property remaining in the cells would be confiscated and sold. Some prisoners were able to get relatives to take their possessions, but others could not organise this in three days — especially those incarcerated long distances from their families.<sup>74</sup>

The confiscation of wedding rings received wide media attention,<sup>75</sup> but the loss of other possessions was equally disturbing and demoralising:

They're allowed one certain size photograph. So for [prisoners] who have a number of children, if they had a number of different photographs of their children, then these were taken... Some of them became very upset and behaved very badly when the photos of their children were taken away.<sup>76</sup>

Radios, cassette players and tapes were also removed, including relaxation tapes used to reduce stress.<sup>77</sup> One prisoner with schizophrenia, who listened constantly to a radio, 'became a behavioural problem and [began] to scream all the time' when the radio was taken away.<sup>78</sup> Another behaviourally disturbed prisoner had a talent for drawing;

[The authorities] took all drawings away, and so [this prisoner and others] were left with nothing to do, you know, so that they're just left for this long period of time being bored.<sup>79</sup>

Prisoners were no longer allowed to wear their own clothing. This was not a unique rule among Australian prison systems, but the NSW policy appeared particularly restrictive:



I think for the women it's...two sets of underwear, one t-shirt, one pair of tracksuit pants and one dress — prison dress.<sup>80</sup>

One survey reported a large number of complaints by prisoners about the clothes they were obliged to wear:

In February 1991, during extreme heat, inmates at Parramatta Gaol were still wearing winter tracksuits because no summer clothing was available... Not all sizes of underwear are available (particularly the more common sizes). Prisoners complained that often the only size available was size 24... Generally there is a shortage of prison issue clothing. One prisoner complained that he 'couldn't change clothes for a week' when first put in remand.<sup>81</sup>

The same survey revealed that the removal of tables from prison cells had created a practice as degrading as it is unhygienic:

One inmate of Maitland Gaol wrote... 'as a result of this new measure, [we] have to eat our food on the floor or toilet seat, which of course goes beyond the bounds of humanity or human rights.'<sup>82</sup>

Other aspects of the personal possessions policy also compromised prisoners' physical health:

Among items confiscated were prisoners' hats, thongs and sunglasses. As a result, many prisoners working outside in the hot summer sun had no protection from the sun's rays. Ironically, this occurred as the Department of Health launched a high-profile campaign ('Me-No-Fry')...urging 'common sense' preventive measures (such as wearing hats and using sunscreens)... In a similar vein, the prohibition on prisoners owning thongs has directly increased their chances of contracting tinea in communal showers.<sup>83</sup>

The prohibition on hats was subsequently relaxed, and prisoners could apply for thongs on medical grounds — but only after they contracted tinea.<sup>84</sup>

Another policy change was a drastic reduction in educational facilities, which particularly disadvantaged prisoners who had had difficulty in their pre-prison education.<sup>85</sup>

Conditions in the NSW jails also affect prisoners from the ACT, who are sent there to serve their sentences because the ACT has only a remand centre. This arrangement is a cause for concern in the Territory:

There is no guarantee that these prisoners will receive treatment for their illness or even be housed in safety. There is no supervision by ACT authorities of prisoners in this system.<sup>86</sup>

On the eve of this Report going to print (August 1993) the NSW Minister for Justice announced the official abandonment of the harsh personal possessions policy.<sup>87</sup> The Inquiry considers this decision to be long overdue.

### *Other aspects of prison conditions*

Although NSW jails were the most frequently criticised, evidence to the Inquiry also indicated routine abuse and neglect of human rights in other states. A Western Australian witness pointed to the very harsh punishment meted out to escapees:

They can receive up to three years' extra time, plus withdrawal of all privileges, eg no radio, TV, library, no contact visits, plus solitary or near solitary confinement for six months. The first time the harsh escape punishment was applied, one of the two men committed suicide after two weeks. He left behind a two-year-old child, a wife and two step-children. You can imagine the mental health stress on that family, and the family of the second man... If such harsh treatment were for deterrence, then it failed, for three men attempted to escape, two successfully, from the same prison not many months later.<sup>88</sup>

Prisoners generally have little or no choice about the geographic location where they serve their sentences; and forensic psychiatry services are only available in certain jails. This can result in even more isolation from family and friends. In Queensland:

One of the difficulties with forensic services is it's all centralised... For those patients who have family members and who come from outside the general Brisbane metropolitan area, it involves long distance travel in order to maintain social networks.<sup>89</sup>

One practice which causes significant distress is the abrupt forced relocation of inmates to different prisons.<sup>90</sup> A forensic psychiatrist told the Inquiry:

Inmates are moved very quickly from prison to prison and sometimes are cut off...and I think that the stresses involved are unreasonably punitive... For example one of the prisons which I currently visit is the prison at Lithgow... There's quite a distance between the town and the jail; travel arrangements are not easy, and in the first three or four visits that I made to that place I had a constant series of prisoners coming and, with very good reason, explaining why having been transferred to that prison at short notice made it almost impossible for them to either organise their defence properly or to keep in contact with wives or loved ones or to see their children.<sup>91</sup>

The witness pointed out that this makes a mockery of the right Australia has committed itself to under Standard Minimum Rule 37:

Prisoners shall be allowed under necessary supervision to communicate with their family and reputable friends at regular intervals, both by correspondence and by receiving visits.<sup>92</sup>

A common complaint from transferred prisoners is that their few personal possessions are not transferred with them, but are lost, damaged or delayed en route.<sup>93</sup> The same applies to their records — including health records. In the case of one severely mentally ill prisoner with a history of violence, who was transferred from Long Bay to Lithgow:

Three weeks after he was transferred there, the psychologist at Lithgow was unaware of his existence.<sup>94</sup>

Prison psychiatrists are sometimes not consulted about transfers of prisoners whom they are treating:

I think the communication certainly should be improved about things like the movement of prisoners that we're [treating]. If we were consulted sometimes, we might be able to prevent problems by suggesting the prisoner not be moved, or **should** be moved...<sup>95</sup>

Victoria's Police Surgeon gave evidence of a practice colloquially known as 'cell circuit shuffle', whereby prisoners believed to be mentally ill are moved to a different watchhouse every few days. He said this severely dislocates any continuity in assessment and medical care.<sup>96</sup>

The abusive social environment in prison is itself dangerous for inmates affected by mental illness. In a setting where any vulnerability is liable to be exploited, they may be easily victimised by other prisoners. The Inquiry received evidence of harassment, harsh punishment and violence,<sup>97</sup> which in at least one case apparently precipitated the suicide of the mentally ill prisoner.<sup>98</sup>

### *Alice Springs Prison*

The dormitory [we] visited occupied a whole building... The interior was entirely open plan but was subdivided by wire mesh into seven or eight discrete sections, in each of which were six or seven beds (bunks and singles), an unscreened urinal and a cold water tap. There were no facilities, nor indeed any space, for prisoners to keep personal belongings... It was hot and despite the open eaves, smelled strongly of sweat and urine... Prisoners are confined to the dormitories for 16 hours a day...[and] obliged to use toilet facilities within their caged subdivisions with little or no privacy.<sup>99</sup>

This visit led Amnesty International to single out the Alice Springs Prison as probably breaching international human right standards on 'cruel, inhuman or degrading treatment'.<sup>100</sup> (These conditions also constitute a breach of ICCPR Article 10, requiring that people 'be treated with humanity and respect for the inherent dignity of the human person'.)

One submission to the Inquiry concerned conditions at Alice Springs Prison and an inmate who had been affected by mental illness all his life. He was initially detained in 'isolation' — at his own request, because he feared harassment from other prisoners. However, his isolation lasted four years, in conditions which clearly violated Australia's human rights treaty obligations.

He was not allowed to speak or otherwise communicate with other prisoners and they were not allowed to approach him. The cell is [2m] by [3m] and consists of a fully enclosed room with one high barred window. Outside the cell is a small yard...about twice the size of the cell, and [he] was allowed about half an hour exercise in the yard per day.

During the winter [he] was often subjected to his cell and his person being hosed down at night. In winter the overnight temperatures in Alice Springs often drop below zero.<sup>101</sup>

### Conditions in Police Custody

While most complaints about conditions of incarceration related to prisons, the Inquiry also received evidence about police cells and watchhouses, where many prisoners are held while awaiting trial, bail or transport to jail. The police surgeon in Victoria observed:

[As for] psychiatrically disturbed prisoners in police custody...the majority of such prisoners are housed in appalling conditions. The state's largest holding facility, the City Watch House, bears a striking resemblance to its neighbouring structure, the Old Melbourne Gaol, which thousands of tourists visit to view the horrific conditions prisoners experienced a century ago.<sup>102</sup>

In early 1993 the Legal Aid Commission of Victoria expressed concern that the holding cells in the State's newly built court complexes breach the UN Standard Minimum Rules for the Treatment of Prisoners:

Unfortunately the Victorian Police Department's viewpoint in the past has been that the UN standards are guidelines only and there is no requirement to comply.<sup>103</sup>

The Commission's specific concerns were with the design of the cells, which breach the Rules requiring access to fresh air, decent toilet facilities and open air exercise. However, it also cited individual cases of abuse and neglect. For example, one offender was sentenced to a lengthy prison term and should have been taken immediately to jail. Instead:

[He] was held in the cells for ten days after his hearing. He had not had a change of clothes in that time, nor had he seen daylight.<sup>104</sup>

For a person with a mental illness, such a delay can be especially damaging:

A defendant with psychiatric problems was held in custody pending a bail application, with a direction that a forensic psychiatric report be prepared. The Office of Corrections refused to send a psychiatrist, and the defendant was not transferred to the Remand Centre or other facilities where psychiatric services could be available. The defendant was held in local cells for three weeks before being brought to court, again for a bail application — without the report.<sup>105</sup>

Other issues raised by the Commission include overcrowding, the total denial of visits at some police cells, and health problems including food poisoning, skin rashes and colds. In addition, the conditions in which solicitors are expected to speak to their clients are primitive.

A solicitor interviewing a prisoner must stand behind a white line some ten feet away. There is no desk, bench or seat. The interviewer stands in the open air and is exposed to all weather.<sup>106</sup>

Instructions from prisoners are taken through a grill door... Instructions can be overheard by both police and other prisoners.<sup>107</sup>

The Royal Commission into Aboriginal Deaths in Custody identified chronically bad cell conditions as one factor contributing to the high rate of deaths in police custody. Since the Royal Commission, governments have exerted pressure on police to improve conditions and procedures. Conditions have improved, particularly in some areas of Queensland and the Northern Territory.<sup>108</sup> New police stations are now built to better designs — but many are still inadequate, considering the extended periods some prisoners spend in police cells (see below). For example, the new police stations at Innisfail (Queensland) and Katherine (NT) have spacious cells designed for multiple occupancy:

They are well lit and ventilated and protected from the hot sun. Both employ closed circuit television, are fitted with cell alarms, are manned for 24 hours, are clean and well decorated, and are fitted with laboratories, drinking fountains and showers. However, neither provides any natural light, nor has any outside exercise facilities, nor offers even a semblance of privacy... It is doubtful whether prolonged custody in such cells could be described as humane.<sup>109</sup>

The Inquiry also heard disturbing accounts of the conditions in which people known to be mentally ill are transported to jail or to hospital by police:

I was taken from Townsville to Brisbane in the back of a police paddywagon, psychotic and very distressed. When the police would have a meal break or something, they'd just throw me into one of the local cells, wherever they happened to be... One of those was a padded cell with no toilet facilities, no furniture, and bloodstains all over the cladding.<sup>110</sup>

(This issue is addressed in more detail in Chapter 8.)

## Assessment for Mental Illness in Prison

The medical services...shall include a psychiatric service for the diagnosis and, in proper cases, the treatment of states of mental abnormality.<sup>111</sup>

Before an illness can be treated it must be recognised. However, a great deal of mental illness goes undiagnosed in prison. This is due, in part, to inadequate assessment on initial admission to prison.

A South Australian witness referred to 'a lack of formal process as to how people with mental illness are identified as they enter the correctional services system.' Even when psychiatric reports are presented during a trial or at sentencing, those reports are not necessarily passed on to prison or probation officers.<sup>112</sup>

In NSW the prison regulations provide that the prison medical officer should 'cause each prisoner to be examined as soon after reception as is practicable'; and then 'to cause to be carried out such medical examinations, investigations and treatment of such prisoners as may be reasonably necessary.'<sup>113</sup> However, a review of the NSW Prison Medical Service found that in practice,

nursing staff generally have total responsibility for the assessment process. Medical staff are only called on where necessary, generally through referral to Doctor's 'sick parade' when next available. The assessment process is generally short, and revolves around the completion of a reception form...which collects only limited information.<sup>114</sup>

Evidence presented to the Inquiry suggests an even less thorough process is the norm. One expert witness gave evidence that most prisoners undergo a blood test for HIV on reception; but apart from that, there is no routine medical or psychological assessment:

This is not done, because there is no funding. All agree it should be done.<sup>115</sup>

Despite this lack of systematic assessment, a psychiatrist who works as a consultant to the NSW Corrective Services Department claimed that 'the great majority of prisoners with psychiatric disorders do come to the attention of the Prison Medical Service, and do receive at least some psychiatric attention while in jail.'<sup>116</sup>

By contrast with NSW, Victoria has a systematic reception process which is the joint responsibility of the correctional and health authorities. A doctor examines and assesses all new prisoners; certain categories are typically referred on to other professionals such as a psychiatric nurse, psychiatrist or Aboriginal welfare worker. These categories include young prisoners, sex offenders, first-

timers, prisoners who are despondent, distressed, overly anxious or psychiatrically disturbed, those withdrawing from drugs or alcohol and Aboriginal and Torres Strait Islander people.<sup>117</sup>

A witness from a prisoner support group said this assessment process 'has been a great asset...a great improvement'.<sup>118</sup> Even so, it is far from 100 percent effective:

Not all people who have either mental illness or severe behavioural disorders are in fact identified through the process...and even [among] those who are identified, those who don't appear at the time to require immediate treatment often move through into the mainstream of the prison environment, and often the...illness can [become worse] at a later stage.<sup>119</sup>

This witness particularly lamented the fact that the reception process applies only in adult jails, and not in juvenile correctional facilities.<sup>120</sup> NSW witnesses also raised the absence of assessment for juvenile offenders in custody. This omission means mentally ill juveniles are denied the treatment they need; but also has more far-reaching implications:

It also means that those young people who have mental health problems specifically arising as a result of their custody tend to go untreated. And obviously, for...custody centres it creates all sorts of management problems, and that results in more young people being transferred to adult facilities.<sup>121</sup>

A more detailed discussion of issues affecting mentally ill juveniles in detention is contained in Chapter 20.

### **Assessment on Entry into Police Custody**

Well before alleged offenders reach jail, they become prisoners of the police. Over 25,000 people are taken into police custody in an average month.<sup>122</sup> The police themselves recognise that being arrested and locked up can be a traumatic experience:

Several factors combine to traumatise a prisoner, eg the indignity and shame of arrest, guilt about the offence, concern about imagined police harassment, the physically depressing nature of many cell areas, isolation and confinement in a cell, fear of the legal process, worry about the social and employment consequences, etc.<sup>123</sup>

Over one-third of suicides in custody (and nearly 40 percent of custodial deaths) occur in police custody.<sup>124</sup> Clearly the period immediately after arrest is a critical time for assessing the mental health of prisoners. Anyone taken into custody who appears to require mental health treatment should be taken immediately to a hospital.

Victoria requires anyone in police custody to be assessed if they appear to be psychiatrically disturbed. Police officers themselves decide whether a particular individual requires assessment; to this end all police receive specific training in mental illness.<sup>125</sup> The assessment itself is conducted by one of 45 medical practitioners who are on call for this purpose throughout the State.<sup>126</sup>

Frequently the assessments are performed in less than adequate surrounds: rooftops, prison cells, the rear of divisional vans and backyards, intermingled with screaming and yelling, blue uniforms and weaponry, distraught family members and angry neighbours... The luxury of fixed appointment times, subdued lighting, soothing music, designer colour schemes and couch are never available.<sup>127</sup>

In principle, NSW police have a screening procedure too. It is based on the Prisoner Admission Form, a questionnaire which officers are required to follow with every person detained. However, a recent inquiry by the State Ombudsman found that the procedure is sometimes regarded as merely a routine task preceding incarceration. Sometimes it is performed inadequately; sometimes not at all.<sup>128</sup>

In North Queensland the police apparently lack even the most rudimentary screening procedure. One witness, representing a prisoner support group, said 'the Cairns watchhouse...is notorious.'<sup>129</sup> She cited the example of one prisoner,

who was, amongst other things, on medication for epilepsy. He wasn't getting it. We had quite some difficulty...to arrange that he did get taken to hospital to get it. [By then] he had been fitting over a number of days.<sup>130</sup>

### *The importance of assessment*

The Royal Commission into Aboriginal Deaths in Custody stressed the importance of identifying prisoners at risk of suicide. It recommended that all police and prison officers receive basic training in recognising warning signs, and 'Suspicion that all is not well must result in urgent medical referral.'<sup>131</sup>

Similarly, the NSW Ombudsman has observed:

One of the major factors in suicide prevention is an effective screening process. The basic elements of the process are well recognised — the practical implementation of them does not appear to have received sufficient attention.<sup>132</sup>

It appears that Victoria's screening process has been effective. When the procedure was first implemented, Victoria was averaging six or seven prison suicides each year, with 11 in the previous 18 months. By early 1991, after



more than two years of the screening procedure being used, there had been no further suicides.<sup>133</sup>

## **Treatment of Mental Illness in Custody**

Our management of psychotic prisoners is made extremely difficult by lack of time, lack of proper facilities, and the fact that almost inevitably a psychotic prisoner has to go into segregation. And...segregation means an awful lot of time in a cell, very little exercise, and at times conditions close to sensory deprivation — which almost inevitably predicts a worsening of the psychotic condition.<sup>134</sup>

A recurring irony throughout evidence presented to the Inquiry was that the people who are most needy and most vulnerable in our society are precisely the ones who are denied the treatment they need. The evidence about prisons was no exception. Most prison medical services include some form of mental health care dispensed by doctors, nurses, psychologists or social workers. However, these services are seriously deficient — in terms of both resources and coordination with prison authorities. As a result, the treatment offered to prisoners affected by mental illness is usually inadequate, often inappropriate and sometimes downright brutal.

The Inquiry was told ‘the care of people with schizophrenia in Queensland jails is practically non-existent.’<sup>135</sup> In prison systems which do provide ‘treatment’ for severe mental illness, one of the most frequently used ‘tools’ is isolation:

The traditional method of [treating] someone who’s showing bizarre behaviour is to strip them naked and leave them in a cell, sometimes for 24 or 48 hours — but sometimes that isolation goes on for days and even weeks.<sup>136</sup>

At Mulawa Women’s Prison in Sydney, the Inquiry was told, prisoners believed to have suicidal tendencies are put in a ‘dry cell’, which contains nothing except a bucket toilet and a gym mat on the floor. In 1991 there were two of these cells:

One of them is in a very old building which is very dilapidated, and actually has a toilet basin which is not connected to the plumbing so it’s not useable... The other dry cell, which was built only a few years [ago]...has no ventilation at all, no windows, except for a small slot very, very high: I think the intention here was to provide something which was said to be suicide-proof. And a very heavy iron door — it faces east, and...I was called down there on a very hot day this summer, when the temperature must have been about 30° outside, and it must have been 50° inside the cell. It was just dreadful, and the smell of urine from the bucket and the cramped, dark conditions are just horrible. I think it’s terrible to consider that it was built so recently — that anybody could have designed anything like that so recently.<sup>137</sup>

A South Australian witness said that when treatment is provided, it is overwhelmingly 'medical', with no rehabilitation. Even the limited program of activities available to ordinary prisoners may be inaccessible to those with a mental illness because, being especially vulnerable to violence, they are often housed in special protection units which restrict their movement.<sup>138</sup>

The Inquiry heard disturbing allegations of the use of psychiatric medication as a management tool in prisons. For example, in Western Australia:

Although we have no accurate statistics...one comment to come to us regarding Fremantle Prison was that 70 percent of inmates were on prescribed medication. From practical experience, we have noted an alarming number of women whom we have interviewed at Western Australia's women's prison, Bandyup, being under the influence of presumably prescribed drugs.<sup>139</sup>

We are concerned that these people [who are not really mentally ill] are given medication whilst they are in prison, and people who actually do have some mental illness which should be treated are also given medication, so it is hard to distinguish one from the other. Everybody is just seen as taking some sort of medication to keep them quiet.<sup>140</sup>

The use of medication as a management tool is an abuse of the human rights of all prisoners, mentally ill or not. It also inspires little confidence that those affected by mental illness will have their needs appropriately met.

An allegation that trading in medication occurs was also made to the Inquiry:

When a psychiatrist sees mentally ill people in jail and prescribes medication, I believe that the medication is not made up and given personally by the doctor, but the prescription is given to the prison warders. There is a strong inference that this medication then finds its way not to the patients, but is used for 'trading' in sedatives.<sup>141</sup>

## Denial of Treatment in Prison

My son was denied psychiatric assistance when all the circumstances screamed out that this was essential, and according to the *Mental Health Act* was his right, and was requested.<sup>142</sup>

In most parts of Australia prisoners have no legal right to treatment for mental illness **as prisoners**; prison statutes require only that inmates be given access to such medical treatment as is considered necessary by the prison authorities.<sup>143</sup> Sometimes prisoners receive no treatment at all, even if they are known to have a mental illness before going to jail:

In recent times...it was not uncommon at times for a person with very severe psychiatric illnesses being admitted to prison, perhaps on remand, automatically having their treatment stopped, because...those were the rules.<sup>144</sup>

It is particularly abhorrent that people who are in jail largely (or entirely) because of their mental illness are denied treatment for it:

You are actually preventing the inmate from seeking treatment... I saw people who had been in prison for eight years in such a way, and prevented from seeking treatment of any kind.<sup>145</sup>

One report to the Inquiry concerned psychiatric medication being denied to prisoners as a form of punishment.<sup>146</sup>

In most parts of Australia a prisoner who displays current, obvious and extreme psychotic symptoms will eventually attract some form of medical attention. However, 'lesser' conditions, including depression, neuroses or personality disorders, are often not seen as meriting intervention:

Where people are defined as being not psychotic, it is [assumed] that they don't necessarily require the same expertise or delivery of service, in terms of quantum or services available.<sup>147</sup>

Unfortunately, these other conditions can be extremely serious and sometimes even fatal.

### **Denial of Treatment in Police Custody**

If treatment for mental illness is difficult to obtain in prison, it is virtually impossible in police custody. Every prison system provides at least a rudimentary health service which has no counterpart in the police lock-ups.

In theory there should be little need for mental health care in police cells. They are designed for very short stays. The prisoners are people who have been denied police bail and are only being held until they can be brought before a magistrate — the next day, or at most over the weekend. Generally speaking, this is true: half the people taken into police custody are held less than five hours, and 87 percent less than 24 hours.<sup>148</sup>

However, in reality, police cells are frequently used as back-up accommodation for the prisons.

Police cells were employed whenever prison accommodation was full; or pending (in remote locations) intermittent escorts to prisons; or by arrangement with the prison authorities because it was judged more economical or humane to let prisoners remain in police accommodation near their own community... In the northern outback of Western Australia, for instance, it is normal for remand or short-sentence prisoners...to remain in small police lock-ups.<sup>149</sup>

The Inquiry heard evidence of mentally ill people being held in Queensland watchhouses for two weeks,<sup>150</sup> and of a young man held for three weeks at a suburban Melbourne police station.<sup>151</sup> Melbourne's 'cell circuit shuffle', in which prisoners are moved between watchhouses every few days, has already been mentioned. Holding prisoners for such long periods must entail a responsibility on custodial authorities to provide (or at least allow) treatment for mental illness. Yet this concept is apparently unknown at some police stations. For example, people who know they are mentally ill and need medication may be denied it:

Because they don't have training, [Queensland] police don't realise the importance of people continuing to take anti-psychotic medication. And because their behaviour doesn't immediately deteriorate, they don't realise that it will deteriorate over a period of days or weeks, and they will...suffer more and more.<sup>152</sup>

The young man held by Melbourne police for three weeks was withdrawing from drugs, suffering acute depression and anxiety, and bore obvious marks of a suicide attempt. His mother told the Inquiry that he was not allowed to see family members or any other people significant to him — including those who were treating him for his drug problem. Both he and his mother asked that he be seen urgently by a mental health worker, but these requests were ignored or denied.

After three weeks in the police cells he was taken to Pentridge Prison, where he was placed in a cell by himself:

With a history of serious and recent suicide attempts, his pleas and cries for help were ignored. He died within 24 hours.<sup>153</sup>

For his mother the nightmare continued after his suicide:<sup>154</sup>

The handling of [the] situation was appalling and lacking in any sensitivity to [my son] or his family... For example, I was not even informed of [his] move to Pentridge, until the Community Police came to tell me that my son had died in 'protective custody', and to go and claim his body. The Prahran police were the first to offer any sensitivity and a kind word. For hours afterwards, I was not able to locate my son's body; then [I was] told I didn't need to identify him, just to make arrangements to bury him.<sup>155</sup>

Such abuses of basic rights are intolerable. In a modern democracy they are also inexcusable.

### **Transfer to Hospital for Treatment**

Persons who are found to be insane shall not be detained in prisons and arrangements shall be made to remove them to mental hospitals as soon as possible.<sup>156</sup>

All Australian prison systems have provision for individuals who are severely mentally ill to be transferred into a psychiatric hospital ward and treated as inpatients. Some jurisdictions have such a ward within the prison system: eg Long Bay Gaol in Sydney. In other systems, severely mentally ill inmates are transferred out of the prison sector and into a secure ward in an ordinary psychiatric hospital. South Australia has a special ward for prisoners, James Nash House, which is part of the public hospital system. The question of whether these inmates should be treated in the health sector or the prison sector is controversial (the arguments on both sides are addressed below).

The Inquiry heard few complaints about the treatment which mentally ill prisoners receive once admitted to hospital. However, getting to hospital can be extremely difficult — virtually impossible in some cases, eg for women prisoners in NSW (see below).

This issue was raised by a number of witnesses, including several from the ACT, which has no jail and therefore transports its offenders to serve their sentences in NSW. The Territory Government is concerned that prisoners affected by mental illness should have access to treatment. Yet prisoners from the ACT are forced to go without treatment at Goulburn Gaol, where there is no psychiatric service, while awaiting classification for the NSW prison system:

There is no care, no control... We had a horrendous case two years ago of a young man who suicided after three days in Goulburn. He should not have ever been sent there. He was just too ill and too vulnerable — and that is always going to be a problem when we send people in a vulnerable condition to places like that.<sup>157</sup>

The ACT authorities advised the Inquiry that they are trying to arrange for ACT prisoners who are mentally ill to go direct to the special facility at Long Bay in Sydney.<sup>158</sup>

A blatantly discriminatory practice was brought to the Inquiry's attention in Tasmania: prisoners who become mentally ill in jail and are transferred to hospital do not have their time in hospital credited as part of their sentence:

So a man sentenced to, say, one year's imprisonment, who falls sick within the first two months, is sent to a mental hospital, where he remains treated but incarcerated for a year before recovery — he has to return to prison to serve the rest of his sentence. So his sentence virtually becomes two years. In contrast, if he were physically ill, no such disadvantage would obtain.<sup>159</sup>

This practice is apparently not confined to Tasmania. It was raised in evidence to the Inquiry in Queensland,<sup>160</sup> and has also been highlighted by the Committee appointed to review the operation of the NSW *Mental Health Act*.<sup>161</sup>

Thus prisoners who are psychiatrically disabled are punished for their disability as though it were a further crime. Apart from being grossly unfair, this practice strongly discourages prisoners from seeking psychiatric assistance if they need it. This perpetuates the problem of mental illness going undiagnosed and untreated in prison.

## Special Needs Groups in Prison

### Women

Recent changes have resulted in a decreased level of care so that the situation at Mulawa [Women's Prison] is the worst for many years.<sup>162</sup>

Women comprise about 5 percent of the prison population,<sup>163</sup> but the information available to the Inquiry suggests the prison system has largely failed to recognise their needs.

Expert witnesses gave evidence that female prisoners affected by mental illness are often more disabled than their male counterparts. Female prisoners are reported to have more physical and mental illness generally,<sup>164</sup> and an especially high rate of alcohol and/or drug problems.<sup>165</sup> The diagnosis of 'personality disorder' is more frequent among women.<sup>166</sup> They generally have less education, inferior social skills and less family support than male prisoners.<sup>167</sup> Being incarcerated also creates particular difficulty for women who have children:<sup>168</sup>

Pregnant women have no opportunities to bond with their babies, and for those children the opportunities for visits are limited ...<sup>169</sup>

And they are not able to deal with problems that arise with their children. They may receive [bad] news about the children or other family members and can't deal with it from where they are.<sup>170</sup>

As mentioned earlier, a recent Tasmanian study established that about one-third of female prisoners admitted over the last ten years had a psychiatric history;<sup>171</sup> but the absolute number with psychiatric disorders has steadily increased in that time.<sup>172</sup> Some have chronic, severe mental illness, but the most common diagnoses are 'personality disorder' or drug abuse.<sup>173</sup>

### *Prison conditions for women (NSW)*

In Sydney the Inquiry heard from a psychiatrist who works as a consultant to the NSW prison system that conditions generally for women prisoners are even worse than for men: for example, there are fewer activities, educational

programs, employment or training opportunities and little prospect of transferring within the jail system.<sup>174</sup> At Mulawa, the women's prison, overcrowding created by the Government's new policy is particularly acute.<sup>175</sup> In 1989 there were 150 inmates at Mulawa; by 1991 there were over 300. At the same time,

The facilities for treatment of prisoners suffering from any kind of emotional or psychiatric disturbance have decreased, so that there are less facilities available now than there were when there were only 150.<sup>176</sup>

### *Treatment for women with mental illness*

The NSW prison system provides no inpatient psychiatric facilities — and in fact no proper medical facilities — for women. Female inmates suffering from mental illness are generally 'treated' within the prison mainstream.<sup>177</sup>

The Mulawa treatment regime contains several serious deficiencies. One is the use of the segregation unit to isolate women who appear to have psychiatric or emotional difficulties, especially if they are deemed by prison officers to be potentially suicidal. The segregation unit was purpose built, at low cost, as a punishment and deterrence unit:

The general atmosphere evokes a feeling of punishment and indignation which is not conducive to any form of psychiatric treatment. There are no facilities for examination/interview and assessment, or for observation of prisoners. There is no 24-hour nursing cover. Medication and files are not stored in the unit. Inmates are locked in cells from 3.30pm to 8.30am.<sup>178</sup>

This building also contains the new 'dry cell' described earlier in this chapter. As if the setting were not punishment enough, segregated prisoners may be subject to the humiliation of being stripped naked. This is 'said to be for their own protection', to prevent them hanging or strangling themselves with items of clothing:

And on some occasions...they are stripped by male officers and left stripped, sometimes for long periods of time...under observation by male (or maybe male and female) officers. There's only this gym mat and no blankets or covers.<sup>179</sup>

This kind of treatment is distressing for anyone, but especially for a person with a mental illness. Moreover, a large proportion of female prisoners have previously been victims of sexual harassment or abuse;<sup>180</sup> this practice creates the potential for such abuse to be repeated by prison staff.<sup>181</sup> Even on grounds of simple physical health it is objectionable: the cell which gets so hot on summer days can also be very cold at night, but a woman who has been stripped is obliged to sleep naked and uncovered on the gym mat.<sup>182</sup>

Incredibly, the decision to put a prisoner into a dry cell and strip her is made entirely by prison officers, without any assessment or advice by any health worker. The psychiatrist who described this practice to the Inquiry made a plea for some health expertise to be involved:

I would recommend first of all that there should be assessment by someone from the health team, preferably by a psychiatrist, but certainly at least by a nurse who's got some psychiatric training... I'm not saying prison officers are wrong to be concerned, but they should get professional help quite early.<sup>183</sup>

In any event, the witness said she does not believe it is ever necessary 'to strip anybody completely and then leave them naked'. As a practicality, she suggested the use of heavy calico gowns and special blankets which are hard to tear into strips.<sup>184</sup> However, there is obviously great scope to reduce the danger of suicide merely by involving staff who have some expertise in mental health — and by eliminating 'treatment' practices which actually exacerbate mental illness.

#### *Transfer to hospital*

In extreme cases, women who become acutely ill can be transferred to hospital. However, this is no simple matter. Unlike male inmates, for whom a hospital exists within the prison system, women must be transferred out into the general mental health system.

In principle, Cumberland Hospital makes five beds available for female prisoners. But these five beds may be already full; even if they are not, the bureaucratic delay in transferring an inmate out of jail can be up to 14 weeks!<sup>185</sup> For a person who is suicidal or suffering from an acute psychotic disturbance, this delay is tantamount to official medical negligence. (It is certainly a violation of a sick woman's basic right to appropriate treatment.) The process of transfer essentially consists of a form being completed by two doctors, one of whom is a psychiatrist. It is a procedure which should take, according to the witness, 'a few days at the longest'.<sup>186</sup>

In practice, for the many prisoners who are on remand awaiting trial, a quicker way to get into hospital is simply to wait for the day of their court hearing to arrive. A forensic psychiatrist makes the application under the *Mental Health Act*; the magistrate has the power to act on the application and send the person directly from the court to a hospital, 'if he considers that mental illness may have been a factor in the commission of the offence, or that the person needs urgent treatment.' Even so, severely disturbed women can spend several weeks in prison — a totally unsuitable environment — waiting for their court cases to come up.<sup>187</sup> For example:



A 54-year-old woman suffering from early dementia was admitted to Mulawa. She had been charged with 'trespass'... She had harassed the owners of a house where she had previously lived, telling them it was her house. Police took her [first] to a mental hospital, who refused admission. She spent three weeks in prison before she was transferred to a mental hospital from the court.<sup>188</sup>

While waiting for a transfer, these acutely ill women are kept in conditions likely to aggravate mental illness. The expert witness gave other examples — including that of a young woman who had a history of psychotic episodes. She was sentenced to three months in prison. At the time of her admission to Mulawa she was stable and not on medication. However, she soon became distressed and then developed psychotic symptoms:

When she expressed her delusional beliefs to prison officers, she was told not to tell lies and was transferred to a 'dry' cell because of her disruptive behaviour. At first she settled, but when she went to the toilet and realised the toilet could not be flushed, there was no toilet paper and she could not wash her hands, she became increasingly psychotic and her agitation increased. She began screaming and was told that the longer her noise continued, the longer she would remain in this cell.<sup>189</sup>

The psychiatrist was gravely concerned:

A Schedule 3 certificate was written by myself and also the other attending psychiatrist, for her transfer to a mental hospital as a matter of urgency. Medication was administered and she was seen as often as possible by one of us — but this young woman remained in the 'dry' cell for most of her three months imprisonment, as the Health Department stated that no beds were available in a mental hospital facility.<sup>190</sup>

Such treatment of sick people is not only a violation of human rights — it is a disgrace to a nation that considers itself civilised.

### *Women in male prisons*

Up until 1990 female prisoners who were mentally ill could be transferred to the hospital at Long Bay, an otherwise all-male prison. The Inquiry was told the women received 'very inadequate' treatment, and encountered strong prejudice from staff: 'a feeling that there was something really quite aberrant about being a female prisoner.'<sup>191</sup> Women were strip-searched by male staff at Long Bay,<sup>192</sup> and many were refused admission:

There was a tendency...for them not to be accepted but just sent back on the grounds that they were being 'manipulative'... They were simply [deemed] 'personality disordered' and 'manipulative' and should be sent back to Mulawa — and a very high number of them were sent back within half a day or a day or so, some of whom I consider were actually quite psychotic and who later ended up in mental hospitals.<sup>193</sup>

Women prisoners are no longer transferred to Long Bay psychiatric unit; however, the current arrangement with Cumberland Hospital is also patently inadequate. The psychiatrist who gave this evidence noted recent suggestions that disturbed women should again be moved to Long Bay:

I am open to any of these ideas as they certainly would offer better opportunities than the present lack of facilities at Mulawa. However, these women are placed in a position where they are the minority in a group of psychiatrically disturbed inmates and they are thus in a very different to a normal situation... Their experience of males is mostly adverse, and their transfer to a male institution is generally regarded as negative and sometimes perceived as a punishment.<sup>194</sup>

She maintains the women prisoners 'would be better off being treated within the female prison system, with programs devised for females.'<sup>195</sup>

### **Aboriginal and Torres Strait Islander People**

We're the most imprisoned race of people in the world.<sup>196</sup>

Aboriginal and Torres Strait Islander people are over-represented in prisons: they constitute 1.5 percent of Australia's population (and less than 1 percent of the adult population), but 14 percent of prisoners.<sup>197</sup> They are especially over-represented in Western Australia, South Australia and the Northern Territory.<sup>198</sup> Furthermore, these statistics on prison populations do not cover police cells. In police lock-ups the proportion of Aboriginal people is even higher: nearly 29 percent of those taken into custody nationally — an over-representation by 26 times.<sup>199</sup>

In Sydney the Inquiry heard evidence from LINK-UP, the support agency for Aboriginal people removed from their families as children, that the overwhelming majority of Aboriginal people in jail have suffered the mental effects, either directly or indirectly, of this separation.<sup>200</sup> Witnesses also referred to the dispossession of Aboriginal people as a cause of profound spiritual, emotional and mental harm.<sup>201</sup>

One of the functions of forensic psychiatrists and psychologists is to provide assessments for the use of courts, legal services, probation and parole officers. These reports allow mental disturbance to be taken into account in preparing a case, and for making decisions about sentencing and parole. A psychologist who regularly performs this role in the Northern Territory told the Inquiry that Aboriginal offenders do not get the benefit of this service, because the 'experts' understand so little about Aboriginal mental health:

We can do it for non-Aboriginal people, [but] we really, at this stage, cannot do it with any sound theoretical base for Aboriginal people. I guess it raises a social justice issue: they are not getting a thorough enough job done.<sup>202</sup>

One specific characteristic which still appears not to be understood by our traditional penal and mental health systems is that incarceration itself creates severe mental disturbance for Aboriginal people. The consequences are sometimes fatal, as the Royal Commission into Aboriginal Deaths in Custody has revealed. Witnesses to the Inquiry repeatedly stressed the seriousness of this issue, which is a deeply ingrained cultural difference between Aboriginal and non-Aboriginal people. As the parents of one prisoner said:

While he's in jail over there...you know, he's not — just not like an Aboriginal over there. It's not [right] for an Aboriginal to be in that sort of situation all the time — locked up — because, you know, it's against our culture.<sup>203</sup>

Whether the incarceration is in a prison or a psychiatric ward, the problem is the same. A solicitor in Darwin told the Inquiry the story of one of his clients, an Aboriginal man from a remote community who has schizophrenia.<sup>204</sup> Arrested in 1986 for a series of offences, he was sentenced in 1987 to detention under the *Mental Health Act* for up to six months. Taken to Alice Springs Hospital, he became violent, insisting he wanted to leave. He was then medicated and transferred to the security ward at Royal Darwin Hospital. He remained there, '1500km away from his family, his community, his language, his culture, his land', for over five years. When the Inquiry sat in the Northern Territory (and visited him) he was about to be transferred back to Alice Springs Hospital, closer to his community — but was still no closer to release.

Why was this man's six-month sentence extended for so long? His solicitor explained what the hospital records reveal:

All that [he] has ever wanted throughout the last seven years of custody up here is to be allowed to return to the Centre... Again and again, all the entries made...as to [his] conduct and his utterance throughout the day repeat this: 'When am I going home? When can I get back to Alice Springs?'

The other thing that is quite clear...is the man's frustration... On several occasions during this seven years he was told by staff, 'Another six weeks in Darwin with a view to moving you down.' The next day's notes: '[Patient] very happy'; and the concepts they used disturb me, but these are the concepts they used: 'No management difficulties. Behaviour excellent. Not upset. Very happy. Excited about, looking forward to going down.' This would happen continuously over that period of seven years and then something would happen — an incident would occur... It did not happen. The Health Department would say, 'We didn't have the resources down at [Alice Springs]... He is dangerous. He fulfils the criteria.'

[He] would misbehave. Entries in the notes describing his misbehaviour follow thus: '[He] refuses to do the dishes.' [He] would always refuse to do the dishes! It is against his culture — he is an Aboriginal man from a settlement in Central Australia. There is no accommodation for that, it would appear, in the treatment of the man by the staff.<sup>205</sup>

One Aboriginal witness warned against the assumption that disturbed Aboriginal people in prisons should be transferred to the mental health system, saying this 'doesn't actually treat the cause, it just transfers one problem to another.'<sup>206</sup>

### **People of Non English-Speaking Background**

A particular difficulty for prisoners from non English-speaking background who are affected by mental illness is the lack of interpreter services.<sup>207</sup> The problem is not only insufficient services:

We've had one instance of a prison warder refusing to allow an interpreter to go into the prison, because the warden felt all conversations should be in English — because they weren't sure what was actually being discussed.<sup>208</sup>

Resistance may also come from the interpreters themselves:

There have been a lot of interpreters who have not particularly wanted to go [out] to the prison, but...have been willing to meet elsewhere, at the courthouse in town, down in the cells there.<sup>209</sup>

### **Other Groups**

Children and young people in custody who have a mental illness are another special needs group. They are discussed in Chapter 20 of this report. Two other groups of prisoners also at particular risk are older men with dementia or severe depression, and prisoners with developmental disability and behavioural problems.<sup>210</sup> (See Chapter 21 — People with Dual and Multiple Disabilities.)

### **Shortage of Staff and Resources**

It may be that one of the roles of a Commission such as this is to point out to governments that they really shouldn't go on doing things like this — establishing prisons, which of course we must have in our communities, but not staffing them properly.<sup>211</sup>

The main reason why mental health care in jails is so poor is the shortage of staff.<sup>212</sup> The Standard Minimum Rules require 'a sufficient number of specialists such as psychiatrists, psychologists [and] social workers'.<sup>213</sup> Yet every forensic psychiatrist who addressed the Inquiry referred to the severe understaffing of mental health services for prisoners — a group with a very

high rate of mental illness and other disabilities, living in an inherently stressful environment, and prevented from seeking assistance privately.

The Prison Medical Service is the worst staffed area in the health (hospital or community) system in NSW.<sup>214</sup>

The NSW Prison Medical Service (PMS), responsible for the health of nearly half of Australia's prisoners, relies mainly on part-time consultant psychiatrists. In October 1990 the amount of psychiatric time available was 100 hours a week — equivalent to less than three full-time psychiatrists! PMS psychiatrists are also required to provide court and tribunal reports and to attend some court hearings. When these activities are taken into account there is even less time available for providing psychiatric care to patients.<sup>215</sup> Given the number of prisoners requiring care, the number of psychiatrists available is hopelessly inadequate.<sup>216</sup>

Other mental health workers are similarly scarce. For example, at Mulawa Women's Prison in Sydney:

There are no social workers or other kinds of ancillary staff that we'd like. There are two good psychologists at Mulawa and they work [well], but they have a very full load.<sup>217</sup>

At Lithgow Corrections Centre,

which is a much better appointed prison and the segregation facilities there are much more sensibly designed — the jail has been opened for six months, [and] there is still no psychologist. They have appointed a drug and alcohol worker.<sup>218</sup>

The problem is by no means confined to NSW. In Queensland the Inquiry heard:

The psychiatrists from the community psychiatry team go up to Lotus Glen [Prison] once a month, I think. There is a psychologist employed at Lotus Glen, but there are no programs.<sup>219</sup>

In Western Australia:

The prison medical service is small and deals with minor health problems. As more mentally ill offenders are imprisoned, the system will increasingly fail to address the real issues associated with this group.<sup>220</sup>

In Victoria the shortage is especially acute in the detention centres for young offenders:

We have about 250 young people in our youth training centres in this state, with one medical person who's specifically involved with their mental health.<sup>221</sup>

The staff shortage in prisons is due to a lack of funding for positions; but even the positions which are funded are difficult to fill. Forensic psychiatry is not perceived as an attractive field of work,<sup>222</sup> and the work environment is hardly alluring:

Conditions are difficult for staff as well as prisoners, and qualified staff accept a much lower standard of conditions than their counterparts in the community.<sup>223</sup>

### **Lack of Training for Police and Prison Staff**

Too many police are sent to stations without this knowledge — and even if they gain it, they are transferred [away] and the rapport is lost; and the people with mental illness and their families are left without any support once again.<sup>224</sup>

The distress suffered by mentally ill people in the criminal justice system is made worse by the fact that most police and prison officers have no training in recognising or dealing with mental illness.<sup>225</sup> Yet they are routinely the only people present when someone is taken into custody. Many police and prison officers are humane individuals who 'make a valiant effort to do what they can'<sup>226</sup> — but they are not trained to deal with mentally ill or disturbed people. Given the potential seriousness of the consequences, the absence of training for these officers is a dangerous oversight which must be corrected.

Additionally, in a society where mental health crisis teams are a rarity, police are frequently called specifically to deal with episodes of mental illness, even if no offence has been committed.<sup>227</sup> These officers must assess whether an individual is likely to be dangerous, and if so how much force to employ in subduing or arresting the person. Sometimes they use too much force, causing further distress and humiliation for the mentally ill person and their family.

Obviously they need training for these emergencies. The Inquiry was told that all Victoria's police now receive such training;<sup>228</sup> clearly our other police forces should follow the Victorian example.

### **Consequences of the Staff Shortage**

I think the longest list of prisoners I've been asked to see in any one visit is 27, which really doesn't allow for any more than band-aid psychiatric management.<sup>229</sup>

For highly trained and committed professionals, the job satisfaction available in our prisons appears to be absolutely minimal. They have little contact with

individual prisoners, very few resources and no say in the administrative fate of their patients.<sup>230</sup> Notions like 'continuity of care', 'best available treatment' or 'the doctor-patient relationship' appear to be unknown to prison authorities.

The concept of health workers being primarily concerned with the health of their patients is comprehensively overridden by the demands of penal administration:

The institutional mental health professional at any one time is wearing two hats. He's wearing the hat of the person contracted to the institution...is containing [disruptive behaviour] and providing administrative answers — not necessarily acting entirely for the therapeutic benefit or value of the prisoner or patient.

And the second hat we wear in delivering services is, in fact, to consider what illness the prisoner or patient exhibits and the most appropriate form of treatment.

Now, I think a lot of the time we see ourselves operating in the second mode, whereas in actual fact we are operating in the first mode. And where there is a shortage of time to offer what I consider an adequacy of services, almost exclusively we're operating in the first mode and therefore treatments are actually not delivered.<sup>231</sup>

Even prisoners identified as being 'in treatment' for mental illness have very little contact with their treating professionals. As one former inmate told the Inquiry:

The treatment was absolutely minimal, perhaps ten minutes a fortnight for people such as myself who were needy, and almost nothing at all for [other] patients.<sup>232</sup>

A further effect of the staff shortage is the potential denial to forensic patients of their legal rights. For example, in South Australia the law requires that involuntary hospital detention orders be issued and reviewed by different psychiatrists. But because of the shortage of forensic psychiatrists:

it would be fair to say...that the same people are reviewing those orders and maintaining them on occasions... And the same person may be providing the assessment and also providing the treatment.<sup>233</sup>

Another legal consequence of the shortage was noted by the PMS Review Committee:

The Committee has been informed of instances where prisoners appear before parole review hearings, and are refused parole on the basis that they have not undertaken appropriate psychiatric or psychological counselling.<sup>234</sup>

Despite their extremely difficult conditions, the mental health staff who choose to work in our prison systems are capable and dedicated. When prisoners

actually get to see a mental health worker, they are often satisfied with their treatment:

- My psychiatrist has given me the most help in my life, excellent.
- I have had occasion to have assessment by Department psychologists and found these people very helpful.
- I have seen three different psychiatrists/psychologists and they have all been most understanding and helpful.
- We would like to see more of the psychiatrist please.<sup>235</sup>

A psychiatrist working in the NSW prison system told the Inquiry:

The nursing staff in all of the ten years that I've been there have been of the very highest standard and calibre. My job has been made enormously more easy by their common sense and caring approaches and principles.<sup>236</sup>

### *Country jails*

The shortage of staff — and thus the inadequacy of service — is especially acute in country jails. According to one psychiatrist:

In the early 80s, I was visiting [Bathurst Gaol] once a week...probably offering four hours a week — I think up to 20 hours a month was my contract. Now, partly through the way the system has contracted, partly because of my own practice requirements, I travel to the country once a month and probably only go to Bathurst Gaol maybe ten times a year. And four hours, of course — even if it were ten hours a month, that is not enough time.<sup>237</sup>

This witness told the Inquiry that he was the only consultant psychiatrist available to the Bathurst and Lithgow jails. At the time (mid 1991) there were over 650 prisoners in those two facilities,<sup>238</sup> for whom he was available three days per month in total!<sup>239</sup>

In NSW, where prisoners are all too easily transferred between jails at short notice, arranging a transfer from a country jail to the prison hospital in Sydney is difficult:

Unless somebody is very crazy indeed, and of course I'm using that term in the lay sense, it is not easy to transfer them as an emergency... [There is] a resistance that crops up in maintaining what some of us in the country would see as a proper flow, proper clinical care.<sup>240</sup>



## Release from Jail

Often they leave prison without medication, though they may have been taking medication whilst in prison. And they are released often without any accommodation being arranged for them at all.<sup>241</sup>

Prison systems are frequently criticised for failing to prevent crime because some inmates commit further offences after release into the community. The standard response from governments is to call for longer sentences and crack down on conditions, day leave, remissions and parole. This recent and increasingly strident emphasis on punishment clearly contravenes the Standard Minimum Rules' requirement for rehabilitation to receive appropriate emphasis.

Rule 58. The purpose and justification of a sentence of imprisonment...is ultimately to protect society against crime. This end can only be achieved if the period of imprisonment is used to ensure, as far as possible, that upon his return to society the offender is not only willing but able to lead a law-abiding and self-supporting life.

Rule 59. To this end, the institution should utilise all the remedial, educational, moral, spiritual and other forces and forms of assistance which are appropriate and available, and should seek to apply them according to the individual treatment needs of the prisoners.<sup>242</sup>

These Rules recognise that punishment alone will not prevent reoffending; and that offenders should not be incarcerated in prisons which do not attempt to equip them for a self-supporting life. This is especially true for mentally ill offenders, for whom imprisonment actually reduces the chances of a self-supporting life.<sup>243</sup>

It seems a very obvious point — but one the evidence demonstrates is widely ignored; almost all prisoners are released eventually. If mental illness contributed to their breaking the law in the first place, and the illness is not treated, then it is very likely they will break the law again.

Prison mental health staff are in a position to observe first-hand the failings of a system that makes no attempt to rehabilitate offenders, nor to establish even the most minimal safeguards which might prevent them coming back to jail. For example, NSW prison psychiatrists are not even informed when an inmate whom they are treating is about to be released or transferred to another jail:

I have often just gone to find a patient to write up medication or something, and found that they have been released.<sup>244</sup>

There are no case management plans, nor any system of notification. Whether a psychiatrist hears of an impending release 'depends on individual personalities working together,' ie on the goodwill of prison staff. The prisoners themselves

are not always notified of their release date in advance. Even if they know they are due for release, planning for aftercare is difficult because

[Prisoners] don't always have the right information either, because there are complications about giving particular dates and sometimes they don't know what area they are going to live in.<sup>245</sup>

The absence of a notification system implies a lack of respect in the penal system for the doctor-patient relationship. On a practical level, it also prevents psychiatrists making any follow-up arrangements for individuals who are often extremely vulnerable: as well as being mentally ill, they may have lost many of their social ties and coping skills while in prison. Discharge procedures at prisons (like psychiatric wards) are at times quite inappropriate. For example, a psychiatrist told the Inquiry of a prisoner suffering from 'schizophrenia and quite a lot of social disadvantage', who was released in the middle of the night:

From this prison which is situated right in the middle of — well, a very long way from public transport anyway — with no money at 2.30 am, because [the prisoner] had a 48-hour sentence and the 48 hours finished at 2.30 in the morning.<sup>246</sup>

Obviously it would be unfair to keep inmates in prison for longer than their maximum sentence requires. But the alternative should not be release into a vacuum. If mental health workers in the prison system are notified, they can try to arrange some support for these prisoners to ease them back into the community.

In Western Australia prison officers sometimes contact Outcare, a housing and support agency for ex-prisoners, before an inmate is released on parole. Having secure accommodation can be a prerequisite for parole being granted — but if none is found, prisoners will often be released anyway. Prisoners who have served their full sentences are generally released without such a referral being made.<sup>247</sup>

### **Follow-Up after Jail**

I would say that in most of Sydney the follow-up of former prisoners either is inadequate or doesn't take place at all.<sup>248</sup>

The lack of support for mentally ill people released from jail was one of the most common concerns raised in the Inquiry. Mental health service providers often discriminate against ex-prisoners (see below). But prison systems also make no provision for psychiatrists to arrange follow-up care for their patients on release. Concern about inmates' health, while minimal at the best of times, evaporates completely when they walk out the prison gates.

Forensic psychiatrists who do try to maintain contact with their ex-patients are often obstructed by the corrective services culture itself. A psychiatrist who visits the NSW country jails said that if he makes a 15-20 minute STD phone call to check on a former patient, 'people start to ask questions' about the cost.<sup>249</sup>

In October 1990, members of the forensic psychiatry section of the RANZCP wrote to the NSW Minister for Health expressing concern about the grave difficulties in securing psychiatric care for ex-prisoners, and especially for discharged forensic patients. One of those psychiatrists told the Inquiry there were about 500-600 prisoners on parole in NSW in need of psychiatric care, but most of them are probably not receiving it.<sup>250</sup> Such a situation is short-sighted in the extreme; not only are the rights of sick individuals not observed — the rights of the wider community may well be imperilled.

Apart from meeting the needs of prisoners, appropriate follow-up care can provide a means of reducing overcrowding:

Any method of reducing the prison population is well worth looking into. And this is one method: that a number of psychiatrically ill prisoners could in fact be released, providing that appropriate psychiatric follow-up were available.<sup>251</sup>

### **What Happens to Mentally Ill People Released from Jail?**

Mentally ill people released from jail often follow a path like that of people released from psychiatric hospital wards. However, they bear the additional stigma that goes with a criminal record. This makes it even harder to obtain the health care and other services they need:

Either criminal behaviour or mental disorders, when viewed separately, create prejudices and rehabilitation difficulties. However, when clients have a history of both criminal and mental health issues, [they] tend to be shuffled from one agency or hostel to another... Whatever their pressing problem is at the time [determines] where they go.<sup>252</sup>

#### *Discrimination against offenders on the grounds of mental illness*

People coming out of jail frequently have no job, nowhere to live, and little social support. If they are also affected by mental illness, these problems are compounded by the inadequacy of the support available. For example, they have extreme difficulty in securing accommodation (see Chapter 10).

In Perth a witness from Outcare told the Inquiry that ex-prisoners generally face discrimination in trying to rebuild their lives; but prejudice against mental

illness is greater still.<sup>253</sup> As another witness who works with ex-prisoners in Melbourne said:

It's easier to be forgiven if you're just bad. If you're mad and bad, you've got real problems.<sup>254</sup>

The Outcare worker described a common reaction from support agencies approached to assist Outcare clients who are mentally ill:

Initially, they are probably a bit put off about helping, because...they know we only deal with newly released prisoners. But once anything about mental illness is mentioned, they withdraw totally from providing any assistance.<sup>255</sup>

### *Discrimination by mental health services against ex-prisoners*

If they endeavour to get services from agencies or institutions that provide assistance to people with psychiatric disabilities, the fact that they are ex-prisoners goes against them.<sup>256</sup>

Mental health services themselves are not immune from prejudice. One of the reasons prison psychiatrists have considerable difficulty arranging follow-up care is that many community health services are reluctant to take on patients who bear a forensic label.<sup>257</sup> (As mentioned previously, this reluctance can be the reason why a prisoner went to jail in the first place, instead of receiving a non-custodial sentence involving mandatory treatment.)<sup>258</sup>

It is ironic to find such prejudice among mental health professionals, many of whom work hard to dispel the myth that mental illness equals violence. The idea that all ex-prisoners are dangerous is equally an overgeneralisation.<sup>259</sup>

Some mental health services refuse assistance outright. Outcare cited this experience of trying to help a mentally ill prisoner about to be released:

We approached the psychiatric hospital where he had most recently attended before he went to prison, and we were told that they were not prepared in any way to re-accept him, to provide outpatient follow-up support, nor to refer him to the community psychiatric division for accommodation... It was suggested that we organise accommodation for him in a single-sex hostel. However, when we checked the prisoner's [records], the same hospital had prepared a report indicating that this prisoner should not be released to unsupported accommodation.<sup>260</sup>

This prisoner was released from jail with no supervision or medication program. He very soon re-offended and found himself back in prison.<sup>261</sup>

In some parts of Australia prisoners can be released directly from jail to a psychiatric hospital, ostensibly to ease the transition to the community. However, hospitals may not understand how disabling the effects of incarceration itself are. The Outcare witness told the tragic story of a prisoner who, after 17 years in jail, was released to a hospital for 'resocialisation' — a one-week program. As well as being mentally ill, he was physically disabled and on medication for epilepsy. Within a very short time he was released into the community with no support structures in place. Outcare several times raised concerns with the hospital about the lack of support. Eventually he reoffended, served another short prison term and another stint in hospital, then drifted into a boarding house where he contracted pneumonia and died.<sup>262</sup>

One solution for following up mentally ill inmates, described to the Inquiry by a forensic psychiatrist in Sydney, is for a few community mental health clinics to receive extra resources to develop a specialist expertise in caring for patients with a prison record. These centres would employ staff with experience of dealing with offenders. The Prison Medical Service would refer selected prisoners to the centres on release, thus ensuring continuity of care. The centres could also provide a consultative service to Probation and Parole Services.<sup>263</sup> This proposal was put to the NSW Government in 1990, but no response was ever received.

A version of this proposal operates in Melbourne, but it has its own shortcomings. The Parliament Place clinic is a psychiatric outpatient facility for people on probation or parole. But this focus on formal status in the penal system excludes ordinary prisoners who have been released after serving their full sentences:

If you're not on a corrections order then you're really not eligible to use that particular service.<sup>264</sup>

## **Probation and Parole**

The mental health system's refusal to treat ex-prisoners has adverse consequences for the prisoners' health and liberty. But it also creates deep discontent among workers in the criminal justice system, including probation and parole officers. These officers are charged with supervising offenders who are released conditionally into the community: either on parole (after serving part of a jail term) or on probation (instead of a jail term, eg a community service order or a bond).

If the offenders have a mental illness, probation officers are often expected to seek treatment for them. According to the Probation and Parole Officers'

Association of NSW, this task is made 'difficult, if not almost impossible' by the health services' reluctance to take on these clients. The officers are thus left by default with a responsibility for which they have no training, and which they insist should be shouldered by the health sector rather than the penal system.

The Association rejects the suggestion that the officers should merely be trained in how to supervise a mentally ill offender on parole:

What is needed is better coordination with the Health Department, an increase in resources available for these people [mentally ill offenders] and for the health system to accept responsibility.<sup>265</sup>

The officers' main concern is with prisoners who are floridly psychotic, aggressive or dangerous. In some cases the criminal justice system, recognising that jail is an inappropriate solution, will recommend hospitalisation of such offenders. However, such recommendations are hardly enforceable if the hospital takes a different view of the matter:

A leading Sydney psychiatric hospital proposed discharging a long-term psychotic patient on the grounds of lack of facilities for aggressive/dangerous patients. On a prior discharge, against family wishes, the patient had killed his mother. It took the coordination and intervention of both responsible Ministers to block the proposal.<sup>266</sup>

On the other hand, court-ordered treatment can fail for more mundane reasons. Witnesses from the Epistle Post Release agency in Melbourne told the Inquiry of a young man with schizophrenia who, being 'quite a resourceful person', was able to get a job when released on parole. However, his parole conditions required him to attend the Parliament Place clinic, in the centre of Melbourne, to receive his medication. The clinic did not make out-of-hours appointments. His job was in the outer suburbs, so he constantly had to leave work early to honour his appointments. If he did not attend, he was breaching his parole order; if he did, he was breaching his employment obligations. Epistle Post Release tried to get the parole conditions altered so that he might receive treatment closer to work; but before this could be resolved he gave up his job.<sup>267</sup>

### *The Northern Territory Mental Health Service Forensic Team*

The Inquiry heard of one forensic psychiatry service which appears to have surmounted some of the bureaucratic obstacles to aftercare. The forensic team in the Northern Territory Mental Health Service 'operates at the interface between the health system, the criminal justice and corrections system.'<sup>268</sup> It is a multidisciplinary team with a part-time consultant psychiatrist. It provides all forensic psychiatry services, including running security Ward 9 at Royal

Darwin Hospital; assessing inmates at Darwin Prison and the juvenile detention centre, then making recommendations to the prison medical service about treatment; monitoring and counselling individual prisoners where necessary; training prison officers in mental health issues; and consulting to the courts during trials and at sentencing. In addition, the team provides a regular outpatient service for offenders. The existence of this service allows the Parole Board to grant parole, and the courts to order non-custodial sentences, on the condition that the offender attend for treatment — and to be confident that the condition will be fulfilled.<sup>269</sup>

### **Are Mentally Ill People Violent?**

It's important to recognise that nearly all the people who are discharged from psychiatric hospitals are just like everyone else. But there is a tiny number who are extremely dangerous and have a high recidivist rate in violent crime.<sup>270</sup>

Discrimination against mentally ill people, especially if they have been to jail, is based largely on the public perception that these individuals must be violent. The evidence to the Inquiry overwhelmingly stressed that this view is greatly exaggerated. Not all ex-prisoners have a history of violence;<sup>271</sup> nor does mental illness equate with violence.<sup>272</sup>

The presumed link between violence and mental illness was described by one expert witness as 'a furphy and a red herring'.<sup>273</sup> According to another:

The facts of the matter are that most mentally ill people are not violent... There is a slightly higher proportion of violence amongst the mentally ill than amongst the non mentally ill. However... the strongest indicators of violence are age and sex... All [the] research indicates that we are at much greater risk of violence from males between the ages of 18 and 25 than we are from the mentally ill.<sup>274</sup>

### **Do Mentally Ill Offenders Re-offend?**

All people released from prison without adequate support face the very real risk of re-offending. For those with any degree of mental illness this risk is compounded, not only by their health difficulties, but also by the lack of suitable community care.<sup>275</sup>

Expert witnesses to the Inquiry agreed that mentally ill ex-prisoners are most likely to re-offend if they do not receive treatment and support after their release from jail.<sup>276</sup> In the absence of appropriate aftercare, the 'revolving door syndrome' becomes established:

They are released without any follow-up arrangements being made, and they turn up again a week or so later.<sup>277</sup>

Prisoners with a dual disability are doubly disadvantaged. The following account of an inmate with a mental illness and an intellectual disability was typical of several presented to the Inquiry:

This was a young man serving a short prison sentence following a fairly trivial offence...and towards the end of the sentence we became aware that he had nowhere to live on leaving prison — that he'd essentially been living on the streets prior to the offence, and unless something was done quickly he would return to living on the streets. We wrote to the community mental health clinic which tries to provide a service including accommodation for the developmentally retarded; [but] they were not able to offer any help with accommodation. The man left prison, went back to the streets, and...reoffended within a matter of weeks, and simply came back to prison again.<sup>278</sup>

The witness pointed out that each person in prison costs taxpayers at least \$50,000 a year. As a form of housing for people affected by mental illness, this is a ludicrously expensive and unsatisfactory solution.<sup>279</sup> From a human rights perspective it is repugnant.

## Prison vs Hospital

I've seen psychiatric facilities which are as dehumanising as any jail. On the other side of the coin, you see some prison facilities which are very modern in certain parts of the world...which emphasise aspects of human dignity.<sup>280</sup>

Should offenders who are mentally ill be detained in the prison or the health system? Mental illness per se does not justify hospitalising a prisoner as an inpatient, any more than it does a person outside jail. One witness drew an analogy between prisoners living in the main jail and other mentally ill people living in the community:

The majority of individuals with emotional or mental difficulties are cared for by the prison medical service, who are the equivalent of general practitioners. That mirrors the situation in the community at large where the majority of mental disorder is dealt with by non-specialist practitioners and only a small proportion enters into specialist psychiatric care.<sup>281</sup>

Wherever people live they are entitled to the 'best available mental health care' (Mental Illness Principle 1.1). The prison medical services in most parts of Australia are clearly failing in this respect.

All prison systems acknowledge there are some severely ill offenders who need hospital treatment. The question then becomes whether this should be provided in a prison hospital ('a hospital within a prison') or in a secure psychiatric ward of an ordinary civil hospital ('a prison within a hospital'). Both models are in use in Australia.



Apart from standards of care, both models raise the issue of competing rights. In an ordinary psychiatric hospital, the competition is between the rights of forensic and civil patients:

It is a very difficult balance between the rights of individuals with mental illness to receive optimal treatment in the least restrictive environment...and the rights of those who have a mental illness and a co-existing criminal justice problem to receive optimal treatment.<sup>282</sup>

In the prison system, the rights of mentally ill inmates compete with those of other prisoners, and of staff untrained to handle mental illness:

Some [non mentally ill] inmates believe they are imprisoned in an institution for mentally disturbed people rather than a prison... We have observed increasing tensions in both staff and inmates.<sup>283</sup>

The existence of a psychiatric ward within the prison system does not make it easy to obtain treatment for mental illness: as described above, transferring an inmate out of the cells and into the prison hospital can be extremely difficult. Standards of care in these wards are not immune to the effects of gross understaffing in prison medical services. The punitive atmosphere pervading corrective services is also uncondusive to mental health. For these reasons the Inquiry takes the view that prisoners who become seriously mentally ill should be treated in the health care system, not a prison hospital. It is, after all, their right to receive the same standard of health care as other mentally ill people.

### **Hospital Within a Prison**

Psychiatric wards inside prisons are found in Victoria (G-Division at Pentridge), Queensland (Security Patients Hospital, Wacol Prison), and NSW (Malabar Psychiatric Unit at Long Bay). The Malabar unit was established to replace an old 'prison within a hospital', the forensic Ward 21 at Morisset Hospital near Newcastle.<sup>284</sup> This was in response to recommendations by the Royal Commission into NSW Prisons, which was highly critical of conditions at Morisset.<sup>285</sup>

### **Prison Within a Hospital**

In most Australian jurisdictions forensic psychiatry is treated as part of the health care system. South Australia switched to this approach when it closed its old 'hospital within a prison', Northfield Security Hospital at Yatala Labour Prison. It now has a specialist forensic psychiatry hospital, James Nash House, built in the grounds of Hillcrest Hospital and run by hospital staff.<sup>286</sup> Hillcrest itself is now being closed, but the forensic unit will remain.<sup>287</sup>

Individuals from the criminal justice system are admitted [to James Nash] as either voluntary or detained patients, depending on their mental state, as any other citizen would be to a hospital. But because they're within the criminal justice system the legal convention is used that they are placed on special leave from the prison system... We have found [this] to be a successful strategy for ensuring that the custodial system retains an interest in these individuals, but that they are managed within the health care system.<sup>288</sup>

Victoria also has three forensic wards in psychiatric hospitals, two at Mont Park and one at Aradale Hospital.

Elsewhere, inmates affected by severe mental illness are transferred out to an ordinary secure ward in a public psychiatric hospital. This is the case, for example, in Western Australia (at Graylands Hospital), the Northern Territory (Royal Darwin Hospital's Ward 9), Tasmania (Royal Derwent Hospital) and for women prisoners in Sydney (Cumberland Hospital).

One problem with relying on transfers to the health system is that only a few beds are generally allocated for forensic patients. If those beds are full, the prisoner must remain in jail,<sup>289</sup> or else:

Sometimes we'd have to negotiate with a hospital to get a bed [for] someone with a mental illness who was a prisoner, and then we would have to get prison officers to come and stand outside the room.<sup>290</sup>

Some witnesses to the Inquiry also objected to this transfer system, believing mentally ill offenders could pose a danger to ordinary patients in the hospital.<sup>291</sup> On the other hand, the manager of forensic services in the Northern Territory told the Inquiry the two classes of patients are not so different from each other:

In the majority of cases, civilian patients admitted to [Ward 9] have an extensive history of involvement in the criminal justice system, even if they are not currently involved.<sup>292</sup>

#### *Darwin's 'multi-purpose mental health facility'*

One option for hospitals which cannot afford to build an entirely separate forensic unit is Royal Darwin Hospital's proposal for a 'multi-purpose mental health facility'. This will be a high-security ward accommodating three groups of inpatients: civil acute patients, mentally ill prisoners and sexual offenders diagnosed as having personality disorders. The first purpose-built psychiatric facility in the Territory, it will replace Ward 9, the secure ward which currently takes all acute patients from throughout the jurisdiction.

This proposal was the subject of a great deal of the evidence heard by the Inquiry in Darwin. A witness from the NT Association for Mental Health said:

Relatives and friends of acute admission patients who have seen the plans are both appalled and distressed that their loved ones will be housed in such an integrated structure.<sup>293</sup>

One objection is to the proposal's 'very dominant forensic ethos...[its] oppressive security-oriented design and surveillance systems'. Another is that non-forensic patients may be harmed by sharing facilities with prisoners, and their rehabilitation hindered by having to live in a highly restrictive, maximum security environment. The cost is very high — \$7 million, which is equivalent to most of the mental health service's annual expenditure. In addition, the Association told the Inquiry that the community had not been adequately consulted in the planning process.<sup>294</sup>

In response to these grievances, NT Government witnesses insisted that separation will be maintained between civil and forensic patients in the new unit. The three groups of patients will be accommodated in different wings, with common facilities like the gymnasium allocated for the use of each group at different times.<sup>295</sup> The capital funding will be additional to the current mental health budget.<sup>296</sup>

The government also maintains there is a need for an inpatient treatment program for sexual offenders:

The sole aim of this program is to reduce the rate of reoffending in this group, and thereby reduce the number of children and women who would otherwise be abused and traumatised in the future.<sup>297</sup>

As a result of the concerns raised during the Inquiry's visit to Darwin, the Government agreed to modify the proposal's design to provide, for example, separate entrances to each of the three wings.

## **Governor's Pleasure Prisoners**

One of the worst things that could happen to anybody in this State is to be found not guilty of an offence on the grounds of mental illness.<sup>298</sup>

The classic 'forensic patient' is an offender who goes to trial and pleads not guilty by reason of insanity.<sup>299</sup> If the plea succeeds the accused is acquitted, but still kept in custody for mental health treatment 'at the Governor's pleasure'. The same occurs if the accused did not stand trial because mental illness rendered him or her unfit to plead.

The purpose of the insanity defence is to recognise that mental illness can rob people of the capacity to understand what they are doing. Conviction for a crime requires that both the act itself and the requisite intent be proved. An

acquittal on the grounds of mental illness means the accused person committed the criminal act, but cannot be held responsible for it.

This solution appears to emphasise treatment rather than punishment of the offender. However, the purpose of Governor's pleasure detention is not treatment, but only protection of the public.<sup>300</sup> In reality, such detention can be a particularly severe punishment because it is not subject to the normal legal protections which apply to those convicted of crimes.

The most obvious disadvantage of Governor's pleasure detention is that it is indeterminate.<sup>301</sup> An ordinary prison term is proportional to the offence committed and its maximum duration is clearly stated by the sentencing judge. By contrast, Governor's pleasure detainees have no idea when they can expect to be released. In fact, their detention can turn out to be much longer than they would have served if they had actually been convicted:<sup>302</sup>

I give as an example a 23-year-old mentally retarded invalid pensioner charged with aggravated burglary...[who] was permanently unfit to plead... He was committed to the prison in April 1985, having already been in custody two months. It was not until a year later that he applied through the efforts of the prison psychiatrist for transfer or release. It [then] took some months before the tribunal secured his release.<sup>303</sup>

Governor's pleasure cases are reviewed regularly by an advisory body,<sup>304</sup> but it is the executive government which makes any decisions about a detainee's release or continued detention, and about treatment, transfer in or out of hospital, and fitness to be tried. Several expert witnesses told the Inquiry that this use of executive discretion sometimes produces serious injustices.

## **The Review**

Forensic patients' 'rights' in the review process vary widely from State to State. In NSW, the Mental Health Review Tribunal reviews cases every six months; the patient may give evidence to the Tribunal and normally has legal representation. However, neither the patient's evidence nor the lawyer's submissions are transcribed or passed on to the ultimate decision-maker.<sup>305</sup>

In Tasmania the Tribunal is specifically exempted, where the patient being reviewed is a prisoner, from its normal requirement to give reasons for an adverse recommendation.<sup>306</sup>

In Victoria the review is conducted by the Adult Parole Board once a year, and patients have

no right of appearance before the Board, no right to make any submissions, no right to be informed of the matters which the Board takes into account. Often the material which is placed before that Board is coordinated by parole officers and not by qualified medical practitioners.<sup>307</sup>

In Western Australia the review is also conducted by the Parole Board, which under statute is specifically exempted from requirements of natural justice.<sup>308</sup> An expert witness in that State called this 'the very antithesis of a judicial procedure'.<sup>309</sup>

### **The Decision**

A review body can recommend to its executive government that a detainee is no longer dangerous and should be released. However, the executive can accept or reject the recommendation. In Victoria the recommendation goes to the Attorney-General:

Again the patient has no right of appearance, no right to be informed of materials which are placed before the Attorney-General, and no right of questioning anyone who might be saying anything adverse to their interests.<sup>310</sup>

The matter then goes to Cabinet, where (still without the patient having had any involvement) the decision is made. The president of the Victorian Mental Health Review Board told the Inquiry:

That system is simply terribly wrong and terribly unfair.<sup>311</sup>

In NSW the decision-maker is the Minister for Health:

No reasons have to be given by the Minister if he chooses not to accept the [Tribunal's] recommendations, and therefore the patient has no opportunity to address any fresh concerns or correct apprehensions of fact with which he or she disagrees.<sup>312</sup>

As well as being unfair, it seems likely that this process would result in poor quality decisions — since very little information is provided to the decision-maker. In NSW, for example, the Tribunal supplies the Health Minister with brief written reasons for any release recommendation. Based entirely on this information, the Minister alone must decide whether transferring or releasing the patient would pose too great a danger to the community. Clearly this assessment would be more competently made by an expert body which has had the benefit of hearing the evidence.<sup>313</sup>

Perhaps mindful of how poorly equipped they are for the task, decision-makers tend to make very conservative assessments. The impression of witnesses who gave evidence on this topic was that regardless of what the advisory body

recommends, the decision-makers generally decide against release.<sup>314</sup> A Tasmanian witness said that even where the recommendation is merely to transfer a patient from prison to hospital, about half the time it is refused.<sup>315</sup> It seems improbable that such decisions are always based on a rational assessment of the prisoner's potential threat to the rights of the wider community. The prime criterion is sometimes the potential for political damage to a government perceived by the public as being soft on criminals.<sup>316</sup>

The Minister, if he's got any sense, is going to think about votes — and it's easier to play it safe than to let someone go.<sup>317</sup>

Apart from the consequences for individual patients, this outcome undermines confidence in the legal process and insults the expert members of the advisory bodies. The Committee reviewing the NSW Mental Health Act observed that if the Tribunal judges patients to be no longer dangerous,

As persons found not guilty [by reason of mental illness] they are entitled to their liberty. To effectively impose a sentence of an unspecified additional period...makes a mockery of both the verdict and the review system.<sup>318</sup>

One witness to the Inquiry was an eminent Tasmanian psychiatrist who publicly resigned from that State's Tribunal in protest over this issue.<sup>319</sup>

## **International Human Rights**

Article 9(4) of the ICCPR requires that anyone in detention be able to seek review of that detention by a court. This should mean that a prisoner who is recommended for release by an expert tribunal, but kept in custody by the executive rejecting that recommendation, can apply for judicial review. However, the High Court of Australia has held there is no obligation on the executive to follow the tribunal's advice:

The executive council can ignore that recommendation, and can do so on the grounds of what has been termed 'high level political responsibility'.<sup>320</sup>

Effectively this means there is no judicial review of the decision to keep in custody a person who a) was legally acquitted in the first place; b) is deemed by the advisory body to be no longer dangerous or even mentally ill; and c) has already spent more time in custody than he or she would have if convicted.

One witness pointed out the irony of blatantly political decisions being accepted in this area, at a time when the general trend is to de-politicise the administration of criminal justice.<sup>321</sup> In his opinion this practice also breaches Article 9(1) of the ICCPR, which requires freedom from arbitrary detention:

'Arbitrary', in this sense, must necessarily mean where the detention is ordered by an entity...that is not an entity that gathers and sifts the facts, [ie] a non-judicial determination. In fact, the notion of Governor's pleasure detention has been referred to, quite rightly in my submission, as political detention of those who are mentally ill at the time of commission of their offences.<sup>322</sup>

The United Kingdom, which gave Australia its Governor's pleasure system, was taken to the European Court of Human Rights in 1983 for these same breaches of international law.<sup>323</sup> As a result the UK changed its law, giving the Mental Health Review Tribunal the power to order the release of an offender whom it considers no longer mentally disordered or dangerous.<sup>324</sup> The wishes of the executive (ie of the Home Secretary) must still be considered, but the detainee also has the chance to refute them.<sup>325</sup>

The human rights principle is clear: an individual's liberty should only be denied by a judicial determination, not an unfettered and sometimes secretive political decision. As for danger to the public, evaluation of the Tribunal's decisions since 1983 has found:

The Tribunal is no better, and in fact no worse, than the Home Secretary in terms of the right number of decisions as to release. In other words...the chances of making an incorrect decision are the same whether it is the Home Secretary or the Tribunal itself.<sup>326</sup>

Apart from Article 9, two other human rights are endangered by the executive discretion to extend detention of a person judged to be no longer mentally ill. Article 10(1) of the ICCPR requires that people deprived of their liberty be treated with humanity; Article 7 prohibits cruel, inhuman or degrading treatment. The Inquiry was told it is cruel, inhuman and degrading treatment to detain in a mental hospital a person who is no longer mentally ill.<sup>327</sup> This view has also received recent support from the European Court of Human Rights,<sup>328</sup> and from the English Court of Appeal.<sup>329</sup>

### **Avoidance of the Defence**

The practical consequence of all these drawbacks, according to evidence presented to the Inquiry, is that the insanity defence 'is almost universally rejected' by people accused of major crimes. Even if they are mentally ill, their lawyers advise that 'it is worse for their clients to [chance] the Mental Health Review Tribunal than to face a custodial sentence.'<sup>330</sup> This means some people are convicted who otherwise may well have been found not guilty; it also means people whose greatest need is for psychiatric treatment prejudice their chance of receiving it; and it obscures the role that mental illness plays as a contributing factor in offences being committed. In addition, it leads to second guessing in the courts. Sometimes the sentencing judge will see mental

illness as a mitigating factor to take into account in sentencing.<sup>331</sup> On the other hand, the defendant may be disadvantaged:

The judges will see that a person has avoided a mental illness defence because that is likely to lead to longer confinement... But at the same time, the judges realise how potentially dangerous that person is. They have the reports of the psychiatrist who interviewed him, and so they tend to move towards something that is perhaps harsher in the long run than if [he] were treated under a well-balanced mental health review system.<sup>332</sup>

## **Abandoning the Executive Discretion**

Several reviews and inquiries in Australia have urged that procedures for dealing with mentally ill offenders be overhauled. One important reform is the abolition of Governor's pleasure detention, or at least executive discretion in the disposition of these patients. Instead, an expert body such as a Mental Health Review Tribunal should have the power to order their release — as is the case in the UK.<sup>333</sup> No Australian jurisdiction has yet taken this step.

Other reforms need to be implemented to give the police and the courts more flexibility in the apprehension, remand or sentencing of people who are mentally ill or disordered — to allow and encourage non-custodial treatment rather than detention.<sup>334</sup> Effective action must be taken to bring this area of our mental health and legal systems into line with the accepted international and domestic legal principles of natural justice and human rights.

## **Personality Disorders**

Expert witnesses from forensic mental health services referred frequently to 'behavioural' or 'personality disorders'. These conditions do not qualify as mental illnesses under mental health legislation<sup>335</sup> — even though they are listed as psychiatric disorders in the standard diagnostic tool, DSM-III-R. Thus an individual diagnosed with a personality disorder cannot be hospitalised as an involuntary patient; cannot rely on the defence of insanity in a criminal trial;<sup>336</sup> and will often be turned away by psychiatric hospitals and crisis services.<sup>337</sup>

Yet personality disorder is the single most common diagnosis among patients seen by prison psychiatrists.<sup>338</sup> It is also among the most serious conditions, in terms of the risk of physical harm. People with personality disorders often engage in self-mutilation; in fact the symptoms can be as horrifying and dangerous as any psychosis:

If you've got a personality disorder to the extent that...you're cutting bits off yourself, mutilating yourself, chopping fingers off, defecating, throwing urine...growling, and



basically very uncontrollable — then if you're not deemed to have a mental illness and somebody who may have a well-controlled chronic delusion is deemed to be mentally ill, then there is some sort of perversity in that.<sup>339</sup>

It is not only the patient who is at risk: personality disorder is often associated with actual or threatened crimes against others.<sup>340</sup> This may be one reason why so many people with personality disorders are found in jail.

The mental health system's refusal to treat personality disorders causes frustration, bewilderment and anger among people whose work brings them in contact with the individuals affected. Police, prison officers, probation and parole officers, prison psychiatrists, refuge and shelter workers see the consequences as the same individuals move through their services, often creating extensive disruption, then move on without receiving any treatment at all — only to reappear later:

We have a number of long-term clients on our records who constantly repeat the same pattern of behaviour and the same pattern of referral: they are referred to public hospitals for observation and assessment; then they go to Graylands [Hospital] where the diagnosis is generally that they are of mixed anti-social personality disorders. They move between the hostels, lodging houses, Graylands and back to the prison system.<sup>341</sup>

The Inquiry was told the refusal to treat personality disorders is based on a belief that these disorders cannot be treated.<sup>342</sup> The Inquiry was also told this is not true:<sup>343</sup>

This group is notoriously difficult to treat, and frequently require management rather than just treatment... [The] reluctance by psychiatric professionals to treat such people [is] because of the length of time and amount of resources required.<sup>344</sup>

Treating personality disorders is costly and time-consuming, because it requires behavioural programs rather than medication. However, as well as the time and cost involved, one expert witness suggested another reason why hospitals reject these patients — prejudice against prisoners:

In many psychiatric hospitals, 'personality disorder' is the label assigned to virtually any patient who comes from the criminal justice system. They write that on the file to justify sending them back to prison.<sup>345</sup>

Often patients rejected on this basis are also being denied treatment (or early intervention) for a 'recognised' mental illness, which may accompany or follow a personality disorder.<sup>346</sup> Because they are frequent reoffenders, they often develop a third problem which overlays and aggravates the first two: destructive behavioural patterns as a result of long-term institutionalisation in prisons.<sup>347</sup>

I haven't got a personality disorder...I call it a social disorder. I haven't learnt skills like paying taxes or catching trams.<sup>348</sup>

It's obvious that a lot of the outbursts...are affected by environmental factors. The fact [is] that he is in the prison service and he has learnt behaviours. We feel these behaviours will have to be untaught and he will have to be re-educated...back into society.<sup>349</sup>

Given the size of the problem, and the severe impact that people with personality disorders often have on their families, the wider community, welfare agencies and the prisons, it is essential that this unjustifiable stand-off between the health and prison sectors is resolved:

Management of people suffering from personality or behavioural disorders requires co-operation from a number of agencies including Health, Police, Corrections, Alcohol and Drug authorities and Community Services. There is a need for joint initiatives to ensure that the rights of these individuals and the community are upheld.<sup>350</sup>

## **Conclusion**

The Inquiry recognises that several of the issues raised in this chapter are complex and present difficult questions of both policy and practice. However, the human rights abuses currently being committed against people affected by mental illness in remand and correctional facilities cannot be allowed to continue. Australia has undertaken to honour certain standards clearly set out in a range of international instruments — and these obligations must be honoured.

1. Robin Gurr, President, NSW Council of Social Services. Oral evidence, Sydney 17.6.91, p78.
2. In some jurisdictions, including NSW, the definition also includes some prisoners who have a developmental disability. Robert Hayes et al, *A Profile of Forensic Patients in New South Wales and an Assessment of the Role of the Mental Health Review Tribunal in Effecting Their Release*, Mental Health Review Tribunal, 1991, p1.
3. Dr David Ben-Tovin, Director of Mental Health Services, South Australia. Oral evidence, Adelaide 22.10.91, p219.
4. Hayes et al, op cit, p1. These 86 comprised: 65 found not guilty on the grounds of mental illness, 9 unfit to be tried, and 12 who had been transferred out to a psychiatric hospital ward, having been diagnosed as mentally ill while in prison.
5. NSW Department of Corrective Services, 'Weekly states for the week ending 27 October 1991'.
6. Ben-Tovin, op cit, p219.
7. The exception is Victoria: see the section of this chapter on assessment.
8. Marion Leach, Outcare Civil Rehabilitation Council of Western Australia. Submission, p3. The same view was expressed by Sister Bernadine Daly, Sister of Mercy and prison visitor. Submission.
9. A US survey of the research found an extraordinary range of prevalence: from 5 percent with 'psychosis' to 75 percent with schizophrenia. Linda Teplin, 'The prevalence of severe mental disorder among male urban jail detainees: Comparison with the Epidemiologic Catchment Area Program,' *American Journal of Public Health*, June 1990, v80, n6, p669. The disparities are partly due to methodological variations: some studies (and some jails) take random samples of prisoners, while others focus on inmates on remand or those referred for psychiatric assessment. Another inconsistency is in the criteria used to define a mental illness or disorder: many studies count substance dependency as a mental disorder, while others do not.
10. id.
11. Helen Herrman, Patrick McGorry, Jennifer Mills and Bruce Singh, 'Hidden severe psychiatric morbidity in sentenced prisoners: An Australian study', *American Journal of Psychiatry* 148:2, Feb 1991, pp236-9.
12. Dr Yvonne Skinner, consultant psychiatrist to the NSW Prison Medical Service. Oral evidence, Sydney 8.7.91, p669.
13. Dr Yvonne Skinner. Submission, p1. Also Libby Steeper, Mental Health Task Force, ACT Council for Social Service. Submission, p2.
14. Prof Ivor Jones, University of Tasmania. Oral evidence, Devonport 14.11.91, pp426-7.
15. *ibid*, p427. A Sydney psychiatrist also confirmed that the rate of mental illness is especially high among women prisoners: Skinner, op cit (oral evidence), p668.
16. Prof Brent Waters, Department of Children and Adolescent Psychiatry, Prince of Wales Hospital. Oral evidence, Sydney 17.6.91, p29.
17. Dr Hugh Jolly, consultant psychiatrist to the NSW Prison Medical Service. Oral evidence, Sydney 8.7.91, p647.
18. Dr Ronald Barr, forensic psychiatrist. Oral evidence, Sydney 20.6.91, p421.
19. Name withheld, Schizophrenia Fellowship of Queensland. Submission No440, p30.
20. Steeper, op cit, p2.

21. Dr Joan Ridley, Director, Northern Territory Mental Health Services. Oral evidence, Darwin 21.7.92, p130.
22. D McDonald and C Howlett, 'Australian Deaths in Custody 1990 and 1991', *Deaths in Custody Australia* No1, Australian Institute of Criminology, Oct 1992, p8.
23. Leslie Wightman, Consumer Advocacy Program. Oral evidence, Adelaide 22.10.91, p212. Also Assoc Prof Joseph Reser, Department of Psychology, James Cook University. Oral evidence, Townsville 13.8.91, pp1274-5.
24. Jolly, op cit, p655.
25. *ibid*, pp649, 655.
26. Skinner, op cit (submission), p1.
27. *id*. Also Peter Mels, manager, forensic team, Northern Territory Mental Health Services. Oral evidence, Darwin 21.7.92, p123.
28. Herrman et al, op cit; Jones op cit, p427.
29. Skinner, op cit (submission), p1.
30. Herrman et al, op cit, p236.
31. Jones, op cit, p427.
32. *id*.
33. Dr John Ellard, NSW Branch President, RANZCP. Oral evidence, Sydney 17.6.91, p69.
34. Skinner, op cit (submission), p1.
35. Ridley, op cit, p130; Mels, op cit, p123.
36. Peter Chivers, ACT Housing and Community Services Bureau. Submission, p1.
37. Name withheld. Oral evidence, Newcastle 9.7.91, p845.
38. Dr Rod Milton, forensic psychiatrist. Oral evidence, Sydney 8.7.91, p686.
39. Name withheld. Submission No391, p1.
40. Dr Marie Bashir, Director, Central Sydney Area Health Service. Oral evidence, Sydney 20.6.91, p505.
41. Judy Andrews, Far North Queensland Families and Prisoners Support. Oral evidence, Cairns 9.8.91, p1126.
42. Leach, op cit, p3. Also Dr Geoff Smith, Director of Policy and Planning, Mental Health Services, WA Health Department. Oral evidence, Perth 12.2.92, p412. Also Orme Hodgson, Schizophrenia Fellowship of South Queensland. Submission, p17.
43. Karen Abram and Linda Teplin, 'Co-occurring disorders among mentally ill jail detainees', *American Psychologist*, Oct 1991, p1042.
44. Andrews, op cit, p1126.
45. Hodgson, op cit, p18.
46. Dr Yvonne Skinner pointed out that illiteracy is fairly common among the mentally ill; some people receive fine notices or bills in the mail and simply put them aside because they cannot read them. (Information provided to the Inquiry after the close of formal hearings.) In 1988 NSW introduced a scheme to keep fine-defaulters out of prison, following the near-fatal bashing of a young defaulter, Jamie Partlic. However, the scheme has been declining steadily since 1989, and people now regularly go to jail in NSW for non-payment. Ivan Potas, 'The Sentencing Act 1989: Impact and review', in (1992) 3(3) *Current Issues in Criminal Justice* 318-328, p321.
47. Leach, op cit, p3.

48. *Sun Herald*, 28 March 1993.
49. Dr Jenny Thompson, Forensic Study Group, RANZCP. Submission, p1.
50. Skinner, op cit (oral evidence), p663.
51. Kay Lancefield, Epistle Post Release Service. Oral evidence, Melbourne 8.4.91, p147.
52. Father Peter Nordan and Bernie Geary, Brosnan Centre Youth Service, Catholic Prison Ministry. Oral evidence, Melbourne 9.4.91, pp292-3.
53. Barr, op cit, p423.
54. Robin Banks, Disability Advocacy Service, Alice Springs. Submission, p2.
55. *ibid*, p6.
56. John Hopkins, Disability Services of Central Australia. Quoted in Banks, op cit, Attachment 1, p6.
57. Andrews, op cit, p1129.
58. Name withheld. Oral evidence, Townsville 13.8.91, p1305.
59. Andrews, op cit, p1128.
60. Jolly, op cit, p25.
61. Dr J Opie, Australian Catholic Health Care Association. Submission, p7.
62. Name withheld. Submission No391, p1.
63. Nordan, op cit, p299.
64. Daly, op cit, p2.
65. *Eg Report of the Royal Commission into New South Wales Prisons*, Government Printer, Sydney 1978; Australian Law Reform Commission, *Sentencing*, AGPS, Canberra 1988; Australian Law Reform Commission, *Sentencing: Prisons*, AGPS, Canberra 1987; G Hawkins, *Prisoners' Rights*, Human Rights Commission Occasional Paper No12, AGPS, Canberra 1986; G Zdenkowski, 'Review of disciplinary proceedings in Australian Prisons', (1983) 7 *Criminal Law Journal* 3; G Zdenkowski and D Brown, *The Prison Struggle*, Penguin 1982; D Brown, 'Putting the value back in punishment,' (1990) 15 *Legal Service Bulletin* 239; S Hatty (ed), *Women in the Prison System*, Australian Institute of Criminology, Canberra 1984; R Harding and W Cramond, *Report of Inquiry into the Appropriate Treatment of Mentally Ill and Intellectually Handicapped Offenders*, WA Department of Prisons and Health, Perth 1985; *Report of the NSW Women in Prison Task Force*, March 1985; Robyn Read MP, Elizabeth Kirkby MLC, Dawn Fraser MP and John Hatton MP, *Report on Prisons Following Visits to Bathurst, Goulburn and Parklea Gaols*, Nov 1990; *Royal Commission into Aboriginal Deaths in Custody*, AGPS, Canberra 1991; *Report of the NSW Prison Medical Service Review Committee (PMS Review)*, NSW Health Department, Aug 1991; Amnesty International, *Australia: A criminal justice system weighted against Aboriginal people*, Jan 1993. The Human Rights Commissioner has objected on many occasions to prison conditions. However, these representations have met with considerable opposition from several State Governments.
66. Another contender is Alice Springs Prison, which was singled out in Amnesty's report for 'conditions which could well be judged unacceptable according to international standards'. Amnesty International, op cit, p11. Amnesty concluded that conditions in some Australian prisons could amount to 'cruel, inhuman or degrading treatment' — the terminology used in the UN Convention Against Torture (Article 3), the Body of Principles for the Protection of All Persons Under Any Form of Detention or Imprisonment (Principle 6), and the Universal Declaration of Human Rights (Article 5). Its delegation 'observed extremely varied conditions...ranging from the excellent to the quite bad'. One of the

worst conditions was gross overcrowding in cells — eg in one wing of Long Bay Gaol in Sydney, prisoners were living three to a cell measuring about 3m by 2.2m. (However, prisoners in that wing were only confined to their cells for eight hours at night.) Of course, Amnesty was considering prison conditions from the point of view of ordinary prisoners who are not mentally ill. Those affected by mental illness are even more needy and less able to cope with hardship.

67. Barr, op cit, p421. Also Skinner, op cit (oral evidence), p670. This concern about NSW prisons is borne out in the academic literature. For example at Parklea Prison, which was designed to house 210 inmates, the population in mid 1991 was 350. Angela Gorter, 'Impact of the Sentencing Act 1989 on the NSW prison population', (1992) 3(3) *Current Issues in Criminal Justice*, 308-317, p312.
68. John Walker, *Australian Prisoners 1991*, Australian Institute of Criminology, Canberra 1992, p17.
69. id, p109.
70. Barr, op cit, p421; Skinner, op cit (oral evidence), p670. The *Sentencing Act 1989* abolished remissions and aimed to ensure 'truth in sentencing'. As a consequence, fewer offenders now receive non-custodial sentences (eg community service) and those who go to jail are imprisoned for longer. Gorter, op cit, p317.
71. Skinner, op cit (oral evidence), p670.
72. ibid, p665.
73. Robyn Read, Elizabeth Kirkby, Dawn Fraser and John Hatton, *Report on Prisons Following Visits to Bathurst, Goulburn and Parklea Gaols* (Independents' Report), Nov 1990. Submitted to the Inquiry by the NSW Prisons Coalition. p40.
74. ibid, pp7, 57. David Brown, 'The state of NSW prisons: Crisis — what crisis?' Paper to the Australian Sociological Association Conference, University of Queensland, 15 Dec 1990, p11.
75. Eg Lenore Nicklin, 'Yabbers takes up the cleaver,' *Bulletin* 2 Oct 1990; Richard Glover, *Sydney Morning Herald* 14 Sept 1990.
76. Skinner, op cit (oral evidence), p665. The official policy was to allow each prisoner six photographs, but its interpretation was left to individual prison governors, some of whom took an especially harsh approach.
77. NSW Prisons Coalition. Submission, p44.
78. Skinner, op cit (oral evidence), p665.
79. ibid, p666.
80. id.
81. NSW Prisons Coalition, op cit, p45.
82. id.
83. *Report of the NSW Prison Medical Service Review Committee* (PMS Review), NSW Health Department, August 1991, p116.
84. id.
85. Ellard, op cit, p66. Also Skinner, op cit (submission), p4.
86. Steeper, op cit, p3.
87. NSW Attorney General and Minister for Justice, 'New property policy for NSW inmates'. Press release, 30 Aug 1993.
88. Daly, op cit, p3.

89. Dr Warwick Middleton, RANZCP Queensland Branch. Oral evidence, Brisbane 14.8.91, p1355.
90. Skinner, op cit (submission), p4.
91. Jolly, op cit, p648.
92. Standard Minimum Rule 37, cited by Jolly, op cit, p648.
93. Independents' Report, op cit, pp20,32,55.
94. NSW Prisons Coalition. Information provided to the Inquiry after the close of formal hearings.
95. Skinner, op cit, p666.
96. Dr David Wells, Police Surgeon and Director of Forensic Medicine, Victoria Police. Submission, p3.
97. Skinner, op cit (submission), p2; Daly, op cit, p1; Hodgson, op cit, p18.
98. Steeper, op cit, p3.
99. Amnesty International, op cit, pp11-12.
100. *ibid*, p5.
101. Banks, op cit, p1.
102. Wells, op cit, p3.
103. Legal Aid Commission of Victoria, 'Custody in Police Cells — A Report', 1993, p1.
104. *ibid*, p2.
105. *id*.
106. *id*.
107. *ibid*, p3.
108. Amnesty International, op cit, p8.
109. *id*. Similar criticism could apply to the lock-up at Sydney Central Police Station, built in 1987 to accommodate up to 150 inmates. All the cells are underground. *ibid*, p9.
110. Name withheld, op cit endnote 58, p1305.
111. Standard Minimum Rule 22(1), cited by Jolly, op cit, p647.
112. Ursula Dahl, former executive officer, Management Assessment Panel, SA Health Commission. Oral evidence, Adelaide 23.10.91, p405.
113. NSW Prisons (Administration) Regulation, clause 11. Quoted in PMS Review, op cit, p108.
114. PMS Review, op cit, p108.
115. Thompson, op cit, p2.
116. Barr, op cit, p423.
117. PMS Review, op cit, p109.
118. Nordan, op cit, p293.
119. *id*.
120. *id*.
121. Gurr, op cit, p78.
122. D McDonald, 'National Police Custody Survey 1992: Preliminary Report', *Deaths in Custody Australia* No2, Australian Institute of Criminology, March 1993, p2.

123. *NSW Police Service Custody Manual*, paragraph 1.104, quoted in David Landa, *Inquiry into the circumstances surrounding the injuries suffered by Angus Rigg in police custody and into the subsequent police investigations*, Ombudsman's report to the NSW Parliament, Jan 1993, p111.
124. McDonald and Howlett, op cit, p8.
125. Dr David Wells, Police Surgeon and Director of Forensic Medicine, Victoria Police. Oral evidence, Ballarat 11.4.91, p595.
126. ibid, p594.
127. Wells, op cit (submission), p2.
128. Landa, op cit, p130.
129. Andrews, op cit, p1125.
130. id.
131. Royal Commission into Aboriginal Deaths in Custody, Interim Report, p45.
132. Landa, op cit, p131.
133. PMS Review, p108.
134. Jolly, op cit, p650.
135. Hodgson, op cit, p18.
136. Nordan, op cit, p299.
137. Skinner, op cit (oral evidence), p659-60. Since this evidence was given, a toilet has been installed. In Victorian jails the special isolation cells are called 'wet cells' — because they can be hosed down for cleaning. Geary, op cit, p299.
138. Dahl, op cit, p406.
139. Leach, op cit, p2.
140. Marion Leach, Outcare Civil Rehabilitation Council of Western Australia. Oral evidence, Perth 10.2.92, p50. A similar report came from a former inmate in Queensland. Name withheld, op cit endnote 58, p1299. See also Skinner, op cit (submission), p16.
141. Name withheld. Submission No440, p30.
142. Name withheld. Submission No45, p1.
143. Ian Campbell, *Mental Disorder and Criminal Law in Australia and New Zealand*, Butterworths 1988, p189.
144. Dr Joan Lawrence, senior psychiatrist, Royal Brisbane Hospital. Oral evidence, Brisbane 16.8.91, p1745.
145. Name withheld, op cit endnote 58, p1300.
146. Hodgson, op cit, p18.
147. Jolly, op cit, p652. Also Nordan, op cit, p290.
148. McDonald, op cit, p2.
149. Amnesty International, op cit, p7.
150. Andrews, op cit, p1126.
151. Name withheld. Submission No45.
152. Andrews, op cit, p1127.
153. Name withheld. Submission No45, p6.
154. She believes there is doubt about whether her son's death was a suicide.



155. id.
156. Standard Minimum Rule 82(1).
157. Libby Steeper, Mental Health Task Force, ACT Council for Social Service. Oral evidence, Canberra 18.3.92, p30.
158. Chivers, op cit, p1.
159. Dr Russell Pargiter, consultant psychiatrist. Oral evidence, Hobart 12.11.91, p149.
160. Ted Watson, Incarcerated People's Cultural & Heritage Aboriginal Corporation. Oral evidence, Brisbane 15.8.91, p1529.
161. NSW Mental Health Act Implementation Monitoring Committee, *Report to the Hon R A Phillips MP, Minister for Health, on the NSW Mental Health Act 1990*, Aug 1992, p39.
162. Skinner, op cit (submission), p1.
163. Walker, op cit, p17. In 1991 there were about 730 women in Australian jails, out of a total of 15,000 prisoners. About 400 of those female inmates were in NSW.
164. Skinner, op cit (oral evidence), p668.
165. Skinner, op cit (submission), p5.
166. *ibid*, p16.
167. *ibid*, p15.
168. 'Most have children and few are married or have a stable relationship (less than 10 percent).' *ibid*, p5.
169. id.
170. Skinner, op cit (oral evidence), p668.
171. Jones, op cit, p427.
172. *ibid*, p428.
173. *ibid*, p427.
174. Skinner, op cit (submission), p2.
175. See endnotes 68 and 71.
176. Skinner, op cit (oral evidence), p667.
177. id; also Skinner, op cit (submission), p1.
178. Skinner, op cit (submission), p15.
179. Skinner, op cit (oral evidence), p660.
180. Skinner, op cit (submission), p15.
181. *ibid*, p16.
182. Skinner, op cit (oral evidence), p660.
183. id.
184. id. The NSW Ombudsman has pointed out that tear-resistant blankets exist and are officially standard issue for NSW police lock-ups — but in practice many old blankets are still in circulation. One was used by Angus Rigg, a juvenile offender who hanged himself in police custody in July 1991. Landa, op cit, pp107-111.
185. Skinner, op cit (oral evidence), p669.
186. id.
187. id.
188. Skinner, op cit (submission), p10.

189. *ibid*, p9.
190. *id*.
191. Skinner, *op cit* (oral evidence), p661.
192. *ibid*, p662.
193. *ibid*, p661.
194. Skinner, *op cit* (submission), p15.
195. *id*. The issue of women inmates being moved to male prisons has arisen this year in Victoria, where the Government proposes to close down the main women's prison, Fairlea. At Fairlea the women have been living in shared cottages where they can cook and spend substantial amounts of time with their children. Local women's services operate programs at the prison. The planned closure would see the women moved to Pentridge, a male prison where conditions are much more restrictive. Shelley Burchfield, 'Fairlea closure', *Framed* No22, Aug 1993, p7.
196. Watson, *op cit*, p1528.
197. Walker, *op cit*, p22.
198. The jurisdiction with the highest proportion of black prisoners is the Northern Territory, where they make up 70 percent of inmates. But based on their share of the general population, the disproportion is worst in Western Australia, where Aboriginal people are in prison at 29 times the average. In South Australia the ratio is 23.6. In the Northern Territory the over-representation is by a factor of 11; but the Territory also imprisons non-Aboriginal Australians far more than elsewhere. Walker, *op cit*, p23.
199. McDonald, *op cit*, p2. Over-representation rates in police lock-ups also vary widely. The worst are in Western Australia (where Aboriginal people are over-represented by a factor of 52), South Australia (a factor of 21) and NSW (a factor of 16). In the Northern Territory, 80 percent of people taken into police cells are Aboriginal or Torres Strait Islander — an over-representation by a factor of 14.
200. Carol Kendall, LINK-Up. Oral evidence, Sydney 21.6.91, p593.
201. See Chapter 23 for a more general discussion of Aboriginal people and mental illness.
202. Trevor Cox, senior psychologist, NT Department of Health and Community Services. Oral evidence, Alice Springs 23.7.92, p201.
203. Name withheld. Oral evidence, Brisbane 14.8.91, p1458.
204. John Lawrence, North Australian Aboriginal Legal Aid Service. Oral evidence, Darwin 21.7.92, p94-5.
205. *ibid*, pp95-6.
206. Watson, *op cit*, p1515.
207. Claudette Elaro, 'A prison within a prison', *Speakout* (Newsletter of the Immigrant Women's Speakout Association of NSW), June 1992, p4.
208. Marie Gibson, Coordinator, Migrant Resource Centre. Oral evidence, Townsville 12.8.91, p1145.
209. *id*.
210. Thompson, *op cit*, p2.
211. Jolly, *op cit*, p650.
212. Lawrence, *op cit*, p1745; Geary, *op cit*, p292; Leach, *op cit* (oral evidence), p55.
213. Standard Minimum Rule 49(1), cited by Jolly, *op cit*, p649.

214. Thompson, op cit, p3.
215. PMS Review, p55.
216. The PMS Review Committee described the number of psychiatric hours available to prisoners as 'grossly inadequate'. *ibid*, p56.
217. Skinner, op cit (oral evidence), p668.
218. Jolly, op cit, p650.
219. Andrews, op cit, p1132.
220. Leach, op cit (submission), p2.
221. Geary, op cit, p292.
222. Middleton, op cit, p1355.
223. *id*. Also Skinner, op cit (submission), p4.
224. Cheryl Kneebone, Schizophrenia Fellowship, Albany. Submission.
225. Andrews, op cit, p1127; Dahl, op cit, p405: 'There is still considerable confusion as to what is mental illness and what is intellectual disability and what is difficult behaviour.'
226. Skinner, op cit (oral evidence) p668. See also Hodgson, op cit, p19.
227. Wells, op cit (submission), pp1-3. Also Hodgson, op cit, p17, observing that Queensland police — especially the younger ones — are 'on the whole...most co-operative and sympathetic in handling involuntary admission'.
228. Wells, op cit (oral evidence), p595.
229. Jolly, op cit, p650.
230. *ibid*, p654.
231. *ibid*, p648.
232. Name withheld, op cit endnote 58, p1299.
233. Dahl, op cit, p405.
234. PMS Review, op cit, p57.
235. Prisoners quoted in *ibid*, p136-139.
236. Jolly, op cit, p650.
237. *id*.
238. Walker, op cit, p13.
239. Jolly, op cit, p651.
240. *ibid*, p650.
241. Leach, op cit (oral evidence), p55.
242. Standard Minimum Rules 58 and 59, cited by Jolly, op cit, p649.
243. Jolly, op cit, p649.
244. Skinner, op cit (oral evidence), p671.
245. *ibid*, p672.
246. *ibid*, p671.
247. Leach, op cit (oral evidence), p56.
248. Barr, op cit, p422.
249. Jolly, op cit, p653.
250. Barr, op cit, pp421-2.

251. *ibid*, p421.
252. Leach, *op cit* (oral evidence), p50.
253. *id*.
254. Tony Calabro, Epistle Post Release Service. Oral evidence, Melbourne 8.4.91, p154.
255. Leach, *op cit* (oral evidence), p50.
256. Calabro, *op cit* p146.
257. Barr, *op cit*, p422; Jolly, *op cit*, p24; Leach, *op cit* (oral evidence), p51.
258. *id*.
259. Lancefield, *op cit*, p154.
260. Leach, *op cit* (oral evidence), p52.
261. *id*.
262. *ibid*, p51.
263. Barr, *op cit*, p422.
264. Lancefield, *op cit*, p148.
265. Sue Marlin, Probation and Parole Officers' Association of NSW. Submission, p1. Similar evidence was given by Barr, *op cit*, p422.
266. Marlin, *op cit*, p2.
267. Lancefield and Calabro, *op cit*, pp153-4.
268. Mels, *op cit*, p122.
269. *ibid*, pp122-124.
270. Ellard, *op cit*, p61.
271. Calabro, *op cit*, p147.
272. Milton, *op cit*, p684. The Victorian Parliament's Social Development Committee has also challenged the assumption that psychiatry has expertise in predicting dangerous behaviour. See Parliament of Victoria, Social Development Committee, *Third Report upon the Inquiry into Mental Disturbance and Community Safety: Response to the Draft Community Protection (Violent Offenders) Bill*, April 1992, p83.
273. Neil Rees, president, Victorian Mental Health Review Board. Oral evidence, Melbourne 8.4.91, p25.
274. *ibid*, p26.
275. Leach, *op cit* (submission), p1.
276. *eg* Leach, *op cit*; Jolly, *op cit*; Skinner, *op cit*; Marlin, *op cit*.
277. Skinner, *op cit* (oral evidence), p671.
278. Barr, *op cit*, p425.
279. *id*.
280. Middleton, *op cit*, p1372.
281. Ben-Tovin, *op cit*, pp219-220.
282. Ben-Tovin, *op cit*, p224.
283. Clodagh Jones and Marie Sykes, prison visitors, Risdon Prison, Tasmania. Submission.
284. 'The notorious ward 21 — thank goodness it has finally closed.' Prof Rodney Morice, Director, Division of Mental Health Services, Hunter Area Health Service. Oral evidence, Newcastle 9.7.91, p27.

285. Campbell, op cit, p194.
286. Ben-Tovin, op cit, p219. About 7 percent of admissions to Hillcrest are forensic: Anne Burgess, Mental Health Unit, South Australian Health Commission. Oral evidence, 22.10.91, p216.
287. ibid, p228.
288. ibid, p219.
289. Skinner, op cit (oral evidence), p36; Ridley, op cit, p140.
290. Ridley, op cit, p140.
291. Orme Hodgson, Schizophrenia Fellowship of South Queensland. Oral evidence, Brisbane 14.8.91, p1625. Also Shirley Maher, carer, Queensland. Submission, p2.
292. Mels, op cit, p122.
293. Dr Bill Tyler, NT Association for Mental Health. Oral evidence, Darwin 21.7.92, p22. A community group in Townsville also expressed concern about an apparently similar facility proposed for Townsville General Hospital. However, their main objection was to the 'institutional' character of the plan, rather than the inclusion of forensic patients. Name withheld. Oral evidence, Townsville 12.8.91, p1218.
294. Tyler, op cit, p21.
295. Ridley, op cit, p140.
296. Carol Beaver, manager, Darwin Urban Mental Health Service. Oral evidence, Darwin 21.7.92, p118.
297. Mels, op cit, p123. Also Beaver, op cit, p118; Ridley, op cit, p140.
298. Barr, op cit, p424.
299. The definition of insanity or mental illness for the purposes of the criminal law defence is quite different from that used for involuntary detention in hospital under civil legislation.
300. Campbell, op cit, p186 (citing various judicial decisions).
301. Rees, op cit, p26.
302. Barr, op cit, p424.
303. Pargiter, op cit, p148.
304. except in the Northern Territory, where no such body exists.
305. Mental Health Act Implementation Monitoring Committee, op cit, p31.
306. Pargiter, op cit, p148, citing ss76(4) and 68 of the *Mental Health Act*.
307. Rees, op cit, p26.
308. Dr Ian Campbell, Senior Lecturer in Law, University of Western Australia. Oral evidence, Perth 11.2.91, p119.
309. id.
310. Rees, op cit, p26.
311. id.
312. Mental Health Act Implementation Monitoring Committee, op cit, p31.
313. id.
314. Rees, op cit, p26; Milton, op cit, p690.
315. Pargiter, op cit, p155.
316. Rees, op cit, p26.

317. Milton, op cit, p690.
318. Mental Health Act Implementation Monitoring Committee, op cit, p33.
319. The psychiatrist, Dr Russell Pargiter, resigned after the Attorney General rejected the Tribunal's unanimous recommendation for the release of Rory Jack Thompson, who had been acquitted of murder by reason of insanity. The Tribunal found that the prisoner no longer posed a danger to the public. The Attorney General claimed his decision was not political, but based on certain information in his possession. However, he refused to reveal what this information was. Michael Lester, 'Rory Jack freedom bid halted', *Mercury* 31 Jan 1991; Dr Russell Pargiter, Submission.
320. Campbell, op cit (oral evidence), p118, citing *South Australia v O'Shea* (1987) 73 ALR 1.
321. *ibid*, p119.
322. *ibid*, p120.
323. *X v United Kingdom*, European Human Rights Court, 5 November 1981, Series A, No46 p20 para43. The court found the UK legislation breached Article 5(4) of the European Convention for the Protection of Human Rights and Fundamental Freedoms, which mirrors Article 9(4) of ICCPR. See also the similar case of *Thynne, Wilson and Gunnell v United Kingdom*, (1991) 13 EHRR 101, pp135-143.
324. *Mental Health Act* (UK) 1983, s73.
325. Campbell, op cit (oral evidence), p124.
326. *ibid*, p120.
327. *ibid*, p122.
328. *Ashingdane v UK*, European Human Rights Court, 28 May 1985, Series A, No93.
329. *R v Home Secretary; Ex parte Herbage* [1987] 1 All ER 324.
330. Milton, op cit, p688. The witness said the lawyers' reluctance to use the defence 'is not because they're ignorant — it's because they're informed.' *id*.
331. *ibid*, p691.
332. *ibid*, p685.
333. Rees, op cit, p31; Campbell, op cit (oral evidence), p125; Mental Health Act Implementation Monitoring Committee, op cit, p32; Victorian Sentencing Committee, *Sentencing (Volume 2)*, Attorney General's Department, Melbourne 1988, p461; Law Reform Commission of Victoria, *Mental Malfunction and Criminal Responsibility* (Report No.34), 1990, p31; Law Reform Commission of Western Australia, *Report on the Criminal Process and Persons Suffering from Mental Disorder* (Project No.69), 1991, pp110,116.
334. Campbell, op cit (oral evidence), p122; Queensland Government, op cit; Smith, op cit, pp406-7.
335. eg the Victorian Mental Health Act states categorically: 's8(2) A person is not to be considered to be mentally ill by reason only...(1) that the person has an antisocial personality.' Cited by Wells, op cit (submission), p5.
336. W Lucas, 'Forensic psychiatry', in P Beumont and R Hampshire (eds), *Textbook of Psychiatry*, Blackwell Scientific Publications, Melbourne 1989, Chapter 18, p286.
337. See Chapter 18 for evidence on homeless agency workers, faced with residents behaving in a bizarre and threatening manner, being denied assistance from psychiatric hospitals and crisis teams on this basis.

338. Skinner, op cit (submission), p1; Jones, op cit, p427; Mels, op cit, p123.
339. Middleton, op cit, p1372.
340. Robert Bluglass, 'Current issues in the management of mentally abnormal offenders', *Forensic Issues in Mental Health*, Proceedings of the 12th Annual Congress of the Australian and New Zealand Association of Psychiatry, Psychology and Law, 1991, p18. Also Marlin, op cit, p2; Wells, op cit, p5.
341. Leach, op cit (oral evidence), p53.
342. Skinner, op cit (information provided to the Inquiry).
343. id.
344. Di Gordon, Australian Association of Social Workers. Submission, p3.
345. Skinner, op cit (information provided to the Inquiry). Dr Skinner said these patients are often also aggressive, manipulative or irritating, which makes hospitals even more reluctant to take them.
346. Skinner, op cit (submission), p1; Wells, op cit (submission), p5.
347. Skinner, op cit (information provided to the Inquiry).
348. Garry David, quoted in Alan Attwood, 'Garry David, and the deeper darkness within', *Age* 14 June 1993.
349. Hopkins, Disability Services of Central Australia. Quoted in Banks, op cit, attachment 1, p6.
350. Gordon, op cit, p3.

## **Part IV**

### **Other Areas of Concern**



# Chapter 26

## MENTAL HEALTH RESEARCH

If you think medical research is expensive, try disease.<sup>1</sup>

### Introduction

It is unfortunately true that by and large those areas which broadly relate to community issues and the problems of the relation of medicine and health to the community and even areas which relate to disability as distinct from mortality have tended not to have been highly regarded by research effort in Australia.<sup>2</sup>

The relative paucity of mental health research in Australia places mentally ill people at a disadvantage by depriving them of opportunities to lead more fulfilling and constructive lives than they can currently enjoy. This constitutes an indirect but nevertheless significant form of discrimination.<sup>3</sup>

Mental health research is important in a number of areas. These include:

(a) Providing basic data on the epidemiology of mental illness and mental health problems in Australia (taking into account special aspects of Australian society such as the status of Aboriginal and Torres Strait Islander peoples; multiculturalism; and rural isolation) — thus providing a sound basis for identifying priorities for service provision and monitoring their impact.

(b) Assisting in understanding the aetiology of mental illness and the treatment of disorders.

(c) Evaluating the data derived from (a) and (b) to determine the contribution of social factors (including social adversity) to mental illness and mental health problems and to develop ways of modifying their impact.

(d) Conducting health services research, including evaluation research, to determine the most effective mental health programs and services and effectively monitor and assess the process, impact and outcome of these services and programs.

However, funding for Australian mental health research is poor<sup>4</sup> — both in absolute terms and in comparison to other OECD countries. No comprehensive national data on the prevalence of psychiatric disorder or the availability or effectiveness of psychiatric treatments have been developed; the mechanisms

underlying nearly all psychiatric illnesses are yet to be identified; treatments are often inadequate or ineffective, objective markers of psychiatric illness (by which, for example, treatment might be monitored) are lacking; and the ability to predict outcomes for individual patients (eg suicide or chronic disability) is still extremely limited.

At a time of major changes in the provision and administration of psychiatric services — with, for example, a changing balance between community and institutional care and an increasing role being assumed by the Federal Government in the formulation of policies affecting the mentally ill — the current limitations in the availability of integrated psychiatric data about the prevalence of psychiatric disorder and the scope and efficacy of current psychiatric services constitute major impediments to our capacity to plan and deliver effective programs.<sup>5</sup> If we are to change this situation — and we must — it is important to identify the factors which have produced it.

Some of the most significant elements contributing to the gap between the need for and availability of psychiatric research in our country are:

- (a) Funding available for medical research generally in Australia is low by international standards.
- (b) It is much more difficult to raise money from the public for research into psychiatric disorders than it is to raise it for research into other major illnesses such as heart disease, cancer and diseases commonly affecting children.
- (c) Few philanthropic organisations target psychiatric illness as a priority area for funding (the Australian Youth Foundation and the Rebecca Cooper Foundation are notable exceptions).
- (c) The tradition of psychiatric research in Australia is only a relatively recent one. (Virtually no significant psychiatric research was undertaken until after the Second World War.)<sup>6</sup>
- (d) The most seriously ill psychiatric patients have, typically, been treated in State psychiatric hospitals. These hospitals have not embraced or fostered a tradition of research — although this situation has been changing in recent years.
- (e) The heavy clinical and administrative demands placed on psychiatrists in the public sector significantly impede their capacity to conduct research.
- (f) Research into major mental illnesses is often hampered by the fact that seriously disturbed patients may not be able to give informed consent to participate in (and therefore do not participate in) research studies.
- (g) Psychiatric research is often very complex and unavoidable methodological difficulties sometimes disadvantage psychiatric research projects

in comparison to more basic, science-oriented disciplines in the competitive grant process.

- (h) Prior to the recent National Mental Health Policy, there was little incentive and even less action taken to create a National Data Set on Mental Illness. The diversity of settings in which psychiatric care is provided (public psychiatric hospitals, private psychiatric hospitals, psychiatric units of general hospitals, community clinics, and general practice) represents a significant impediment to establishing standardised methodologies to develop such a database — as does the difference in the manner in which different States collect their data.
- (i) There is a very large discrepancy between the income a psychiatric graduate can earn in research and in private practice. This 'research disincentive' contributes to the fact that very few psychiatrists apply for Post Doctoral Scholarships or Fellowships within the National Health and Medical Research Council (NHMRC).<sup>7</sup>
- (j) Despite the outstanding efforts of community support groups such as the Schizophrenia Fellowships, there is still inadequate recognition given to the need to effectively lobby for improved psychiatric research funding at the community, professional, bureaucratic and political levels.

This chapter attempts to analyse these and other obstacles impeding progress in mental health research in Australia — with some attention to the organisational structure within which psychiatric research is conducted in our country (in order to ensure that if much needed funding increases for such research are provided following this Inquiry, they can be effectively allocated.)<sup>8</sup>

## Support for Medical Research in Australia

The thing that...has enabled people with mental illness to become as self-reliant as possible has not been legislation, it has been the development of new treatments for mental illness.<sup>9</sup>

Overall, Australia devotes a relatively small proportion of its GDP and also of its total health expenditure to medical research. The recent Independent Commission on Health Research for Development recommended the investment of at least two per cent of national health expenditure on medical research.<sup>10</sup> The Commission estimated that in 1986 Australia spent only a third of its total health expenditure — 0.7 percent — on publicly-funded medical research. In fact, of the 20 industrialised countries for which estimates of this percentage were made, Australia ranked third to last (ahead of only Spain and Ireland.)<sup>11</sup>

There are many reasons why medical research expenditure generally should be increased, including the following:

1. Australia has a good track record in biomedical research, despite comparatively poor funding — but an increasing percentage of highly recommended project applications to the NHMRC are remaining unfunded. This fact, together with the relatively poor opportunities for professional advancement within medical research organisations (and this applies particularly to psychiatry) means that as a country we will find it increasingly difficult to retain the researchers of the future.

2. Australia must continue to increase the number of its medical researchers who are in the forefront of the international medical research community — in order to improve our capacity to identify and translate the more promising medical research results from around the world into methods of improved diagnosis and treatment here. It is also important for our medical research community to be able to critically assess and reject unpromising leads in order to save funds which might otherwise be wasted on the development of inappropriate and unsuccessful treatments or technologies.

3. Improved treatment not only enhances longevity, it saves money. For example, in the United States (which spends substantially more than Australia on research), the average length of life has increased at an average rate of ten weeks per year since 1950. Impressive savings have been made with the conquering of important diseases.<sup>12</sup>

Because these savings are gradually introduced into the community, they are not as apparent to economic planners as more immediate economies. To some extent they are offset by the costs associated with increased longevity. The need for the community to support people into their old age is, however, a treasured expectation — especially as one passes middle-age.

4. Australia has generated excellent peer-review mechanisms in medical research which ensure that funds are used very efficiently. (In fact we have been recognised as having one of the best medical research peer review systems in the world.)<sup>13</sup>

## **Cost of Mental Illness and Funding for Research**

The greatest curtailment to the rights of the mentally ill is produced by the disease itself...<sup>14</sup>

## **Costs of Mental Illness in Australia**

Psychiatric illnesses affect the very core of human existence and result in terrible suffering — primarily to patients, but also, and substantially, to families and loved ones.

The quantification of the cost of psychiatric illnesses to the Australian nation has not been satisfactorily addressed. In order to produce a 'best estimate' it is necessary to approach the task from several different vantage points — to determine if a consistent range of estimates is possible.

In this context, preliminary estimates for the cost of mental illness to Australia may be derived from a number of sources:

### **(a) The Eisen Wolfenden Report**

The Eisen Wolfenden Report, commissioned by the Commonwealth Department of Community Services and Health and published in 1988, estimated that the overall cost of psychiatric illnesses to Australia was \$2.74 billion per annum.<sup>15</sup> Adjusted by the CPI index this represents **\$3.53 billion** (in 1992 dollar terms).<sup>16</sup>

### **(b) Estimate of Total Costs from Direct Care Cost Data**

An assessment of the direct cost of psychiatric care was provided in the 1991 Report of the Mental Health Task Force of the Australian Health Minister's Advisory Council.<sup>17</sup> Combining State expenditure on psychiatric services (\$863 million); Commonwealth Medical Rebates on psychiatric consultations (\$116 million); the cost of acute psychiatric care in public hospitals (\$450 million); private hospital care (\$126 million)<sup>18</sup> and expenditure via the Pharmaceutical Benefits Scheme on drugs commonly prescribed in psychiatric care (\$60 million) results in a total direct care expenditure estimate of \$1.615 billion. Indirect costs of major psychiatric illnesses such as schizophrenia are estimated to exceed direct costs by a ratio of 3:1.<sup>19</sup> Based on this formula, the indirect economic burden would, therefore, be \$4.845 billion and the total cost **\$6.46 billion**.

### **(c) Estimates from the National Foundation for Brain Research, Washington DC, USA**

The Consultancy firm Lewin/ICF recently undertook an economic analysis of the cost of disorders of the brain in the United States. They concluded that psychiatric illnesses cost that country \$US136 billion.<sup>20</sup> This represented 2.48

percent of the gross domestic product.<sup>21</sup> The gross domestic product for Australia in the financial year 1990-91 was \$256.9 billion.<sup>22</sup> If the treatment and consequences of psychiatric disorders incur costs of a similar magnitude and a similar percentage of GDP in Australia to the figures calculated for the United States, this would represent an approximate cost of **\$6.36 billion** (1992 Australian dollars).

The average of these three estimates for the cost of psychiatric illnesses (\$3.53, \$6.36 and \$6.46 billion) is \$5.45 billion. (It is consistent with the correct figure being of this order of magnitude that just one of the many psychiatric disorders affecting the Australian community, schizophrenia, is estimated to cost our country \$1.89 billion per annum.)<sup>23</sup>

#### **(d) Estimates from the Australian National Association for Mental Health**

In 1988 the Australian National Association for Mental Health (ANAMH) estimated the costs of mental illness to the Australian community at \$3 billion in direct costs — without including pensions.<sup>24</sup>

#### **Funding for Mental Health Research in Australia**

It is difficult to establish precisely how much money is currently being spent on mental health research. However, a preliminary estimate suggests that approximately \$8.2 million was spent in 1992 on **identified** psychiatric research.<sup>25</sup> Other funding for such research is provided via the University Departments of Psychiatry and via psychiatrically-relevant neuroscience grants from the NHMRC.

When all these funds are combined perhaps \$10 million per annum is currently being spent on psychiatric and related research in Australia.<sup>26</sup> This represents 0.28 percent of the costs of psychiatric illness to the community, using the most conservative global estimate of these costs (\$3.53 billion) and 0.18 percent of the averaged global costs (\$5.45 billion). Perhaps, more significantly, it represents less than one per cent (0.62 percent) of the identified direct costs of psychiatric care (\$1.615 billion). If one applies the recommendation that 2 percent of health care costs should be invested in medical research<sup>27</sup> specifically to psychiatric care costs, then we should be spending at least \$32.3 million on psychiatric research per annum.<sup>28</sup>

## **Commonwealth Funding Sources**

It is necessary to understand the structure and function of certain key Commonwealth medical research funding agencies in order to evaluate ways of increasing effective psychiatric research in Australia.

### **The National Health and Medical Research Council**

The NHMRC was established in 1937. Its mandate is to improve health, to consider matters relating to the improvement of health, the prevention of disease, health care, medical care, dental care, health research and medical research and ethical issues in relation to health. The 1990 Triennial Review of the NHMRC recommended that it become a statutory body — thereby securing its independence. Legislation regarding this change has been introduced into Parliament.

The NHMRC's main committees with regard to research are the Medical Research Committee (MRC) and the Public Health Research Development Committee. The MRC, which is biomedically oriented, allocated \$101 million in 1992. The Public Health Research Development Committee, which oversees population-based research, allocated \$4.8 million during the same year.

### **Australian Institute of Health and Welfare (AIHW)**

The Australian Institute of Health was established in 1987.<sup>29</sup> Its role was expanded in May 1992 to include the collection of data relating to community welfare. Its functions now are to:

- collect and assist in the production of health and welfare-related information and statistics;
- conduct and promote research into the health of Australians and their health services;
- develop statistical standards relevant to health, and to health and welfare services;
- publish methodological and substantive reports on work carried out by or in association with the Institute;
- undertake studies into the provision and effectiveness of health service and technologies;
- make recommendations on the prevention and treatment of diseases and the improvement and promotion of health and health awareness of the people of Australia.

Until now, neither the Census nor National Health Surveys have collected much data on mental illness.<sup>30</sup> However, the Australian Bureau of Statistics (ABS) has approached the Australian Society for Psychiatric Research to improve the quantity and quality of the mental health data which it is collecting.<sup>31</sup>

Obstacles to the systematic and comprehensive collection of national mental health data include:

- The difficulty in defining what constitutes mental health and psychiatric illness.
- The fact that psychiatric hospitals do not contribute to the hospital morbidity data base compiled by AIHW. (The Institute does receive data from psychiatric units within general hospitals.)
- The variation in the quality of data from each State.
- Financial constraints. (In order to collect a uniform data set on mental health, the States will need to adjust and augment their data collection systems — in some cases in a substantial and costly manner.)
- Concerns about confidentiality — which is an important issue when one considers the stigma suffered by people with mental illness. (See Chapter 9 — Community Care and Treatment.)

### **Health, Housing, Local Government and Community Services Research and Development Grants**

The Commonwealth Department of Health, Housing, Local Government and Community Services<sup>32</sup> offers Research and Development Grants aimed at improving the administration, planning and delivery of health and community care within Australia. This program, which does not fund either biomedical research or clinical trials, focusses on:

- medical technologies
- economic and health status impact;
- financing and utilisation of services;
- preventive health services;
- housing services including crisis and special services;
- research into services for people with disabilities;
- research into rehabilitation services;
- research into services for children and for aged persons;
- examination of economic issues including health, housing and community care, financing and utilisation.

In 1992, 17 mental health projects totalling \$601,949 were funded via the Research and Development Grants Scheme (which had a total funding base of \$1.8 million.)<sup>33</sup>



## **The NHMRC and Mental Health Research**

Experts providing information to the Inquiry indicated several cogent reasons why an augmented psychiatric research effort should remain under the umbrella of the National Health and Medical Research Council. The principal reason advanced was that the NHMRC provides a proven and effective infrastructure within which research grants can be thoroughly assessed. To develop and maintain a similar system separate from the NHMRC would be both expensive and difficult.

A second reason for ensuring that the NHMRC remains the auspicing organisation for the majority of psychiatric research is that such an arrangement ensures psychiatric researchers are part of an integrated and mutually supportive community of medical researchers. Such collegiality is of considerable importance when research projects with cross-disciplinary input are involved.

### **The Performance of Research in Psychiatry and Psychology in NHMRC Project Grants**

The precise proportion of NHMRC funds allocated to psychiatry, psychology and related areas of research is unclear.<sup>34</sup> According to an analysis by discipline in 1989, psychiatry and psychology received only 2.6 percent of all NHMRC funds, whereas according to clinical categories, 10.1 percent of project funding was allocated to mental health and neurosciences.

While 2.6 percent is clearly an underestimate (because a number of neuroscience research projects have significant relevance to psychiatric disorders), the figure of 10.1 percent is clearly an overestimate (because in the neurosciences Australia is particularly strong in areas such as vision, autonomic nervous system and neurotoxicological research and most of this is unlikely to have much relevance to psychiatry.) The precise figure is therefore somewhere between these two figures — but probably closer to the lower one.

A number of reasons have been advanced to explain this relatively poor success rate of psychiatric grant applications within the NHMRC framework.<sup>35</sup> They include the fact that it is difficult for clinical disciplines such as psychiatry to compete with those disciplines which have large basic science components and which rely on the use of animal experimentation or cell cultures and technically sophisticated methodologies. Researchers from such disciplines have a greater capacity to design experiments which are comparatively free of confounding variables and which address fundamental mechanisms or aetiologies of disease in comparison to clinical studies, especially in psychiatry, where issues such as

previous medication, problems with informed consent, use of recreational drugs, variable nutritional status and secondary psychological problems make the task of the researcher much more difficult.<sup>36</sup>

In addition, intensive psychiatric research has been much slower to develop and there is not the tradition of psychiatrists doing full time research in Australia. (There are, at most, four full-time psychiatric researchers in Australia at present.)

## **Affirmative Action in Medical Research**

So I would want an increased emphasis given to the social aspects of psychiatry, the epidemiology of mental illness and, in particular, ... such matters as ... social inequality and the mechanisms by which the quality of life of people with a mental illness is affected by the immediate social and physical environment ... they're placed in.<sup>37</sup>

It is obvious from the evidence considered by the Inquiry that proper respect for and protection of the human rights of Australians affected by mental illness requires urgent affirmative action in relation to redressing the gross imbalance inherent in the funds currently allocated to mental health research.

Just as modern economic commentators recognise that the approach to economic planning can be neither purely Keynesian nor Friedmanite, so too the approach to research funding must be a judicious admixture of selection — based on a combination of identified research priorities reflecting human rights considerations and health needs within the Australian community and on scientific excellence.<sup>38</sup>

### **Affirmative Action in the USA: The National Institute of Mental Health**

The amount of federal funding for psychiatric research in the United States is vastly greater than in Australia — on both absolute (a ratio of 238:1) and per capita (14:1) bases. (The population of the US is 15 times greater than Australia's.) In 1989 the NHMRC allocated \$2.4 million to psychiatric research and the US National Institute of Mental Health allocated \$A570 million. Yet even in the United States there is a recognition that funding for psychiatric research is far below the levels warranted by the impact of mental illness on the community.

The administrative structures for mental health research funding in the US have changed numerous times. The National Institute of Mental Health (NIMH) was originally established as part of the National Institutes of Health (NIH — the NHMRC equivalent), became independent in 1968, and rejoined the NIH in

October 1992. It is therefore informative to consider the development of NIMH in the context of considering whether the distribution of Australian federal mental health research funding should remain the general responsibility of the NHMRC, or whether a separate organisation or specified subdivision of the NHMRC should undertake this task.

Just as the Commonwealth AIDS research grants were established because of a particular series of events — specifically the growing prevalence of AIDS in the community and greater public awareness of the tragedy of this disease — the National Institute of Mental Health was established following the forced recognition of the prevalence of mental illness in the community: a recognition which occurred as a result of the Second World War.<sup>39</sup>

The NIMH was established in 1946 under the National Mental Health Act in an effort to foster 'research, investigations, experiments and demonstrations relating to the cause, diagnosis and treatment of psychiatric disorders'. It was hoped that the establishment of the Institute as one of the National Institutes of Health would coordinate and strengthen the disparate psychiatric research efforts around the country.

By 1952 the NIMH research budget had grown to \$5 million. A decision to transfer NIMH away from NIH in 1968 occurred when NIMH added to its responsibilities the considerable service function associated with the Community Mental Health Centres program which was introduced during the Johnston administration. When the National Institute of Drug Abuse (NIDA) and the National Institute on Alcohol Abuse and Alcoholism (NIAAA) were created in 1973, the administration of the three Institutes (ie including NIMH) was placed in the hands of the newly formed Alcohol, Drug Abuse and Mental Health Administration (ADAMHA).

The move to separate NIMH from NIH and place it under the administration of ADAMHA was considered by its supporters to have enabled much stronger advocacy on the part of mental health research and protected non-biological psychiatric research, in particular, from being cut. (As mentioned above, the Institute returned to NIH in 1992.) These factors have some relevance to the current situation in Australia.

A recent review which summarised the latest data on federal support for mental health research in the United States<sup>40</sup> found that in 1988 US health research received funding of \$18.7 billion (which represented 14.8 percent of total US research and development). In the same year, mental health and substance abuse research received only 4.7 percent of this budget — although the costs

of mental health and substance abuse were estimated to be 12 percent of total US health costs.

Put another way, approximately 1.3 percent of [the direct costs of] mental health and substance abuse are invested by society in research on these disorders compared with society's investment of 3.4 percent of overall health costs of general biomedical research.<sup>41</sup>

The equivalent figure for Australia is that 0.62 percent of the costs of mental health are invested in psychiatric research.

### **Affirmative Action in Australia**

#### *Affirmative Action within the Medical Research Council of the NHMRC*

Funding allocation within the NHMRC is primarily determined on the basis of scientific excellence. The NHMRC has, however, also supported research in a number of relatively undeveloped but particularly deserving areas.<sup>42</sup>

One important form of support is the Special Initiative Grant. The threshold for these grants is slightly lower than for grants within the remainder of the project grant system.<sup>43</sup> In 1992, designated special initiative areas were: Aboriginal health; alcohol and substance abuse; asthma; breast and prostate cancer; dentistry and dental services; menopausal health; environmental health and commercialisation.

The designation of special initiative areas is reviewed on a yearly basis. Mental health was a special initiative area for a number of years because of its low success rate, but was not included in 1992 because its success rate had improved in 1991.

The second mechanism by which the NHMRC provides support for deserving clinical research is through the creation of Special Units.<sup>44</sup> Two of the NHMRC's five special units are conducting psychiatric research — the NHMRC Social Psychiatry Research Unit and NHMRC Schizophrenia Research Unit.

#### *The Network of Brain Research into Mental Disorders*

In the August 1992 Commonwealth Budget, provision was made for the establishment of a network of 'Brain Research into Mental Disorders'. \$5 million was allocated over six years.<sup>45</sup> It is anticipated that several centres around Australia will join the network and form discipline-based consortia (eg

neuroimaging, neurochemistry or molecular biology consortia) and disorder-based consortia (eg schizophrenia, mood disorders and Alzheimer's disease consortia).

One compelling reason why neuroscientific research in psychiatry should be even more strongly encouraged is that in recent years the technical advances in the neurosciences have been extraordinarily swift and revealing. These advances have laid the foundations for quite specific research which could not even have been contemplated ten years ago.

### *Commonwealth Aids Research Grants — An Analogy*

Commonwealth Aids Research Grants (CARG) are distributed by the AIDS section of the Commonwealth Department of Health, Housing, Local Government and Community Services. The CARG scheme supports Investigator-Initiated Project Grants, Scholarship and Postgraduate Research Programs and three national centres — the National Centres in HIV Social Research, HIV Virology Research and HIV Epidemiology and Clinical Research.

Theoretically, it should have been possible for the augmentation in AIDS research to occur via established NHMRC mechanisms. One of the reasons that this did not occur was, perhaps, that AIDS was considered to represent a community crisis and that the established mechanisms might have been too inflexible and unresponsive to ensure a major boost to AIDS research within Australia. In contrast, psychiatric illnesses are not seen by many to be a community crisis (perhaps, in part, because they have always been a feature of our society), although the number of patients with psychiatric disorders and the consequences these disorders have on their lives, the lives of their families and of the community at large, make these illnesses the most neglected crisis of our times.

To illustrate the conversion of public awareness into constructive action with regards to HIV research, since the creation of CARG, funding for AIDS research in Australia, since the creation of CARG, has increased from a base of \$1.4 million in 1986 when CARG began, to \$10.6 million in 1992.

## **Some Specific Issues in Mental Health Research**

### **The Performance of Mental Health Researchers in Australia**

Notwithstanding the meagre resources allocated to psychiatric research, Australian researchers are well respected internationally.<sup>46</sup>

Indeed, the extent to which Australian psychiatric research can make a difference is illustrated by the work of John Cade — an Australian pioneer in the discovery of lithium for the treatment of manic depression.<sup>47</sup> The introduction of lithium into psychiatric practice worldwide has not only improved the quality of life for many thousands of individuals, it has also substantially reduced the cost of care for people with manic depression and provided substantial economic gains flowing from increases in productivity — by returning to the workforce many sufferers who had either been unable to contribute at all because of their illness, or only able to do so in a significantly impaired manner. It has been calculated that between 1969 and 1979 an estimated \$US4 billion was saved in the US alone as a result of lithium's introduction into psychiatric practice.<sup>48</sup>

Cade's discovery illustrates the importance of linking clinical and basic research and highlights the fact that the prevalence and expense of psychiatric services makes major discoveries — even though they do not occur with either regularity, frequency or predictability — extremely worthwhile. The savings accruing from such discoveries massively outweigh the cost of investing in productive, marginally productive, and, inevitably, some unproductive psychiatric research.

### **Training Researchers**

Evidence presented to the Inquiry on the general training needs of mental health professionals is discussed in Chapter 6 of this report. In the specialised field of psychiatric research it is clear that much more needs to be done to attract psychiatrists and psychologists into career paths which will lead them to undertake substantial, if not full-time, research activities once they have completed their primary postgraduate qualifications.

One of the main mechanisms used by the NHMRC to encourage young investigators to pursue a medical research career is its Training Fellowship Scheme. Psychiatrists, however, rarely enter the scheme. A review of the period 1979-83<sup>49</sup> revealed that during those years only one out of seventy-six fellows was a psychiatrist.<sup>50</sup>

State governments are also pursuing training initiatives. Examples include the fellowships offered by the NSW Institute of Psychiatry and special research scholarships in Queensland. Professional organisations such as the Royal Australian and New Zealand College of Psychiatrists and the Australian Society for Psychiatric Research also support and encourage research training.

## **State Government Supported Mental Health Research**

State government contributions may be direct (through the mental health divisions of government departments, or the research arms of government health departments) or indirect (through Health Promotion Foundations, such as those operating in Western Australia and Victoria.) The Victorian Health Promotion Foundation, for example, has provided substantial funding for research into schizophrenia, the mental health problems of youth and the elderly, and the impact on carers.<sup>51</sup>

Notwithstanding efforts currently under way in NSW<sup>52</sup> and Western Australia, two State governments are noteworthy for their support of psychiatric research — Victoria<sup>53</sup> and Queensland. The Victorian Government set up the Mental Health Research Institute of Victoria in 1956, as part of the State Health Department. It conducted important epidemiological and health service evaluation work from its establishment until the early 1980s — but was hamstrung by a relatively poor budget, the absence of laboratory facilities and the fact that it was part of a Government bureaucracy. A major change occurred in 1987. The Institute was made independent, given its own Board of Management and, increasingly, a more appropriate budget. Members of the Inquiry inspected the Institute, which is now based at Royal Park Hospital and has a staff of 55. Its expenditure in the financial year 1991-92 was \$2.0 million.

The recently established Early Psychosis unit at Parkville in Melbourne is also undertaking pioneering research work (see Chapter 20 on Children and Adolescents.)

The NHMRC Schizophrenia Research Unit, which operates in Melbourne under the auspices of the Mental Health Research Institute, consists of a number of laboratories and specialist units including the Neuropathology, Neurochemistry and Neuroendocrinology Laboratories and the Psychopharmacology, Genetics and Biostatistics Units.<sup>54</sup>

Queensland also has a very progressive and productive psychiatric research unit which is primarily funded by the State Government. The Wolston Park Hospital Clinical Studies Unit, also inspected by the Inquiry, was established in 1988. Its activities centre on a 22 bed inpatient unit and associated Clinical Electrophysiology Unit at Wolston Park Hospital and laboratories in the Department of Medicine at Princess Alexandra Hospital.

The Unit consists of 40 permanent staff who are members of a number of teams, including the Social Psychiatry and Epidemiology, Psychopharmacology,

Phenomenology and Treatment, and Genetics Groups. The clinical focus of the unit is schizophrenia and its funding for 1991-92 was approximately \$1 million.<sup>55</sup>

There is close co-operation between the Clinical Studies Unit and the Mental Health Research Institute of Victoria. Both groups have also developed strong international links. The Clinical Studies Unit has made excellent progress in the brief period since its establishment and the Queensland Government has demonstrated a welcome commitment to encouraging research into serious mental disorder.<sup>56</sup>

An excellent model for State-supported research facilities exists in the United States, where the main responsibility for psychiatric care is also at the State level and many States have undertaken considerable responsibility for psychiatric research. Despite the comparatively healthy investment in such research by their Federal Government, it is widely recognised in the United States that substantial State contributions are needed to augment Federal Government allocations. Thus, the median annual State contribution to 26 psychiatric research Institutes is \$US6 million.<sup>57</sup> Twenty of the 26 institutes receive at least \$1 million and seven receive at least \$10 million. (The median staffing level of these psychiatric institutes is 152.)

### **Contributions Made by Professional Groups and Organisations**

As mentioned previously, both the Australian Society of Psychiatric Research and the Royal Australian and New Zealand College of Psychiatrists are prominent in the research field. In addition to the provision of research programs, the College has developed a research register, gives small grants-in-aid and conducts training programs.

Psychologists conduct a great deal of research which is relevant to psychiatry and psychiatric treatments. Psychiatric nurses are also becoming increasingly involved in mental health nursing research. The Australian College of Mental Health Nurses promotes research and a Centre for Mental Health Nursing Research has been established at the Queensland University of Technology.

### **Contributions by Consumer Support Groups**

Several of the larger consumer support organisations, such as the Schizophrenia Fellowships or the Mental Health Associations, are actively seeking to promote psychiatric research and are seeking funding. In NSW, for example, the Schizophrenia Fellowship has initiated the Neuroscience Institute of Schizophrenia and Allied Disorders (NISAD).



## **The Need for Further Research into Community Based Programs**

It is clear from the evidence that research is also needed into the practical workings of psychiatric treatment, rehabilitation and care services. (In essence, this is a matter of evaluating what works, what does not work and why.)

The Inquiry received extensive evidence from consumers concerning the apparent effectiveness of some residential, day and outreach support services for people affected by mental illness. There is clearly a desperate need for more such services — which can only be met if there is a substantial allocation of funding.

The Inquiry recognises, however, that policy makers must have research evidence to back up the experience of service providers. More effort therefore needs to be devoted to identifying factors that contribute to successful outcomes for people with mental illness who are utilising non-clinical care and support services. More difficult, but equally important, will be studies that seek to determine the comparative effectiveness of day and residential programs; of accommodation services that are permanently staffed against those where staff are on-call; and of residential services and outreach support services.

## **Research in the Context of the National Mental Health Policy**

The recently created Mental Health Section of the Department of Health, Housing, Local Government and Community Services has the mandate for overseeing implementation of the National Mental Health Policy. The relevant unit was established in 1991 and is currently a small section with a staff of only five people. It will continue to play a major role in determining the manner in which additional funds allocated are spent and in negotiating an agreement with the States with regard to the program.

As funding responsibilities for psychiatric research shift away from the States to the Commonwealth, it is particularly important that any of the psychiatric research funding provided by the States (especially Victoria and Queensland) is either maintained by the States or, alternatively, an appropriate arrangement is made between Commonwealth and State governments to ensure that the Commonwealth assumes responsibility for continuing the funding which is enabling this valuable psychiatric research to be conducted in a manner which would not be possible if the sole funding source was the NHMRC.

Just as Pinel struck the chains from his patients in the late 18th century, the best care... for people with mental illnesses and in turn the best way of improving their human rights is to improve the treatment... so that they are not imprisoned by their illnesses.<sup>58</sup>

1. W Gibson, 'The Cost Of Not Doing Medical Research', *Journal of the American Medical Association*, v244, 1980, pp1817-1819.
2. Prof I Webster, Professor of Community Medicine, University of NSW. Oral evidence, Sydney 20.6.91, p466.
3. See Chapter 2 - Relevant Human Rights Provisions, particularly the commentary on the Declaration on the Rights of Disabled Persons — which recognises that people with disabilities, including psychiatric disabilities, are entitled to: '*any necessary treatment, rehabilitation, education, training and other services to develop their skills and capabilities to the maximum*' (Principle 6).
4. Some witnesses to the Inquiry have described the state of research funding as 'parlous' — see, for example, Dr D Leonard, Director Clinical Services, Royal Park Hospital and Dr M Duke, representing the Victorian Branch of the RANZCP. Oral evidence, Melbourne 14.4.91, p342.
5. *Report of the Mental Health Taskforce to the Overarching Committee on Health and Aged Care and to the Australian Health Ministers' Advisory Council*, AGPS, Canberra, 1991. In its report the Mental Health Taskforce to the Australian Health Ministers' Advisory Council highlighted the fact that mental health research has traditionally had a low priority in gaining access to research resources and indicated the following seven priorities in the area of mental health research and evaluation:
  - (a) development of a national mental health data strategy;
  - (b) regular reviews of outcomes of services provided to the seriously mentally ill;
  - (c) development of effective clinical information systems to enable improved planning and evaluation;
  - (d) increased promotion of basic and applied mental health research and its application in prevention and intervention programs;
  - (e) affiliation of appropriate staff between Universities and Health Departments;
  - (f) development of programs to focus specifically on promoting research skills in mental health;
  - (g) establishment of a comprehensive suicide research and prevention program.
6. Whereas fields such as immunology and cardiovascular research have had the benefit of large and dynamic research institutions, such as the Walter and Eliza Hall and Baker Institutes, little funding has been provided to develop similar institutional structures in psychiatric research. Recent developments at the Mental Health Research Institute of Victoria, the Clinical Studies Unit at Wolston Park Hospital in Brisbane, and the NHMRC Schizophrenia and Social Psychiatry Units point to a growing recognition that such structures are essential to the furtherance of the goals of psychiatric research.
 

Sciences associated with psychiatry have recently made major conceptual and technical advances. Prior to this, the discipline emphasised a broad-ranging collection of empirical data in what was known as the 'pre-theoretical phase', rather than focussing on solid data-based theoretical frameworks. The combination of this fact, and a lack of convincing animal models of psychiatric illness, may have acted as a disincentive to potential researchers seeking a more secure structure within which to develop their research plans.
7. While some organisations such as the NSW Institute of Psychiatry have been providing better funded research fellowships, the point must be made that without a solid training base the future of psychiatric research is very limited.
8. Medical research in Australia is internationally competitive, when considered in relation to the tight budgetary constraints which operate to limit its expansion and development. An independent review of Australian research, including medical research, was undertaken by the Australian Science and Technology Council (ASTEC) in 1989. In its report

(ASTEC, *Profile of Australian Science*, Canberra, 1989) ASTEC stated that clinical and biomedical research in Australia 'has never been in a stronger position in international terms' especially in the specific areas of cardiovascular research, neuroscience, immunology, cellular and molecular biology, vision research and comparative physiology. It noted, however, a worrying trend, in which medically qualified graduates were moving away from medical research. It highlighted the need to provide incentives and encouragement to bring them back. It also noted Australia's weakness in a number of areas of medical research and the particularly low funding levels allocated to certain areas which had a major impact on morbidity and on quality of life.

9. Dr David Copolov, Director, Mental Health Research Institute of Victoria. Oral evidence, Melbourne 8.4.91, p67.
10. Independent Commission on Health Research for Development, *Essential Link to Equity and Development*, Oxford University Press, 1990.
11. id. Of the 23 countries for which publicly funded medical research was calculated as a percentage of GDP, Australia outranked only Spain, Ireland and Greece.
12. In this regard, note should be taken of the subsequent section of this chapter on the Performance of Psychiatric Researchers in Australia for the savings accruing from the discovery of lithium's anti-manic properties.
13. R Smith, 'Science in Australia: Alive, Well, Kicking, and Growing,' *British Medical Journal*, v302, 1991, pp946-948.
14. Leonard and Duke, op cit.
15. P Eisen and K Wolfenden, *The National Mental Health Services Policy: Report of the Consultancy to Advise Commonwealth, State and Territory Health Ministers*, Department of Community Services and Health, Australian Government Publishing Service, Canberra, 1988.
16. The Australian Bureau of Statistics (ABS) states that the CPI for June 1987 for major capital cities was 82.6 and the CPI for June 1992 was 107.3; this represents a 29 percent increase in the CPI between 1987 and 1992. \$2.74 billion increased by 29 percent is \$3.53 billion.
17. Report of Mental Health Taskforce, op cit, p18.
18. It is difficult to obtain precise costings on private psychiatric hospital care in Australia. This estimate was made using the following assumptions:- During the financial year 1991/2 there were 4,700 private psychiatric admissions in Victoria. Extrapolating to the rest of Australia (Victoria represents 25.1 percent of the Australian population) this would mean 18,725 private psychiatric admissions per annum. For an estimated admission length of 21 days at \$350/day - the total cost would be \$138 million.
19. G Andrews, W Hall, G Goldstein et al, 'The Economic Costs of Schizophrenia', *Archives of General Psychiatry*, 1985, v42, pp537-538. Professor Andrews is Professor of Psychiatry and Director of the Health Services Research Group, Clinical Research Unit for Anxiety Disorders, University of NSW at St Vincent's Hospital.
20. Editorial, *Nature*, v357, 1992, p348.
21. The estimate for the total cost of neurological and psychiatric disorders as well as drug and alcohol abuse was \$US401 billion, which represented 7.3 percent of the GDP. Psychiatric disorders, at \$136 billion, represented 34 percent of total estimated costs in the Lewin/ICF Report. 34 percent x 7.3 percent = 2.48 percent of GDP.
22. Data from the Australian Bureau of Statistics.

23. Andrews et al, op cit. In 1985 Andrews and colleagues estimated that schizophrenia cost each person in Australia \$US29 in 1975 dollars. To calculate the total cost in 1992 Australian dollars, the current exchange rate of .715 Australian dollars to 1 US dollar (7 October 1992) was used, as was the total Australian population of 16,849,449 (ABS-1992) people and the adjustment in the Consumer Price Index. The June quarter CPI in 1975 was 28.4 in comparison to the June 1992 CPI of 107.3; this represented a 277 percent increase in the CPI during that time.
24. Prof G Burrows, Professor of Psychiatry, University of Melbourne and Chairman, Mental Health Foundation of Australia. Oral evidence, Melbourne 9.4.91, p220.
25. Comprising \$3.9 million NHMRC Psychiatric & Psychology Project & Unit Grants; \$1.0 million Clinical Studies Unit Queensland; \$1.7 million Victorian Government, including funding for the Mental Health Research Institute; \$1 million from the Victorian Health Promotion Foundation; and \$602,000 from the Health, Housing and Community Services Research and Development Grants.
26. These figures do not include funding by State health departments of some research and prevention programs or mental health promotion activities and research. These are more difficult to quantify but should be taken into account in the overall picture of research development in this field.
27. Independent Commission on Health Research for Development, op cit.
28. An increment of more than \$20 million on the current psychiatric funding base would overextend the existing psychiatric research infrastructure and result in an inability to efficiently and economically utilise the increased funding base. However, it is clear that incremental goals, perhaps of the order of \$2-3 million per annum (in real terms) over the next 8 to 10 years, would bring psychiatric research funding into a range which would be justified by the cost to the community of these diseases.
29. Australian Institute of Health and Welfare, *Australia's Health*, Australian Government Publishing Service, Canberra, 1992. The Institute is based in Canberra but also has four external Units and has developed formal collaborative arrangements with three other Agencies.
30. In late 1992 the Australian Bureau of Statistics introduced an annual survey of private hospitals in Australia. Data from this survey, when combined with public sector health data from AIHW, will form the basis of the first set of national statistics relating to hospitals.
31. The AIHW works closely in association with the Australian Bureau of Statistics which conducts five-yearly censuses, as well as periodic National Health Surveys, surveys of disability and aging and of private health insurance.
32. Formerly the Department of Health, Housing and Community Services.
33. A total of 92 projects were funded.
34. NHMRC Research Evaluation Management Committee, *Allocation of Resources to Disciplines 1979-89*, AGPS, Canberra, 1990. This contains an extremely comprehensive analysis of funding success rates by psychiatric and psychological researchers applying to the NHMRC.
35. R Kalucy, 'An Exploration of the Gap Between Aspiration and Success in Psychiatric Research Funding', *Australian and New Zealand Journal of Psychiatry*, v17, 1983, pp373-382. This provides a detailed analysis of the gap between applications and grants in psychiatric research funding.

36. *ibid*, p374. Another reason that there is a discrepancy between the success rates of other disciplines and psychiatry is that many of the successful disciplines have been funded by the NHMRC since it was established in 1937. Professor Kalucy points out 'They have received funding not only for projects, but also for Training Fellowships within Australia and overseas for many years. In many cases, their disciplines are led by scientists who are the fourth, fifth or sixth generation of full time scientists. Positions within these laboratories are fiercely competed for by scientists who are themselves full-time workers. They form a large community of well trained scientists who invest heavily in the training of their successors'.
37. Webster, *op cit*, pp466-467.
38. J Palca, 'National Institute of Health Strategic Plan Near its Final Form', *Science*, v257, 1992, pp476-477. This issue was recently addressed by the National Institutes of Health in the United States (NIH). The NIH have developed a draft plan which attempts to reprioritise the relationship between individual investigator grants and goal-directed research directives, with greater emphasis being placed on 'research priorities the NIH hierarchy think are necessary to foster the country's physical and economic health'. It is not that the NIH do not recognise the importance of investigator-initiated research — the Institutes state, for example, that such research 'is at the heart of scientific enquiry in which discoveries arise in unexpected places, from improbable insights and through leaps of the imagination'. Such grants will continue to be allocated but will be seen within a broader context of 'the achievement of scientific goals and programs'.
39. R Felix, *Encyclopedia of Mental Health*, ed. Albert Deutch, Franklin Watts Inc., v4, 1963. The US Selective Service system rejected 900,000 men for service because of neuropsychiatric disorders and more than 700,000 were discharged from the services as a result of these disorders.
40. H A Pincus and T Fine, 'Anatomy of Research Funding of Mental Illness and Addictive Disorders', *Archives of General Psychology*, v49, 1992, pp573-9.
41. *id*.
42. In 1992, the Medical Research Council allocated 11.5 percent of its fund to these areas.
43. To be included as a special initiative area, a clinical discipline must be of considerable importance to the Australian community and be considered to have limited chances of success in the project grant process.
44. In contrast to block grants, which are awarded to Institutes which have been established for many years and have a record of excellence in research, special units are established to research important clinical problems and are centred around productive research groups which have not yet had the opportunity to develop the track record of major institutes.
45. The Network proposal grew out of a desire to see psychiatric research taking place within a broader and more scientifically ambitious scope than the research which is currently conducted within individual units. It is also hoped that its creation will encourage neuroscientists not currently working on projects related to psychiatry to begin doing so.
46. G Parker, 'The Australian Contribution to Psychiatry', *Australian Psychiatry in the Tradition of Aubrey Lewis*, Cloister Press, 1991, pp29-38.
47. The results of John Cade's studies are reported in the *Medical Journal of Australia*, September, 1949.
48. A Reifman, R Wyatt, 'A Brake in the Rising Cost of Mental Illness', *Archives of General Psychiatry*, v37, 1980, pp385-389.
49. A Henderson, 'Australian Research: Psychiatric Research in Australia', *Australia and New Zealand Journal of Psychiatry*, v17, 1983, pp369-372.

50. Some of the reasons for this stark record have been discussed in the Introduction to this chapter. They include comparatively poor salaries, lack of identifiable long-term career structures, the extreme complexity of much psychiatric research and, until recently, the lack of psychiatric research centres and institutes where full-time research careers can be pursued in the midst of a 'critical mass' of research colleagues.
51. National Health and Medical Research Council, *Prevention in the Mental Health Field*, op cit.
52. NSW has a number of prominent research facilities such as the Psychoneurology unit at James Fletcher Hospital in Newcastle.
53. There is a greater concentration of medical research in Victoria than in other States. The Government has accepted responsibility for funding the Victorian Medical Research Institute's major infrastructure costs and successive Victorian Governments have taken the view that they should work with the Commonwealth to support the medical research being conducted in their region. This support has ensured that Victoria retains a high proportion of NHMRC Project Grants.
54. The Institute's research programs will be consolidated when it moves from a number of buildings scattered around Royal Park to a purpose-built facility which will include state-of-the-art laboratories and neurophysiological and neuroimaging technology. The building will be funded from a combination of Commonwealth, State and private sources and will be completed by November 1993
55. This figure includes staff salaries and clinical services.
56. The Inquiry has been advised that discussions are under way in both New South Wales and Western Australia to establish research units similar to those in Victoria and Queensland.
57. B Levin et al, 'A National Study of State-supported Psychiatric Research Institutes', *Hospital and Community Psychiatry*, v40, No 4, 1989, pp388-392.
58. Copolov, op cit, pp67-68.

## Chapter 27

### PREVENTION AND EARLY INTERVENTION

The prevention of mental disorders has been neglected but the public health burden now is too high for this to continue. Nearly one half of all mental and neurological disorders are amenable to primary prevention. Effective measures could be applied even in countries with few resources. By and large these measures all rely on available knowledge and commonly involve sectors other than health.<sup>1</sup>

Prevention is critical to the whole area of mental health. While our knowledge of the causes of many conditions is incomplete, the scientific advances of recent years do provide us with many findings that, if systematically applied, could make a significant difference in the levels and severity of many mental health problems and some mental illnesses. Unfortunately, much of this knowledge has simply not been applied to develop prevention policies and programs.

Several recent international and Australian initiatives should, however, be noted. In the United States the National Institute for Mental Health (NIMH) has established an Office of Prevention, undertaken special research initiatives and recently released a number of policies and reviews. The US National Health Promotion and Disease Prevention Objectives, *Healthy People 2000*, have identified key mental health goals, including reduction of the prevalence of mental disorder in children, adolescents and adults living in the community. Similar prevention strategies have been developed in the UK, although in a more limited way.

The World Health Organisation has also made repeated calls for recognition of the urgency of prevention initiatives in mental health — and support for prevention has increased among consumer organisations — both in Australia and overseas.

Recent Australian initiatives have drawn together evidence on which to base a systematic approach to prevention.<sup>2</sup> The development of a National Health Strategy for Australia<sup>3</sup> has incorporated for the first time systematic Goals and Targets for Mental Health,<sup>4</sup> with a program for implementation under the National Mental Health Policy. Thus there is now acceptance of the need for a national approach to the adoption of preventive programs.

Clearly, if opportunities for effective prevention programs exist, but are ignored (or if acceptance of the need for them is not translated into reality), we are mortgaging the rights of those vulnerable to mental illness — and their families.

It should be noted that many of the issues addressed in this chapter draw on evidence analysed in earlier chapters of this report.

## **Community Issues and Prevention in the Mental Health Field**

### **Community Understanding of Mental Illness**

Much of the evidence presented to the Inquiry highlighted the community's poor understanding of mental health issues and lack of compassion for people suffering mental illness. Chapter 14 portrays the impact of stigma, continual rejection and discrimination on those affected. This lack of understanding also makes it much more difficult for individuals to recognise and seek help for the early signs of mental illness — either for themselves, or for family members.

Public education campaigns in the health area have contributed significantly to attitudinal change — promoting greater understanding of disability and general health (especially cardiovascular disease — 'Know Your Heart' and the 'Quit' campaign; and cancer — 'Cancer is a word, not a sentence'). Humanising the impact of illness by depicting real people and their experiences (in programs such as the HIV/AIDS discrimination campaign) has contributed to more tolerant attitudes and behaviour in the community generally, and to individuals affected seeking earlier access to effective prevention and treatment (a phenomenon particularly noticeable in breast cancer screening and pap smear campaigns).

Several campaigns have addressed aspects of mental health and mental illness, but there is a compelling need for a sustained nation-wide campaign to educate our community about mental illness — to demystify it and ultimately to destigmatise it. This needs to build on initiatives such as Mental Health Week and the work of state and national Mental Health Associations, the Schizophrenia Fellowships and ARAFMI (through its school based education programs).

Many witnesses emphasised that unsympathetic attitudes of the media, reflecting populist prejudices and misconceptions, added considerably to stigma and misapprehension about mental illness.

- We as a family know the social stigma associated with mental illness. We all feel that the media portrayal of those with a mental illness does nothing to educate or enlighten the general public. We hope that this situation will somehow be remedied in the future.<sup>5</sup>
- People think that schizophrenia is a split personality... They've seen Alfred Hitchcock thrillers and Psycho movies, and they get an impression that we're generally dangerous.<sup>6</sup>



- I think you have our submission and I think most of it is self-evident, but we do wish to point out the strong negative feelings that do exist against mental illness in the community which get reflected and exaggerated in the media.<sup>7</sup>

## *Stigma*

As described in Chapter 14, social stigma associated with fear and misunderstanding may have an extremely debilitating effect. This is particularly significant in the context of prevention and intervention, since those who are vulnerable or mentally ill are profoundly influenced by these perceptions, compounding their low sense of self-worth and feelings of anxiety and uncertainty.

According to the Schizophrenia Australia Foundation the ‘human rights and fundamental freedoms’ of people with serious mental illness are ‘seriously jeopardised’ by stigma — ‘a mark of dishonour and disgrace’.<sup>8</sup>

The negative effects of stigma and discrimination not only prevent early access to care and limit opportunities for treatment and recovery, they create difficulties in rehabilitation and community living. Stressful experiences of rejection therefore compound the problems of those with mental illness and significantly impair their mental health.

## **Social Adversity**

The correlation between social adversity and some mental illness and disorder has been clearly established.<sup>9</sup>

## *Poverty*

Social disadvantage inevitably means greater exposure to life’s stress factors (stressors) and, for those affected by mental illness, it frequently precludes access to quality health care, decent housing, and employment. It is well established that general health is worse for the economically disadvantaged and that this can contribute to increased risk of mental illness (for instance severe depression). Disempowerment and lack of information may exacerbate the situation. It is also established that mental illness may lead to social disadvantage through downward social drift, incapacity to work, lack of access to adequate living standards and poorer quality of life.

To give an idea of the sort of perception that becomes extremely difficult and involved for a schizophrenia sufferer, the best example I could think of is the poverty cycle. I know it’s difficult for anyone in any situation to get over the... problem of a poverty cycle and the reality of it, but for a schizophrenia sufferer it’s more complicated because of the sense

of blame, of failure in terms of that situation and then needing to get over that hurdle as well as the practical hurdle of the poverty itself. There are a lot of schizophrenia sufferers out there who have had employment positions and are finding it incredibly difficult to now find employment — not because, perhaps, they're not offered jobs in many cases, but simply to get over the perception of having failed.<sup>10</sup>

## *Unemployment*

Unemployment is a particular stressor, both for the mentally ill and those who are at risk of mental illness. It may lead to, or exacerbate depression, anxiety and other mental disorders. The most recent research has indicated very adverse effects on health generally — and mental health in particular.<sup>11</sup>

Recent studies have also indicated that more than 50 percent of unemployed young people suffer from depression.<sup>12</sup> Research has not yet established the effects on mental health of long-term unemployment, or second generation unemployment. However, a 1993 review of statistics on unemployment indicated that 18 percent of young people in Australia are growing up in households where no-one has a job.<sup>13</sup> 12 percent of young people who are unemployed themselves have a parent or parents who are unemployed — ie they are second generation unemployed. This review described the alienation, disadvantage and despair faced by this growing 'underclass'. Clearly, it is imperative we use our mental health expertise, as well as broader social programs, to assist the tens of thousands of our young people so adversely affected.

High unemployment means diminished opportunities for maturation and growth for adolescents. As discussed in Chapter 13, mental illness may significantly interfere with their capacity to pursue education or training to equip them for later life, or may more generally inhibit maturation. As established earlier in this report, the onset of mental illness is often in late adolescence, before education has been completed, tertiary studies or training undertaken and work commenced. Thus young people who are affected may be much more vulnerable to unemployment as well.

## **Socio-cultural Factors and Vulnerability.**

Cultural factors influence perceptions and understanding of unusual behaviour and patterns of response and care. They are also relevant to preventing mental distress and mental disorder (as outlined below).

As indicated in Chapter 23, Aboriginal and Torres Strait Islander people have totally different concepts of mental health and wellbeing. Continued lack of recognition of this fact will only perpetuate morbidity and inappropriate care.

Understanding of culture is relevant in other contexts too. At least 20 percent of Australians are from non-English Speaking backgrounds (NESB) — either they or their parents have arrived in Australia from different cultures and language groups (see Chapter 24).

Not only is an understanding of these cultural issues essential for the provision of mental health care, but unless care is provided in culturally appropriate ways additional stresses occur, adding to the burden, illness and disability of people affected by mental illness.

Preventive strategies must therefore acknowledge the particular cultural experiences of different groups (the effects of colonisation, separation and cultural loss for Aboriginal people; the effects of migration, and resettlement or refugee status for people of NESB) to lessen the likelihood of mental illness developing.

#### *Aboriginal and Torres Strait Islander People*

The likelihood of mental health and social problems among Aboriginal and Torres Strait Islander people is greatly increased by social disadvantage, racism and discrimination.

Many Aboriginal witnesses spoke of the long-term psychological effects of people being moved from traditional lands and separated from their families. The anger, grief and trauma resulting from the removal and institutionalisation of children was a recurring theme in evidence from Aboriginal witnesses.<sup>14</sup>

Among Aboriginal communities, distress manifests itself not only in grief and depression, but also in antisocial and self-destructive behaviours, poor self image and chronic substance abuse.

Older Aboriginal people have special needs, as do young people and women. An adequate understanding of the cultural contexts relevant for these groups (for instance Aboriginal 'women's business' and reproductive health) is a prerequisite for effective preventive mental health programs.

While the development of specialised mental health services for Aboriginal people has been a low priority, recent studies<sup>15</sup> and a planned conference, *Our Way* (the first National Aboriginal Mental Health Conference to be held in Sydney in November, 1993) should contribute significantly to our capacity to address these issues.

There is an urgent need for Aboriginal people to be involved in the development of their own preventive mental health programs. These should build on what is known about trauma and loss, enable Aboriginal people to develop counselling and support programs related to these issues, and inform the design of services to mitigate the effects of disadvantage and deprivation.

The high mortality rate experienced by Aboriginal people is another important factor. Families are stressed by multiple and premature bereavements, as well as unresolved grief from earlier generations. The stresses faced by youth, the problems that arise from substance abuse, domestic violence and family breakdown, and the effects of marginal status and lack of access to services in rural and isolated areas must also be addressed.

There is evidence to suggest that prevention programs developed by and with indigenous peoples can be successful in lessening vulnerability and morbidity.<sup>16</sup>

Whilst it is now accepted that Aboriginal people suffer from psychiatric afflictions, recognition, assessment and management of these illnesses in Aboriginal people is different — because of their disadvantaged situation and because of the non-European styles in which they sometimes present... There are no specific policies for the diagnosis and treatment of Aboriginal people with mental illness.<sup>17</sup>

It is essential that support be given and research undertaken to develop mental health prevention programs that are culturally relevant for Aboriginal people.

### *People of Non-English Speaking Background*

As outlined earlier in this report,<sup>18</sup> a range of factors relating to 'interpretations' of mental illness, cultural practices towards the mentally ill, and traditional or cultural healing processes and practitioners are relevant for people from different ethnic, racial and religious backgrounds. To provide effective prevention programs these issues need to be taken into account.

Such programs should facilitate early recognition and treatment of mental illness and may need to include education of the leaders and practitioners dealing with each group.<sup>19</sup>

Dealing with life crises such as bereavement, which may precipitate mental health problems such as severe depression, may be determined by specific cultural prescriptions. These may assist resolution and recovery (for instance by supporting the grieving process), or may inhibit it. If culturally appropriate practices are not able to be carried out, this may further complicate adjustment to major life events, increasing the risk of mental illness. Clearly, prevention

programs need to take such issues into account, and to ensure that crisis resolution is supported in culturally appropriate ways. Similar principles apply in relation to developmental transitions (eg adolescence) and psychological vulnerabilities associated with them.

Language is a key factor, influencing not only understanding of individuals' distress, but also their access to direct services or prevention programs. As a key element in preventing distress and illness and assisting individuals from different cultural and linguistic backgrounds, it is essential to ensure that culturally specific information is provided and bilingual practitioners or trained health care interpreters are available.

As noted in Chapter 24, refugees are particularly vulnerable and may be suffering from overt or covert mental illness, such as post traumatic stress disorder, as a consequence of their experiences. While several Torture and Trauma Services exist, it is essential that early recognition and care is encouraged, in supportive ways which take into account the special vulnerabilities of this group. If this does not occur, secondary traumatisation is likely — so a preventive approach is particularly important.

Elderly people of NESB have also been identified as a vulnerable group and a preventive approach is likely to be helpful. Women of NESB have been identified as at risk of mental disorder through their isolation, lack of social networks, changed cultural norms concerning the place of women, adverse work environments (or lack of access to work), and lack of opportunities to learn English (see also Chapter 24). Clearly, preventive strategies for women in such settings could significantly diminish their risk of developing mental health disorders.

Evidence to the Inquiry clearly indicated that failure of assessment and diagnosis, and inappropriate treatment, occur when systems of care are not culturally and linguistically appropriate and attuned to these issues. The evidence also suggests some people of NESB are more likely to be admitted to acute psychiatric care, and may be held longer without appropriate treatment, further compounding their problems. Clearly, prevention for people of NESB must address these issues.

# Opportunities for Prevention in Specific Contexts

## Children and Adolescents

As noted in Chapter 20, the extent of psychological disorder affecting children and adolescents is substantial — with approximately 15 percent suffering significant psychological morbidity.

Emotional and behavioural problems are often difficult to diagnose and may merge with distress related to children's experiences and family setting. Not only may such problems significantly interfere with a child's wellbeing and development, but they may also continue into adolescence, or indeed constitute the basis for mental illness or disorders in adult life.

Many witnesses to the Inquiry emphasised the importance of preventive programs for children and adolescents.

A logical next step is for additional funds to be allocated (not reallocated) for extensive and sustained primary prevention and early intervention program aimed at preventing the development of mental disorder in at risk groups. Examples of programs would include stress management, loss, grief and bereavement, education and assistance, early screening for children at risk of developing personality disorders, and people who have suffered from sexual and physical trauma.<sup>20</sup>

The importance of early and effective treatment of children and adolescents in preventing adult disorder was particularly emphasised by expert witnesses.

So, we've got the opportunity, in treating children, to prevent some adult mental illness; certainly not all, but some.<sup>21</sup>

Factors associated with behavioural and emotional problems in childhood and adolescence are usually generic — that is they predispose to disorder generally, rather than to a specific condition. It is also likely that multiple factors will interact to lead to distress or disorder. These include: parental discord; parenting difficulties; loss of a parent or parents through death, separation or divorce; other stressful events; physical, emotional or sexual abuse; parental illness, psychiatric or substance abuse such as alcoholism; genetic vulnerability; biological factors affecting the development or function of the brain, for instance during pregnancy, childbirth, infancy or childhood; and temperament, (ie the child's particular psychobiological responsiveness and make up, and his or her interaction with parents or other carers and their environment). These areas of potential vulnerability may be balanced by elements of resilience and competency — and prevention may also involve enhancing these.<sup>22</sup>

A number of recent studies have underlined the need to develop prevention programs for child and adolescent mental health. In the US, the Office of Substance Abuse Prevention and the American Academy of Child and Adolescent Psychiatry have produced a substantial review of all available scientific data that would constitute a basis for such prevention.<sup>23</sup> Other reviews also highlight opportunities in this field.<sup>24</sup> In Australia, a recent review of the Scope For Prevention in Mental Health<sup>25</sup> detailed potential prevention initiatives and their rationale. In the US the Goals and Targets in the National Health Strategy identify mental health prevention goals for children and adolescents; and the recent Health Goals and Targets in Australia, suggest growing recognition of the need for substantial prevention strategies for child and adolescent mental health.<sup>26</sup>

### *Parental or Marital Discord*

There is a great deal of evidence concerning the distressing and disturbing effect that parental arguments and domestic violence have on children — with work from many senior child psychiatrists suggesting that this is one of the more powerful negative influences contributing to child psychopathology. Such problems often do not occur in isolation. Indeed, they are frequently associated with other factors, such as parental alcoholism. There is evidence that a number of prevention programs can enhance marital harmony<sup>27</sup> and therefore mitigate this contributing factor. Clearly, it is essential that programs of this kind are developed, implemented and evaluated.

### *Effective Parenting*

Effective parenting has been the goal of many programs — from those providing support during the antenatal and post-partum period, to those which teach specific parenting skills. Such programs have also been developed for vulnerable groups (such as single parents) and interventions designed for people in difficult parent-child settings (highly anxious mothers or parents with premature, low birthweight babies).<sup>28</sup>

In all cases, benefits have been demonstrated in sound scientific studies, and there is clear evidence that preventive programs of this kind mitigate later problems for children.<sup>29</sup>

### *Childhood Loss and Separation*

Not only are loss and separation distressing for children, they may also lead to short or longer term vulnerability to a range of associated problems, including depression.

Counselling for bereaved children and families, as well as prevention and support programs for children who have been traumatised, are likely to produce more positive results in terms of better adjustment and lesser vulnerability<sup>30</sup>. A number of US studies have demonstrated the benefit of preventive interventions with families following divorce — a frequent trauma with one in three marriages now ending.<sup>31</sup> While it is true that many children may be more adversely affected by continuous parental discord than by the family break-up, there is, nevertheless, a great deal of grief and adjustment to be dealt with in this context.

### *Child Abuse*

Prevention programs relating to child abuse are essential — in view of its very serious impact on children and adolescents and the contribution of abuse to vulnerability to psychiatric illness in adult life — demonstrated in evidence presented to the Inquiry. Intervention in high risk parenting situations<sup>32</sup> may diminish the risk of physical abuse in infancy, so such programs should be a priority. Further public awareness programs emphasising the importance of preventing abuse are also necessary, as is research to identify causal factors and effective ways of altering these.<sup>33</sup>

Early and effective treatment of sexually abused children may lessen the risk of depression and post traumatic stress disorder (PTSD) in this group.<sup>34</sup> Breaking cycles of abuse — with the long-term aim of preventing the abused child becoming an abusing parent (as one in five may do) — is also critically important.<sup>35</sup>

Programs are also needed to address the role of violence in contributing to the mental health problems of children and families. This can contribute to mental ill health through the effects of domestic violence on the mother (which is frequently witnessed by children), as well as the child's direct suffering. Not only may the child be traumatised, but it may also identify with the violent person and be more prone to violent behaviour in childhood, or later life.

Portrayals of violence on television or videos may contribute by 'sanctioning' violent solutions. The whole issue of preventing violence and abuse is relevant for mental health generally and demands a preventive approach,<sup>36</sup> as indicated by recent reports.<sup>37</sup>

### *The Children of Parents with Mental Illness*

Evidence to the Inquiry highlighted the problems of children whose parents are mentally ill. (Chapter 16 addresses these issues in detail.) Such children are



vulnerable to stigma, rejection, loss, disruption, lack of understanding, depression, grief and fear. (In some instances genetic and other vulnerabilities are also relevant factors.) They may also have to take premature responsibility for a mentally ill parent and care for younger siblings, especially if the partner has left.<sup>38</sup>

Many professionals in the mental health field are now recognising the special vulnerability of such children and the need to provide prevention programs that directly address the problems of impaired parenting that may accompany mental illness.<sup>39</sup>

The President of the Coalition of Child and Adolescent Mental Health Professionals advocated:

1. Programs which provide support and education to children and families while the ill parent is being treated as an inpatient in a psychiatric hospital.
2. Programs which provide support and education to children when their parent is receiving ongoing treatment/support as an outpatient of a community facility such as a community mental health centre.
3. Special assistance for children who appear to have psychiatric, emotional and/or behavioural problems whether these arise from genetic and/or environmental vulnerability.<sup>40</sup>

The Inquiry supports the value of such an approach, especially as these young people are potentially in contact with the mental health care system.

### *Enhancing Resilience and Competence*

Programs designed to increase adolescents' competencies, even when they are vulnerable, are believed to enhance cognitive problem-solving, self esteem, understanding of interpersonal relationships,<sup>41</sup> social skills and other attributes. Existing frameworks, such as personal development programs in schools, can be valuable in this context.<sup>42</sup> Programs targeted to special groups, or for special purposes (eg school transitions) have been demonstrated to have substantial benefit, especially when complemented by educational programs addressing socioeconomic and other disadvantage.<sup>43</sup>

These generic issues need to be addressed to ensure the rights of children and adolescents, and to decrease their vulnerability to psychiatric disorder in childhood and later life. But it is also essential that children have access to effective specialised treatment to ensure recovery when disorder does occur.

Several specific issues warrant special attention:

**1. Youth suicide is increasing alarmingly and expert evidence highlighted the need for prevention programs.**

The prevention strategies target youth in general and try to prevent the occurrence of precursors of suicidal behaviour, and they might include things like self esteem courses, providing crisis counselling, training for health staff or education staff and so on, setting up peer support systems.

Intervention strategies include things like hotlines and suicide crisis counselling so, post-attempt counselling, I should say, and postvention strategies deal with the aftermath of suicide. So that's when school staff and students for instance, after a suicide, have special consultation to debrief, to identify people, kids who might be at risk, to receive information about resources, mental health resources, and possibly help about stress management.<sup>44</sup>

While it is not yet clear how effective these programs are, the rising rates of suicidal behaviour among young people (considered in Chapter 20) make it essential that this issue is addressed. A review of various types of programs indicates there is no easy answer, but it is essential that any suicidal behaviour is taken very seriously, thoroughly assessed in terms of underlying psychiatric problems, and appropriate treatment instituted.<sup>45</sup> To date this is the most effective form of prevention.

**2. Depression in young people is an increasingly frequent and often poorly recognised problem.** Recent studies indicate it occurs in mild, moderate or severe forms in 14.6 percent of adolescent males and 25.2 percent of adolescent females. It is likely to be associated not only with risk of self destructive behaviour such as suicide, but also substance abuse, eating disorders and delinquency.<sup>46</sup> Prevention initiatives include dealing with stressful life crises such as bereavement, the generic issues outlined above, issues of gender specific stresses and self esteem which appear relevant to the heightened rates in girls, and the effects of parental disorder.

US initiatives addressing depression have been formulated into a national campaign, DART (Depression Awareness Recognition and Treatment),<sup>47</sup> to promote early and effective treatment and prevent the related human and economic costs and suffering. Depression in young Australians clearly also warrants a systematic prevention approach.

**3. Conduct Disorder and other disruptive behaviours** are a source of considerable morbidity in child and adolescent mental health, with problems occurring in 3.2 — 6.9 percent of young people.<sup>48</sup> Chronic illness and associated disability may lead to impaired self esteem, poor performance at school — and to aggressive and behavioural disturbance as a consequence.

...and of most concern, aggressive and learning disabled children will not be treated at an early stage, resulting in alienated kids, becoming street kids with increasingly antisocial behaviours in the community...<sup>49</sup>

Poor parenting, including rejection, lack of involvement and supervision of children, large family size, household disorganisation, and marital disharmony all increase risk — as do disadvantaged socioeconomic circumstances. (Children who are vulnerable because of such influences may also be vulnerable to television violence and its effects.)<sup>50</sup>

A Canadian psychiatrist who has conducted extensive research and clinical work with children and adolescents with disruptive and antisocial behaviours has concluded that effective prevention strategies include programs targeted for children and families at high risk, behavioural family intervention, and other programs instructing parents and teachers in dealing with children's aggression and disturbed behaviours.<sup>51</sup>

Recent overseas research has identified multifaceted programs targeting multiple risk factors as the most effective for children living in high risk settings.<sup>52</sup> These findings have also been reinforced by Australian research.<sup>53</sup> The importance of prevention in this sphere has been recognised by identifying the prevention of conduct disorders as one of the primary aims in our National Goals and Targets for Mental Health.<sup>54</sup>

Prevention of conduct disorders in childhood and adolescence, or their early and effective treatment, is of special significance given the great personal, social and economic costs produced by antisocial behaviour and other disorders. Large scale epidemiological studies in the US<sup>55</sup> have established that conduct problems correlate with increased numbers of these and 'externalising' disorders (eg delinquent, acting out behaviours) in later childhood and adolescence, and antisocial personality disorder in adult life (especially for men). These conditions contribute significantly to depression, suicide, substance abuse, violence and other adult disorders — and, more generally, to community dysfunction.

**4. Youth Homelessness** is often associated with deprivation, violence and exploitation and this risk is heightened if the young person is affected by mental illness. Homeless young people are frequently from disrupted families, may not

access health or mental health services, may be at risk of HIV and other sexually transmitted diseases, and may also use a wide range of drugs.<sup>56</sup> Poverty, dropping out of school and general deprivation are compounded in such circumstances. Prevention initiatives must therefore be oriented to preventing homelessness wherever possible — and ensuring a range of properly coordinated responses if it does occur.<sup>57</sup>

**5. Young people are particularly vulnerable in their early encounters with our criminal justice system.** Every effort should therefore be made to deal with the psychological issues and risk factors without resorting to incarceration — with the extremely negative results this often entails.<sup>58</sup>

Aboriginal young people may be particularly at risk in terms of both cultural deprivation and associated stresses, and their generally disadvantaged position. It is essential that special resources and programs are provided for them.

Finally, because the years of later adolescence are the time of onset for many major mental illnesses, these special vulnerabilities must be recognised and specialised prevention, early intervention and treatment approaches developed to respond to early warning signs. Opportunities exist through schools (which exert a substantial influence on many young people), health care systems and community and home-based approaches. Many programs demand a multifaceted framework — involving the young person, parents, school and community — to be really effective. Prevention will always need to take into account and support positive family attachments, and build on the strengths which the young person has.

## **Prevention and Serious Mental Illness**

Evidence before the Inquiry highlighted the suffering and disability caused by serious illnesses such as schizophrenia, bipolar disorder (manic-depressive illness) and depression. Not only do these illnesses themselves exact great costs, but the trauma involved in the illness and the responses to it may cause further adverse outcomes, such as post traumatic stress disorder or secondary depression.

Family members and carers may be so stressed that they themselves develop disorders (such as anxiety and depression) as a result of their burdens of care (see also Chapter 15). These problems show up in many ways and are further aggravated if the affected individual does not receive the earliest appropriate treatment.

As the specific causes of serious mental illness have not yet been clearly identified, it is often not possible to prevent their development. Nevertheless, as with heart disease, many contributing factors which increase risk are now understood and it may be possible, in many instances, to lessen risk by mitigating these factors. As with heart disease and cancer, early detection and treatment before the disorder becomes consolidated with ongoing disability and secondary morbidity is critical to preventing the most adverse outcomes. There is now a substantial scientific basis for early detection and intervention programs for serious mental illnesses and also for other prevention approaches. However, few such programs are currently in place in Australia.

## **Schizophrenia**

While researchers are still attempting to identify the factors that may contribute to the development of this illness, there are several areas where a preventive approach appears to be helpful.

### **Early Detection and Intervention**

Psychiatrists working with general practitioners in an English community have been able to detect the earliest signs of schizophrenia — and with education, supportive interventions and short-term psychotropic medication — prevent the onset of an episode, leading to a much lower than expected rate of schizophrenia in the area involved.<sup>59</sup> Obviously this research must be repeated and tested in different settings, including Australia, but these early findings are encouraging and warrant urgent attention. (The Early Psychosis Centre,<sup>60</sup> recently established in Melbourne, will provide the opportunity to study and work with people in the earliest stages of psychotic illness and, hopefully, prevent onset in at least some cases or promote the fullest possible recovery in others.)<sup>61</sup>

### **Prevention of Relapse and Further Episodes**

It is now well established that individualised assessment and therapy programs providing education and support, medication as appropriate, and suitable rehabilitation regimes will enhance recovery and lessen the risk of future episodes, or enable their early and effective treatment. This may include recognition of the particular 'signature' of symptoms for each person's pattern of relapse — assisting them and their families to understand and rapidly respond to such early indications.

## **Prevention of Traumatisation and Other Secondary Problems**

Many witnesses described the traumatic experiences associated with psychiatric treatment. (See particularly Chapter 8 — Inpatient Care and Treatment.)

Studies have demonstrated that many people with serious mental illness may be so traumatised by these experiences, that they develop post traumatic stress disorder. This condition has symptoms which may lead to continuous re-experiencing of the trauma, numbing and withdrawal from others, and chronically heightened levels of arousal — with disturbed sleep and concentration, hypervigilance and bouts of irritability and anger.<sup>62</sup>

Other studies have also indicated high levels of comorbidity with post traumatic stress disorder in those admitted to psychiatric care<sup>63</sup> (which may reflect illness-related, as well as other traumatisation).

Depression may also appear with awareness of changes in mental functioning and insight into illness processes or the recovery phase after the first acute episode.<sup>64</sup> Thus depression and its causes should be looked for and preventively managed, especially as it may contribute to heightened risk of suicide or to difficulties of recovery.

### *Preventive Approaches for Families and Carers*

While prevention programs for carers have not yet been studied systematically, evidence presented to the Inquiry clearly established that they often suffer severe stress and mental health problems and need education and support to prevent these (see Chapter 15).

It is essential that education, support, respite and close interaction with professionals is provided — as well as specific prevention approaches to lessen the risk of significant mental health problems for carers of people with schizophrenia or other serious illness.

### *Preventive Role of Community Organisations*

Organisations such as Schizophrenia Fellowships and ARAFMI, which are involved in community education and support of consumers and their families and carers, also have a major prevention orientation. Clearly, however, these organisations need to be adequately resourced.

# Depression and Bipolar Disorder

While the Inquiry received less direct evidence concerning depression, it is nevertheless a frequent and severe mental disorder and one associated with considerable human suffering, economic costs, general health care utilisation and increased mortality (especially from suicide). As noted earlier, it may also occur secondarily with other mental illnesses.

## *Early Detection and Treatment*

Major programs to assist in recognition and early treatment of depression are underway in the UK<sup>65</sup> and in the US<sup>66</sup> — but there have been no similar initiatives in Australia.

Overseas evidence (from the UK and especially Sweden) indicates that depression is frequently not recognised by doctors. Enhanced recognition can be achieved by better education of GPs and appropriate screening — to facilitate treatment and referral.<sup>67</sup>

A recent Scandinavian study demonstrated such initiatives could lessen levels of depression in the community and decrease suicide rates and health care utilisation.<sup>68</sup> The benefits of earlier and more effective treatment in preventing depressive suffering, and its associated human and economic costs, should therefore be actively addressed with appropriate programs in Australia.

## *Prevention of Bipolar Disorder*

Evidence has shown<sup>69</sup> that lithium has contributed very significantly to the prevention of episodes of bipolar or manic depressive illness.<sup>70</sup> Education of those affected and their families to enable them to recognise symptoms and patterns of relapse, and the need for care and treatment during an episode, can also produce more positive outcomes.

## *Prevention Programs Oriented to Life Crises*

There is considerable evidence that loss (bereavement) and other stressful events (divorce, illness, accidents, unemployment) may precipitate depression, anxiety and other psychiatric problems. A large number of preventive counselling, education and support programs have been tested and found to be effective in lessening the risk of depression in these circumstances — and increasing the likelihood of positive outcomes.<sup>71</sup>

Self-help and community organisations (eg Sudden Infant Death Syndrome Groups) have also made substantial contributions to effective prevention in this area. Clearly there should be policies and programs to help prevent depression wherever possible.

### *Prevention Related to Earlier Vulnerability*

As noted previously, children whose parents are psychiatrically ill, or suffer from depression, may be at particular risk. Those who experienced depression in adolescence may be more at risk in adult life. Parental loss, parental alcoholism, family discord, childhood separations and a range of other experiences and states (eg low self esteem) may predispose to depression in adult life. Prevention programs should therefore aim not only to care for and support vulnerable children, but to lessen their vulnerability to depression in later life.<sup>72</sup>

Post natal depression may also increase vulnerability — and like all adult problems which potentially impact on children, should be rapidly and effectively treated.

### *Post Traumatic Stress Disorder (PTSD)*

Although not canvassed widely in evidence to this Inquiry, PTSD is a frequent and severely disabling condition, affecting at least 1 percent of the community and 15 percent or more of those who have been severely traumatised<sup>73</sup> (and often also complicating other disorders). Prevention approaches range from preventing trauma and violence in the first place, to the provision of debriefing, counselling and other brief interventions, education, and treatment programs. Self-help organisations (ranging from Victims of Crime Associations to the Vietnam Veterans' Counselling Services) have all made a positive contribution in this context.<sup>74</sup>

## **Groups Which Are Particularly Vulnerable**

Prevention programs for groups which are particularly vulnerable should address relevant social contexts, and associated factors (such as disadvantage and stigma) where they exist. They should also develop preventive strategies to ameliorate particular risks for the group involved.



## **Elderly People**

While there are some preventable dementias, (those related, for instance, to folate deficiency and dementia associated with vascular disease can be treated and dementia outcomes prevented) our current state of knowledge does not provide opportunities for prevention of conditions such as Alzheimer's disease, which is responsible for most dementia related morbidity in the elderly. (See Chapter 17 — Elderly People.)<sup>75</sup> There is, however, considerable evidence to suggest that in the early stages people experiencing dementia may be distressed by the changes in their mental functioning and may also experience depression and anxiety, so that supportive management (addressed in Chapter 17) may help to prevent these secondary problems, even though not preventing dementia itself.

As established earlier in this report, depression may be confused with dementia, or may not be diagnosed in the elderly and thus not adequately addressed. Effective early intervention with older people experiencing a depressive episode in relation to life stresses such as bereavement, or stroke, may prevent chronicity and assist recovery.

Carers of the elderly, frequently daughters or women relatives, but also husbands of elderly women with dementia, are likely to be highly stressed by the burden of care. Preventive programs involving information, education and support have been demonstrated to be effective in diminishing the risk of psychiatric morbidity in those caring for dementia patients,<sup>76</sup> as has institutional care where dementia is severe.<sup>77</sup> (Burdens on professional carers also need to be addressed with programs to prevent burnout.)

Supportive counselling through later life transitions such as bereavement<sup>78</sup> and illness is likely to prevent psychological morbidity, such as anxiety or depression, which are common for elderly people in these circumstances.

Another issue creating morbidity in the elderly is the often excessive and prolonged prescription of psychoactive drugs, which may lead to states of confusion, falls and other injuries. Education of general practitioners, physicians and others who care for the elderly is a critical aspect of prevention in this area.

In summary, much distress and suffering among elderly Australians can be prevented — if their needs and rights are properly recognised and responded to.

## **Homeless People**

As noted in Chapter 18, the homeless are transient and unlikely to receive proper and continuous care (including appropriate medication). They are also vulnerable to violence, physical health problems and suicide. They may be young, sexually abused, involved in prostitution or injecting drug use, and suffer stigmatisation and discrimination for all these reasons.

Accommodation, crisis support, access to appropriate mental health services (community and inpatient) and rehabilitation are essential. (Within this group, young people, women and children, and Aboriginal adolescents may have additional special needs, as may non-English speaking background youth.)

Homelessness itself is so stressful that it is likely to add significantly to the disturbance and suffering of the mentally ill. Conditions in shelters and refuges may exacerbate mental disorders. Further problems arise because there is often a denial of the extent of homelessness, as well as the needs of the homeless — because bureaucracies are not geared to deal with the homeless, nor the homeless to interact with them. As indicated in Chapter 18, many of those directly involved with homeless people do not understand mental illness or do not have adequate staff or resources to address it. Poverty and alienation further afflict this group, and difficult economic and social conditions often add to their burdens.

Homelessness and mental illness are causally interrelated — so prevention programs addressing the former will have some impact on the latter.

## **Women**

Chapter 19 outlines special aspects of vulnerability for women with respect to mental health. Broad issues such as gender inequity may well contribute to low self esteem, the higher rate of depression experienced by women, and violence. While the women's movement, anti-discrimination legislation, affirmative action and equity policies have attempted to address these issues, a great many aspects of inequity are internalised in values and social structures and are resistant to change. Whether changes will prevent adverse mental health effects remains to be demonstrated. Nevertheless, addressing equity should be a central consideration in prevention — because of its profound and pervasive effects on mental wellbeing.

Poverty disadvantages both women and their children — with negative effects for the mental health of both. Single parent households constitute a particular group with special needs, and there is evidence of effective preventive

programs<sup>79</sup> which may lessen the risk of mental health problems in some circumstances. However, these should only be seen alongside appropriate social action to redress issues such as poverty and associated adversities (including poor access to education, health and housing).

Another important factor for women is their psychiatric vulnerability as a consequence of a past history of abuse and their vulnerability to abuse by treating therapists or within a health care system.<sup>80</sup> Continuing education, strict professional standards and review and more effective complaints mechanisms may help reduce the latter; but, as noted earlier, prevention of child abuse and its enduring consequences must be acknowledged as one of the most serious challenges facing our society.

Programs to enhance detection and management of domestic violence when people affected present to health care systems are currently under way<sup>81</sup> and, if persevered with, should lead to better health and mental health outcomes for women in such circumstances.

As noted earlier, women may experience psychiatric disorder as a consequence of violence (for instance post traumatic stress disorder following rape). Available evidence suggests that 97 percent of women do so in the first month and 47 percent even six months later.<sup>82</sup> There is also evidence that preventive counselling may be effective in preventing such outcomes.<sup>83</sup> It is critical, then, that women who need them have access to such programs, that they are not labelled as mentally ill when showing a normal stress reaction to such trauma, and that prevention programs are provided so that long-term morbidity is avoided.

Also mentioned previously, the risk of post natal depression is increased by stress during pregnancy or delivery, depressive symptoms during pregnancy or a past history, and other factors unique to particular women, including non-supportiveness or absence of a partner. Not only are women at risk in the post natal period, but their personal relationships may be substantially damaged, as may the development of their child. Preventive programs should increase support through pregnancy and the post partum period, and enhance the skills of those looking after the woman and her baby to detect this illness in its earliest stages and provide effective treatment. The role of self-help and support groups such as PaNDa is extremely important.

As noted in Chapter 19, women also run the risk of being diagnosed as neurotic when they are not, or being prescribed tranquillisers rather than receiving appropriate assessment and counselling to deal with, for example, environmental stressors which they experience. Women also perceive themselves as being

labelled dysfunctional because they do not conform to certain social and sex role stereotypes. Preventive programs should be developed to ensure prevention counselling, stress management, social network development and support, self-care, relaxation and assertiveness skills. There is substantial evidence of the effectiveness of such interventions in lessening women's risk of psychiatric disorder.<sup>84</sup>

### **People with Dual or Multiple Disabilities**

Effective preventive programs for people with dual or multiple disabilities necessitate recognition of comorbidity in groups such as those with intellectual disability and mental illness, substance abuse and mental illness, deafness and mental illness, head injury/brain damage and mental illness, and HIV/AIDS and mental illness. Early detection and diagnosis, as well as treatment taking into account the multiple issues involved are critical. Involvement and effective coordination of relevant services is essential to achieving such goals.

### **Forensic Patients**

As indicated in Chapter 25, many factors may contribute to patients entering forensic facilities. The forensic system also creates stresses for patients which may increase their mental health problems.

Untreated mental illness, despair and demoralisation may be so profound that suicide results. Trauma and violence may compound psychiatric problems and substance abuse is also frequently a problem.

To be effective, preventive programs need to address both the service aspects (such as provision of specialised mental health assessment and treatment at the earliest opportunity) and particular strategies for those with 'high risk' indicators (such as young Aboriginal people). Policy reforms are necessary to ensure rights to treatment for those in prison or in police custody.

Because of the special factors which affect Aboriginal people, prevention must involve community based-programs which prevent incarceration wherever possible and draw on traditional laws and cultural advantages, where appropriate, to deal with antisocial behaviours. Particular programs to assess risk, ensure support and if necessary treatment, are essential to prevent suicide deaths in custody.<sup>85</sup>

Skills, knowledge and the attitude of police and correctional staff need to be addressed, as well as ensuring access to care and rehabilitation after release.

In addition, it is essential to ensure that youth-oriented programs operate to assess and manage mental health problems or disorders from the earliest stages — to prevent young people entering the criminal justice system and provide alternative programs to imprisonment. This is likely to lessen the risk of chronicity, reoffending and mental illness resulting from imprisonment.

## **Prevention and the Mental Health Care System**

As has been chronicled throughout this report, people who are at risk of or suffering from mental illness may be adversely affected by the system of care itself. The training and expertise of the professionals who care for them, the compassion and empathy with which they are assessed and treated, the quality and range of programs provided will all affect the extent to which their rights are respected. But our systems must, at a minimum, reflect policies and programs which ensure that they do not exacerbate mental illness and operate in the true traditions of care 'first not to harm'.

## **Conclusion**

Prevention programs are not simple — but if carefully designed and appropriately resourced they have the capacity to prevent or significantly diminish the suffering associated with mental illness for many of those affected and their families. It is, therefore, essential that they become an integral part of our mental health care system.

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# Chapter 28

## ACCOUNTABILITY

### Introduction

There is an impressive array of statutory mechanisms to protect and maintain the human rights of people with mental illness in Victoria; yet there is still no doubt that their rights are still contravened, and that the channels of redress are under-used by people with mental illness who have legitimate grievances about these contraventions.<sup>1</sup>

The human rights violations perpetrated in our three most populous States in relatively recent times — including those at Chelmsford Hospital in NSW, Ward 10B of Townsville Hospital in Queensland, Lakeside Hospital in Victoria and elsewhere — have demonstrated the urgent need for appropriate mechanisms to prevent such abuses and provide an effective means of intervening if they do occur.

Inquiries which were set up to investigate these institutions and others have recommended fundamental changes. Recently there has been a great deal of activity, at both institutional and governmental levels, directed at achieving quality control in the delivery of mental health services.

The National Mental Health Policy, launched by the Australian Health Ministers' Conference in May 1992, recognises the importance of developing national standards for mental health services and methods of assessing whether these standards are being met. The Policy also accords priority to the implementation of quality assurance programs; the development of protocols for clinical treatment by professional bodies; the accreditation of mental health facilities; and the development of nationally agreed measures of performance in relation to each of these areas.

The way these commitments are to be implemented is detailed in the National Mental Health Plan. By endorsing the Plan (subject to Commonwealth financial contributions), State and Territory Health Ministers agreed to provide the information required to enable program monitoring; to establish national service standards; and to develop a strategy for nationally consistent mental health data.

The establishment of effective controls and safeguards in the provision of psychiatric services is critically important. Because of the unique nature of these services it is also particularly problematic. Unlike other patients, mental

health consumers may be deprived of their liberty. Even without involuntary detention, the identification of a person as mentally ill still has a profound impact on all aspects of their lives — in a way that diagnosis of most physical illness does not. Psychiatrists are perceived as more powerful than other doctors in that they deal with people's minds.

## Quality Assurance

The term 'quality assurance' is sometimes used in a very general sense to cover most aspects of control and monitoring of the quality of services. For example, a submission to the Inquiry from the WA Branch of the Association of Social Workers defined the main components of quality assurance as:

- professional supervision
- performance management (both professional and administrative)
- accountability
- professional development
- staff orientation
- peer review
- criteria audit
- service review
- statistics and data collection
- specialist practice consultancy.<sup>2</sup>

In other contexts the term is used to refer more specifically to the clinical process of peer review.<sup>3</sup> However, the Inquiry found the most useful definition of quality assurance was that provided in the most recent edition of the Australian Council on Healthcare Standards (ACHS) *Accreditation Guide*:

[Quality assurance is a] formal process whereby the quality and appropriateness of patient care and/or departmental performance is documented and evaluated by the professional group responsible or within a multi-disciplinary team. The process involves a planned and systematic approach to monitoring and assessing the care provided, or the service being delivered, which identifies opportunities for improvement and provides a mechanism through which action is taken to make and maintain improvements. There should be regular feedback of the results of quality assurance activities to the appropriate personnel.<sup>4</sup>

Submissions to the Inquiry from State and Territory Governments indicated widespread support for quality assurance programs and activities — in principle. They did not, however, discuss the actual content of these programs in any detail. Although this can be partly attributed to the early stage of development of such programs, it also reflects the fact that responsibility for

developing programs and activities has been devolved to regional or even institutional levels.

In Queensland, for example, in 1992 a quality assurance coordinator was appointed for each region. The coordinator (or coordinating committee) is responsible for identifying all services in the region and developing minimum service standards for each of them.

In New South Wales, quality assurance activities are coordinated at an institutional level. According to its 1991-92 Annual Report, Rozelle Hospital, for example, has implemented a comprehensive series of quality assurance activities — ranging from a survey of ethnic access and review of medical prescriptions to an evaluation of boarding house accommodation services for people with mental illness in the Central Sydney Health Service and surveys of nursing activities and of occupational stress among psychiatric nurses.

Over a decade ago, the Royal Australian and New Zealand College of Psychiatrists was funded by the Federal Department of Health (as it then was) to undertake the 'Quality Assurance Project'. This involved an extensive review of the relevant literature and consultation with practising psychiatrists and an expert committee. Detailed sets of criteria were developed for optimal individual clinical care in relation to each major psychiatric disorder. These comprehensive 'treatment outlines' were intended to be used in peer review processes and as sources of information, both for health planners and the wider community, concerning treatment options in current psychiatric practice. A discussion of the rationale and methodology of the Quality Assurance Project and the treatment outlines for each illness were published in a series of articles in the *Australian and New Zealand Journal of Psychiatry* between 1982 and 1985. The Inquiry was informed that the profession's involvement in the Project meant that the criteria were regarded as influential guidelines.<sup>5</sup>

The Australian Council on Healthcare Standards, in revising its *Accreditation Guide* for use by health care facilities, included in its 6th edition (1988) a new standard for every category of health care facility. This standard (entitled 'Quality Assurance Program') called for the monitoring and evaluation of both clinical and non-clinical activities. In the current edition of the ACHS guide, quality assurance, in addition to constituting one of the standards for each category of facility, is discussed at some length.<sup>6</sup> The term is defined (see above), and the process of surveying the quality assurance standard is set out in some detail.

## Standards

The quality of services can be measured in different ways. Both minimum and optimum standards are used — and varying degrees of prescription or sanction are attached to them. The most clearly prescriptive are those provided by legislation. Compliance with other standards, such as those laid down by the Australian Council on Health Care Standards, may be voluntary — but may still have significant consequences for funding or for issues such as attracting quality staff.

Some of the most comprehensive standards for mental health services were published in 1991 by the NSW Department of Health a booklet entitled *Standards of Care for Area Integrated Mental Health Services (AIMHS)*.<sup>7</sup> These standards were developed after consultation with experienced mental health professionals and representatives of consumer, family support and voluntary care organisations and they are expected to evolve to meet changing needs and circumstances.<sup>8</sup>

Most importantly, they focus on outcomes for service users and care givers, moving from initial contact and assessment through to long-term follow up. They are designed for use, both by service providers and consumers, as a guide to the provision of quality services and as a check-list of the kinds of services that should be available at any particular stage of mental health care or treatment.

Other initiatives have recently been taken to develop standards for mental health services — including several since the Inquiry was announced — by Federal, State and Territory governments, regional or area health administrations and voluntary bodies.

In October 1991 the Chief Executive of the Northern Territory Department of Health and Community Services approved the *Northern Territory Mental Health Care Standards*, prepared by the Northern Territory's Mental Health Services Quality Assurance Committee after consultation with clinical staff throughout the Territory. These standards consist of general statements of principle (relating to matters such as organisation and administration, staffing, patient care, facilities and equipment, and quality assurance) accompanied by specific criteria describing who is to perform the initial assessment of patients; how this is to be recorded; and the way in which individualised treatment plans are to be documented. The criteria for these standards require monitoring, assessment, evaluation and feedback to staff as well as regular reports to senior manage-

ment. There do not appear, however, to be any particular sanctions attached to non-compliance with these standards.

In March 1990, the Mental Health Services Unit of the New South Wales Health Department published *Guidelines for Psychiatric Inpatient Services*, based on the resolutions from a seminar on quality assurance for inpatient services. Although compliance is not mandatory, the guidelines are 'strongly endorsed' by the Mental Health Services Unit. They set out the desirable standards in relation to matters such as the availability of psychiatric consultants and review procedures, monitoring of medication, handling and monitoring of ECT and the establishment of quality assurance committees.

The Federal Department of Health, Housing, Local Government and Community Services has taken a more prescriptive approach by requiring nursing homes (since July 1987) and hostels (since January 1991) to comply with standards in areas including health care, social independence, freedom of choice, home-like environment, privacy and dignity, variety of experience and safety, as a condition of Commonwealth funding. Compliance is monitored by the Department and inadequate performance can result in the withdrawal of Commonwealth funding.

The national service standards to be developed and introduced in accordance with the National Mental Health Plan, endorsed by the Health Ministers' Conference in April 1992, will presumably also be linked to funding.

The Australian Council on Healthcare Standards provides an annually updated guide containing detailed standards for a wide range of specific health services, including, since the late 1980s, psychiatric services. While adherence to the ACHS standards is purely voluntary, they do form a basis on which facilities are surveyed for the purpose of accreditation. (The accreditation process is described in more detail below.)

During the second half of 1992 a subcommittee of the Royal Australian and New Zealand College of Psychiatrists' Quality Assurance Committee, in conjunction with the ACHS Care Evaluation Program, began to field-test a range of clinical standards, referred to as *Clinical Indicators for Psychiatry*. The test, which is being conducted in fifteen hospitals around Australia, is designed to establish what data are required to facilitate the application of these indicators and whether they are acceptable to health providers as reasonable measures of their performance. Based on the results, the clinical indicators will be further modified before becoming a regular part of quality assurance processes in hospitals and the accreditation process used by the ACHS.

Standards of psychiatric care are also governed by legislative criteria. The disparate mental health laws and regulations in each State contain a variety of provisions relating to the admission, treatment and discharge of patients or the procedures associated with involuntary detention that may be regarded as minimum standards. (These provisions are discussed in some detail in Chapter 4 of this report.)

Other relevant standards are prescribed in legislation relating to the administration of health services and the management of private hospital and health care facilities (in those jurisdictions where such legislation exists).<sup>9</sup>

Following the exposure of abuses of patients' rights at Chelmsford Private Hospital, NSW enacted the *Private Hospitals and Day Procedure Centres Act 1988*, establishing stringent provisions for the maintenance of standards at such facilities. The Act requires private hospitals and day procedure centres to be licensed, and specifies that standards for patient safety, care, quality of life and the quality and conduct of services may be prescribed by regulation. The Private Hospitals Regulation (NSW) 1990 contains detailed provisions in relation to staffing, facilities and equipment, record keeping, clinical standards, professional accountability and quality assurance procedures. Under this Regulation, each private hospital must also elect a medical advisory committee to advise the licensee in relation to the accreditation of practitioners providing services at the hospital and other matters concerning clinical practice or patient safety.

## Peer Review

Everyone seems to be talking about peer review, but no one is able to say exactly what it means.<sup>10</sup>

Peer review is a process involving assessments by clinical colleagues of one another's handling of cases. There are no universally accepted parameters. Nor is it clear what, if any, sanctions exist for clinicians who do not participate in such a process or for those whose handling of cases is found to fall below acceptable standards. Indeed, even the question of what standards are to apply will usually be a matter for agreement among the participants.

## Monitoring

By the middle of this century the principle was established that the State was responsible for the maintenance of standards of medical and hospital practice in the community. There were commissions, boards, committees and other statutory bodies which had both the power and the duty to do so. This position had arisen partly because historically the

profession had shown no great enthusiasm for regulating itself and partly because it had no power to do so.<sup>11</sup>

A number of mechanisms for inspecting and monitoring standards of care in psychiatric facilities have been discussed earlier in this report.<sup>12</sup> In most States and Territories powers of inspection and investigation apply only to hospital facilities. In Victoria, however, they extend to all psychiatric services, including community support services, premises licensed for the administration of ECT, general or private hospitals providing psychiatric treatment and any mental health service provided by a community health centre or psychiatric out patient clinic.

In Victoria, a major monitoring exercise in the form of an *Audit of Treatment and Care in Psychiatric Hospitals in the State of Victoria* was announced by the Minister for Health shortly after the Inquiry began (in April 1991) — following an investigation into Lakeside Hospital. The audit, which reported in March 1992, represents a major, one-off review of clinical practices and standards of patient care in all public psychiatric hospitals in Victoria.

The audit was conducted by a team of five health professionals under the leadership of the Director of Psychiatric Services, assisted by ten senior academic psychiatrists. The team visited 19 hospitals, inspecting physical facilities, minutes of meetings, manuals of policies and procedures and patient case files; and interviewing managers, other staff and patients.

The audit team found that although the State Office of Psychiatric Services had developed written standards for psychiatric nursing, rehabilitation, ECT and general inpatient services; and although quality assurance programs had begun in all but two of the hospitals surveyed, there were still major gaps. The team recommended that the Chief Psychiatrist develop written standards for the management and discharge of patients and for consultation and collaboration between clinical staff and patients, families and carers.

Since the Inquiry began, Queensland has also instituted an audit of all psychiatric facilities, including private facilities, to which involuntary psychiatric patients may be admitted. The objective is to evaluate these services according to the requirements of its *Mental Health Services Act* and regulations. The Federal Department of Health, Housing, Local Government and Community Services has a Standards Monitoring Team, responsible for checking on compliance by hostels and nursing homes with the standards relating to health care, social independence, freedom of choice, privacy, dignity, variety of experience and safety. Action can be instigated for consistent non-compliance and Federal funding can be cut.



Monitoring also forms part of the National Mental Health Plan launched in conjunction with the National Mental Health Policy in 1992. An annual system of reporting progress in implementation of the policy should commence in 1993. The procedures and format are not yet clear. However, it is proposed that all State and Territory governments and the Commonwealth Government will provide 'agreed data', to be collated by the Commonwealth and published as a National Report on Mental Health.

## Accreditation

It is my direct knowledge that a number of psychiatric catastrophes would not have occurred had accreditation been sought.<sup>13</sup>

Accreditation is an evaluation process which accords formal recognition to an institution or individual that complies with defined standards of service and care. Clearly, the accrediting body must have some public standing and, preferably, independence.

Australia's primary hospital accreditation body, the Australian Council on Healthcare Standards, was established in 1974 by the Australian Medical Association and the Australian Hospitals Association with the aim of improving quality of patient care in Australian hospitals. Since that time the Council's scope has expanded to include community health and day procedure facilities. Specific standards for psychiatric services were only developed in the late 1980s.

The process of accreditation by ACHS involves documentation of all services and programs. A survey is then conducted by a team of experts (usually including an administrator, a doctor and a nurse) which visits the facility and recommends to the Council whether it should be accredited. Facilities have a right of appeal against a refusal of accreditation. Accreditation may be granted for periods between one and five years.

Community health centres may also seek accreditation by the Community Health Accreditation Standards Project (CHASP) which provides a comprehensive set of standards. Piloted in NSW and Queensland, and now operating on a national basis, this accreditation process is similar to that conducted by ACHS.

Many witnesses, including one expert witness,<sup>14</sup> suggested that psychiatric practice should be subject to more rigorous accreditation procedures. At present the Royal Australian and New Zealand College of Psychiatrists (RANZCP) provides a form of accreditation in that it confers fellowships on those medical

practitioners who satisfy prescribed standards of training and expertise. Advocates of accreditation argue that this should be extended (to cover areas of sub-specialisation, for example) and associated with a differential fee structure. This system could apply not simply to individual practitioners but to practices conducted by one or more psychiatrists at a given facility or location. (Other aspects of the training and continuing education of psychiatrists and other mental health professionals are dealt with in Chapter 6.)

The RANZCP has recently reviewed its structure and processes to improve the profession's response to the accreditation of clinical standards.<sup>15</sup> The College has upgraded its Clinical Standards Committee and established a new Quality Assurance Committee. These, together with the existing Ethics Committee and a newly formed Continuing Education Committee, will jointly constitute the Practice Standards Board.<sup>16</sup>

The RANZCP published its first Code of Ethics after the Inquiry began — in August 1992. These are principles serving as a guide to good professional conduct — rather than clinical guidelines like the treatment outlines developed by the Quality Assurance Project. The principles deal with matters such as respect for 'the essential dignity and humanity of patients' and the need to obtain consent before undertaking any procedure or treatment.

## **Professional Registration**

Medical practitioners, nurses and certain other health professionals are subject to statutory requirements of registration in each State and Territory and may be deregistered according to procedures laid down in the relevant legislation. The role that can be played by specialist bodies in bringing cases to the relevant professional disciplinary tribunals or even prosecuting alleged misconduct is discussed below under Complaints Mechanisms.

## **Official Visitors**

The scheme of official visitors or community visitors has been addressed previously (see Chapter 4 — The Legal Framework and Chapter 8 — Inpatient Care and Treatment). Their functions and powers differ from State to State. In Victoria the scheme covers both general and psychiatric hospitals, and in NSW it extends to private psychiatric hospitals. In Queensland and Western Australia, however, official visitors are limited to public psychiatric hospitals. The other States and Territories have no statutory provision for official visitors.

There is also a Community Visitors Scheme developed by the Federal Department of Health, Housing, Local Government and Community Services to monitor residents' rights in nursing homes and hostels that receive federal funds.

## Patient Rights and Patient Advocacy

When you enter a psychiatric hospital you leave all your basic rights on the doorstep.<sup>17</sup>

In Victoria and the ACT legislative provision has been made for Government funded advocates to represent the interests of people with disabilities — although the fact that the *Community Advocate Act* in the ACT makes specific reference to representation for forensic patients has been interpreted as limiting the Community Advocate's functions in relation to people with mental illness generally. By contrast, the Office of the Public Advocate established under the Victorian *Guardianship and Administration Board Act* has established specialist mental health advocacy positions. The powers of the Victorian Public Advocate include representation or advocacy on behalf of people with disabilities and reporting on relevant recommendations to the Equal Opportunity Board. (However, as with other arrangements addressed in this chapter, the reality from a human rights standpoint is critically influenced not only by legislative prescription but by the resources which are actually available.)

Advocacy is, importantly, also provided by community based and self-help groups funded (often inadequately) under Commonwealth and State Disability Services Acts. These groups mainly engage in lobbying, providing representation and support for individual clients and conducting community education programs.

Since the Inquiry began, recognition of the rights of consumers and people in the community affected by mental illness has improved at several levels — if statements of rights and principles can be taken as any reliable guide.

The ACHS Accreditation Guide now includes a statement of patients' rights and responsibilities. The Australian Health Ministers' Advisory Council adopted the *Charter of Consumer Outcomes* in March 1991 as the *Mental Health Statement of Rights and Responsibilities*. However, these have no direct sanctions attached. The Charters protecting the rights of residents in nursing homes and hostels (discussed in Chapter 17) are reflected in the standards by which the performance of these institutions is measured (see section above on Standards) and the National Service Standards for the Home and Community Care Program are based on the Statement of Rights and Responsibilities for HACC

consumers.<sup>18</sup> The National Service Standards to be developed in accordance with the National Mental Health Plan will presumably be based on the Mental Health Statement of Rights and Responsibilities.

In Victoria, NSW, South Australia, Queensland and, to a more limited extent, in the ACT, there are statutory requirements for statements of rights to be made available to those subject to involuntary detention. No such provisions exist in Western Australia, Tasmania and the Northern Territory. Evidence to the Inquiry clearly indicated, however, that even where they exist, statutory rights are not always observed in practice.

The Queensland *Health Rights Commission Act* 1991 requires the Health Rights Commissioner, within three years of the commencement of the Act, to develop a Code of Health Rights and Responsibilities for consideration by the Minister. In developing this Code, the Commissioner is required to consult with the Health Advisory Council, consisting of representatives of the interests of service providers and users.

In Western Australia, a Working Party commissioned by the Minister for Health to examine the rights and responsibilities of health care consumers proposed a Charter of Patients' Rights. This Draft Charter, published in 1991, has been a reference point in the process of drafting new mental health legislation in that state. The Western Australian Government has also involved consumer groups in planning, development and evaluation of policy and services. A Mental Health Interest Group forms part of the Health Advisory Network, which advises the Minister for Health, and a Consultative Forum for non-government organisations is intended to facilitate discussion of issues relating to consumers and non-government service providers.

Prior to hearings conducted by the Inquiry, a statutory provision in the ACT for a Mental Health Advisory Council (consisting of representatives of non-government organisations, service providers and administrators) had been allowed to lapse because of difficulties in relation to the roles of different interest groups. In September 1992, however, the ACT Government announced the creation of a new Mental Health Advisory Council comprised entirely of representatives of mental health consumers and non-government carer organisations.

## **Complaints Mechanisms**

Victoria and Queensland have independent statutory Commissioners with powers to investigate and conciliate complaints.<sup>19</sup> In NSW, South Australia

and the ACT there are specialist units established at an administrative level to handle complaints from consumers.

Evidence to the Inquiry established that individuals who are, or have been, receiving treatment for mental illness may experience a number of perceived and real difficulties in accessing the processes of these professional disciplinary bodies. A solution to some, though by no means all, of these difficulties is provided in NSW by giving the Complaints Unit, established by the Health Department, power not only to investigate cases but also to prosecute them before the relevant professional body. The Victorian and Queensland Commissioners refer matters not resolved by conciliation to the relevant registration board without taking an adversarial role.

However, Tasmania, Western Australia and the Northern Territory have no specialised mechanisms for handling complaints. This is a problem for several reasons. In addition to their role in handling individual complaints, specialist units perform an important function in monitoring the overall standards of service provided and identifying problem areas.

In theory, it is open to anyone to bring an action in the courts for medical negligence, assault, battery, trespass to the person, false imprisonment or any other action recognised by law. In Tasmania the *Mental Health Act 1963* actually imposes a legal barrier to someone wanting to institute legal proceedings under that Act against a service provider, requiring leave of the Supreme Court before the action may proceed.<sup>20</sup> While this provision is unique, it highlights the disadvantages that consumers of mental health services face more generally in pursuing legal action. They may, for some period of time, lack capacity to bring proceedings. However, even when capable, they may be faced with grave difficulties of proof in relation to prejudices about the credibility of their own evidence and that of others who might corroborate it. These problems are in addition to those that face any individual who contemplates legal action of any kind<sup>21</sup> and, in particular, against a member of the medical profession.

## Conclusion

There is, at least in theory, a plethora of controls and safeguards in the mental health area. However, there are no uniform, national guarantees of individuals' rights — nor are there adequate mechanisms to ensure basic rights are properly protected. Recent initiatives include legislative measures as well as reforms of administrative and clinical practice. However, all these mechanisms require adequate resourcing if they are to operate effectively.

1. Dr Ian Siggins, (then) Health Services Commissioner, Victoria. Submission, p1.
2. Maria Harries, President, Western Australia Branch of the Australian Association of Social Workers. Submission, p3.
3. See, for example, the discussion of quality assurance, and in particular the quality assurance program at Northside Clinic, in Chapter 9 of the Honourable Mr Acting Justice JP Slattery's *Report of the Royal Commission into Deep Sleep Therapy*, Vol 13, Term 2, pp234-240.
4. Australian Council on Healthcare Standards *Accreditation Guide*, 11th edition, p12a.
5. Dr John Ellard, Director, Northside Clinic. Oral evidence, Sydney 17.6.91, p72. Also see Professor Gavin Andrews, Professor of Psychiatry, University of NSW and Director of Health Services Research Group, Clinical Research Unit for Anxiety Disorders, St Vincent's Hospital, Sydney. Oral evidence, Sydney 17.6.91, p45.
6. In the preamble to the standards.
7. A Rosen, V Miller and G Parker, *AIMHS Standards: Area Integrated Mental Health Standards Project*, Sydney, 1990.
8. id.
9. See the analysis of Federal, State and Territory legislation contained in the Human Rights and Equal Opportunity Commission's Background Paper, *Mental Health Legislation and Human Rights*, December 1992.
10. Dr Peter Wurth, letter to the editor, *Australian and New Zealand Journal of Psychiatry*, Vol 26, No 4, December 1992, p688.
11. John Ellard, 'Chelmsford and After', *Modern Medicine*, August 1990, p87.
12. See Chapter 4 — The Legal Framework.
13. Ellard, 'Chelmsford and After', op cit, p92.
14. ibid, pp91-93; also see *Report of the Royal Commission into Deep Sleep Therapy*, op cit, p236.
15. Ellard, op cit, p95.
16. id.
17. Sara Hutchings, 'Hearing Users' Voices', *Openmind*, v41, Oct/Nov 1989, p17.
18. See Chapter 5 — Mental Health Services and Chapter 9 — Community Care and Treatment.
19. See Chapter 4 - The Legal Framework.
20. This point is examined in more detail in the Human Rights and Equal Opportunity Commission's Background Paper on *Mental Health Legislation and Human Rights*, op cit, p93.
21. It has recently been estimated that the cost of pursuing an action in the District or County Court in most states now exceeds \$40,000 and in the Supreme Court \$60,000. This places litigation beyond the means of the vast majority of Australians affected by mental illness.

## Chapter 29

# LEGISLATIVE PROPOSALS

### Introduction

In most jurisdictions mental health legislation has been under review during the course of the Inquiry, and in several States discussion papers or reports proposing reforms have been distributed. However, only South Australia and Western Australia have released draft bills. South Australia actually introduced its Mental Health Bill and Guardianship and Administration (Mental Capacity) Bill into the lower house in May 1992 — although these had not reached the second-reading stage at the time of writing.

This analysis of proposed legislation<sup>1</sup> does not include discussion papers or reports of legislative review committees or working parties. These, by definition, are liable to change in the processes of consultation and formulation of legislation. Moreover, it has been the experience of this Inquiry that discussion papers and other recommendations for reform of mental health legislation have frequently failed to produce tangible changes. Indeed, so low is the priority accorded to those affected by mental illness that even passage of legislation by Parliament has sometimes been ignored, or its effect postponed, by the Government of the day.<sup>2</sup>

### South Australia

The South Australian Mental Health Bill 1992 does not represent a complete review of the existing *Mental Health Act 1977*. It is the result of changes arising from the separation of the guardianship provisions (dealt with later in this section in the context of the Guardianship and Administration Bill 1992 — together with a limited number of amendments to other provisions).

The definition of mental illness remains unchanged — as do most of the criteria and procedures for involuntary detention. The statutory objectives are not significantly altered, apart from the removal of references to mental handicap and the inclusion of bodies such as the Guardianship Board, and individuals such as directors of approved treatment centres, among those responsible for observance of the objectives. A new position of Chief Adviser in Psychiatry is created by the Bill and provisions relating to the approval of hospitals are broadened to extend to treatment centres.

One new section expressly authorises the involuntary detention of patients admitted on a voluntary basis. The procedures for involuntary detention under the Bill allow for a second order for detention for 21 days before an order for continuing detention (for up to a year) is made. The criteria for continuing detention have been expanded. While the only express requirement under existing law is that further detention of an involuntary patient be considered necessary for the protection of others, the Bill requires, in addition, that the person continue to suffer mental illness and specifies that the patient's own interests may be considered as a criterion for continued detention. Otherwise, involuntary admission criteria are as in the current Act and fall short of the standards set by the UN Principles in that the terms 'in the interests of his or her safety' and 'for the protection of other persons' are very broad and there is no requirement that involuntary detention be the least restrictive alternative.<sup>3</sup>

In contrast to the existing legislation, the Mental Health Bill contains explicit provisions governing administration of psychiatric treatment — distinguishing between cases in which it is permissible to treat without consent and those requiring informed consent. The Bill does not deal with the position of voluntary patients with respect to consent to treatment.

The Bill also stipulates that patients detained for maximum periods of 3 or 21 days, including those detained for a second period of 21 days, may be given treatment despite the absence or refusal of consent. (This does not include ECT or psychosurgery which, as in the existing Act, are subject to special constraints.)

For patients detained for longer periods under continuing detention orders, the Bill requires that treatment be authorised by the Guardianship Board, except in cases where the nature of their mental illness is such that treatment is urgently needed for the protection of the individuals concerned or others; or where in the circumstances it is not practical to obtain authorisation.

The Mental Health Bill makes limited changes to the existing powers of the police to apprehend individuals they believe to be suffering from mental illness. The only significant amendments relate to removing police powers to apprehend someone apparently suffering mental illness whose behaviour is such as to endanger life or property, and to break and enter premises using such force as is reasonably necessary. Powers retained in the Bill permit police to apprehend, with any reasonably necessary force, those believed to be suffering mental illness if their conduct is or has recently been such as to cause danger to themselves or others.



The Bill abolishes the Mental Health Review Tribunal but gives enhanced rights of review to the Guardianship Board which, under the cognate Bill<sup>4</sup>, is reconstituted to include a specialist mental health division. This eliminates the existing overlap between these two bodies. The Bill also provides for review with fewer limitations than required by existing provisions — and with improved procedural safeguards. These include the right to representation before the Guardianship Board (at present only guaranteed in the Tribunal or Supreme Court) and an obligation on the Board to provide a written statement of the effect of any decision or order and rights of appeal.

The Guardianship and Administration Bill reconstitutes the Guardianship Board and establishes a new office of the Public Advocate.<sup>5</sup> The functions of the Public Advocate are: to keep under review programs provided in both the public and private sectors for 'mentally incapacitated persons'; to identify areas of unmet need and promote the development of programs; to speak for and promote the rights of 'mentally incapacitated persons'; to advise on rights under the Act and to monitor the administration of the Act. The Public Advocate may also act as guardian where there is no other suitable person.<sup>6</sup>

In addition, the Bill confers on the Public Advocate duties and extensive coercive powers of investigation in cases where the Guardianship Board is likely to make orders for guardianship or administration of property. In the course of such investigations, the Advocate is empowered, after obtaining a warrant from the Board, to forcibly remove to a place approved by the Minister of Health anyone believed to have a mental incapacity who is being held against their will or treated in a manner likely to jeopardise their safety, health or welfare.

Mental incapacity is defined in the Bill as inability to look after one's own health, safety or welfare as a result of either 'any damage to, or any illness, disorder, imperfect or delayed development, impairment or deterioration of the brain or mind' or 'any physical illness or condition that renders the person unable to communicate his or her intentions or wishes in any manner whatsoever'.

The Bill specifies principles to be observed in its administration. These include according paramount consideration to what the decision maker considers would have been the person's wishes if it were not for their incapacity; and consideration and preservation of existing informal arrangements for their care.

The proposed legislation also alters the constitution of the Guardianship Board. Provision is made for appointment of Deputy Presidents as well as the President and members. The Board is to comprise certain members who are to sit

exclusively in its jurisdiction under the mental health legislation. The Board is also empowered to appoint assistants for particular proceedings who are not to take part in the decision-making process.<sup>7</sup>

The Bill gives the Guardianship Board extensive powers to compel the production of evidence. There are also a number of procedural safeguards, including the right to reasonable notice, the right to call or give evidence, and the right to representation (which may be by counsel, the Public Advocate or any other representative). However there is no guaranteed access to material for the purposes of presenting a case.

The functions of the Board under the Bills<sup>8</sup> combine those of the existing Guardianship Board and those of the existing Mental Health Review Tribunal. The provisions relating to the making of guardianship orders and orders for administration of property are more detailed and subject to far greater safeguards than at present. The Board may no longer receive a person into its own guardianship, but must appoint someone who cannot be a professional carer for the person concerned — unless there is good reason for such an appointment.

The powers conferred on a guardian are to be limited and specified by the Board unless the Board is satisfied that 'full guardianship' is required. A special power is conferred on the Board, if satisfied that the health or safety of the protected person or the safety of others would be seriously at risk, to authorise detention of the person at a place of residence but not at a mental health treatment centre or correctional institution.

The Board is required under the Bill initially to review guardianship orders after six months, then annually where a person is detained under an order of the Board, and at three yearly intervals in other cases. These review powers are in addition to those conferred by the Mental Health Bill in relation to detention under that Bill.

There are provisions in the Guardianship and Administration Bill for appeals to the Administrative Appeals Division of the District Court (a relatively new Division) and to the Supreme Court. Such appeals are subject to fewer restrictions and greater safeguards than appeals from the Board to the Mental Health Review Tribunal under existing legislation.

Potentially the most significant new development in the Bill is provision for a person to appoint an 'enduring guardian' by completing a form set out in a Schedule to the legislation. Such an appointment would come into effect only if and when the person subsequently becomes mentally incapacitated according

to the definition in the legislation. The enduring guardian would have plenary guardianship powers subject to any conditions set out in the instrument of appointment. The Guardianship Board is given power to revoke the appointment of an enduring guardian but only where the guardian seeks revocation or the Board finds the enduring guardian unwilling or unsuitable to act in accordance with the principles set out in the legislation. There is no provision for review or revocation of enduring powers of guardianship on the ground that the 'protected person' has regained capacity.

The Guardianship and Administration Bill also contains innovative provisions enabling the Minister to introduce reciprocal arrangements with equivalent Ministers in any other State or Territory for the administration of guardianship or administration orders — provided the Minister is satisfied that the laws in the other jurisdiction correspond sufficiently to the South Australian provisions.

## **Western Australia**

In December 1992, a draft Mental Health Bill was released for discussion by the Western Australian Minister for Health. This represents a complete revision of the Western Australian *Mental Health Act 1962*. The Bill contains, in simplified English, a number of reforms that would result in legislation more closely conforming to the goals set by the National Mental Health Policy than any existing legislation in Australia. In particular, it provides for specific civil and human rights of patients and makes major reforms in areas such as the criteria for detention, review of detention, and treatment in the community.

The Bill contains a new definition of mental illness that is broad, but includes some relatively objective criteria.<sup>9</sup> It also details the statutory objects (including the least restriction of freedom and least interference with the rights and dignity of people with mental illness), the functions of the Minister and the responsibilities of the Chief Psychiatrist. Among other functions, the Minister is required to consult with ethnic and other disadvantaged groups in the community to ensure that any special needs are understood and to ensure services for the treatment and care of people with mental illness are comprehensive, readily accessible and responsive to cultural diversity.

The authorisation of hospitals for the treatment of involuntary psychiatric patients can, under the proposed Bill, be subject to criteria specified by regulation. There is also provision for the Commissioner for Health to negotiate funding and services agreements with registered community support services.

The criteria for involuntary detention are considerably tighter in the Bill than in the current Act. As in NSW, however, these criteria include the need for protection from serious financial harm, serious damage to reputation, or harm to personal relationships resulting from damage to reputation. The criteria are inconsistent with the standards set by the UN Principles for the Protection of Persons with Mental Illness in that they do not require that the harm be 'immediate or imminent' or that there be a 'serious likelihood' of such harm.<sup>10</sup>

Procedures for detention have also been tightened, requiring a medical practitioner who has personally examined the individual concerned to make a detailed written referral to a specific psychiatrist or place for examination. A person may only be made an involuntary patient after a psychiatric examination and only detained, initially, for up to 72 hours. If the person is to be detained any longer, they must be examined a second time. This examination may result in a further period of detention for up to 21 days. Thereafter the involuntary status may be renewed for periods of up to 6 months on the basis of re-examination by a psychiatrist. The Bill requires the hospital administrator to ensure that each involuntary patient is examined by a psychiatrist at least once a month. There is also provision for automatic review by an independent body (a new Mental Health Review Tribunal — discussed below) within eight weeks. This also falls short of the standard set by the UN Principles — which require that initial detention be only for a 'short period' pending review by the independent body. In other respects, however, the detention procedures are generally consistent with the UN Principles.

The Bill includes new provisions regarding the monitoring of treatment for patients in the community — both on leave from hospital and by way of alternatives to hospital.

Where leave of absence is granted to an involuntary patient, the psychiatrist is required to assess the patient's continuing need for detention and their suitability for a Community Treatment Order. The provisions for Community Treatment Orders include the requirement that their use be considered as an alternative to detention each time a person is assessed for involuntary status. Community Treatment Orders may only be made by a psychiatrist who has examined the person and must be confirmed by a second psychiatrist or another doctor unless the person has been referred by a doctor under the provisions for involuntary admission. There are stringent criteria governing the form, duration, supervision and review of Community Treatment Orders. Failure to comply with a Community Treatment Order may result in admission as an involuntary patient.

The Bill provides for continuing care orders for people who meet specified criteria — including having been an involuntary patient in the previous 18 months and having refused treatment more than once or been unable, due to mental illness, to consent to treatment. These criteria also stipulate that an individual treatment plan must be implemented by a doctor or mental health practitioner who is qualified, willing and available to do so. As with community treatment orders, there are strict requirements for the imposition, duration, supervision and review of continuing care orders. Breach of the terms of an order may result in involuntary admission.

One significant feature of the Bill, which is unique in mental health legislation in Australia and much needed, is a separate Part dealing with treatment and providing a detailed operational definition of informed consent. It also contains explicit provisions indicating when informed consent is required and when it is not.

However, the Bill allows both involuntary and forensic patients to be given psychiatric treatment (other than certain prohibited or restricted treatments) without consent. There is provision for these patients to obtain a second opinion and where this opinion indicates modification or discontinuation of the treatment, the Chief Psychiatrist has a duty to make alternative arrangements. These provisions, however, are clearly inconsistent with the requirements of UN Principle 11 — which limits treatment without the patient's consent to cases in which an independent authority determines that the person either lacks capacity to consent or is unreasonably withholding consent and that a proposed plan of treatment is in the best interests of the person's health needs.

The Bill also specifically authorises treatment without consent if it is 'emergency psychiatric treatment' (which is defined). Certain forms of treatment (deep sleep and insulin therapy) are banned outright and psychosurgery and ECT are subject to stringent controls (unlike the current legislation).

Another unique and important feature of the Bill is a Part devoted entirely to the protection of patients' rights. These include the right to be informed of rights; the right of access to one's own hospital records (subject to a discretion to disclose only to a suitably qualified nominee of the patient); the right not to be ill-treated or neglected (with a \$4000 fine or 2 years imprisonment for breach); the right to store and use articles for personal use; the right to correspond by post without interference; and the right to use the telephone in reasonable privacy. While there is provision for these rights to be restricted or denied by order of a psychiatrist, such an order lapses if not renewed in the course of a compulsory daily review.

Whereas the existing legislation omits provision for any specialist review body, the Bill creates both a Mental Health Review Tribunal and a Forensic Review Tribunal.

The Mental Health Review Tribunal is to be constituted by three members, appointed by the Governor. They must include representatives of various special needs groups such as ethnic minorities and people in rural areas. They must also include at least one psychiatrist, one lawyer and one person who is not a member of the medical or legal professions. The Tribunal is required to automatically review all involuntary detention orders, Community Treatment Orders and Community Care Orders within eight weeks of their being made and at intervals not exceeding six months thereafter. Reviews may also be initiated by anyone considered to have a genuine concern. The Tribunal has the power to discharge involuntary patients, to place them on a Community Order, or to vary the terms of a Community Order. There is a right of appeal from the Tribunal to the Supreme Court on the basis of error of law, fact or jurisdiction.

The Forensic Review Tribunal is similarly constituted — except that it must also include at least one Judge and one psychologist. This Tribunal also has the duty to automatically review orders for forensic patients, within eight weeks of the initial order and at not more than six monthly intervals. In addition, there is provision for automatic review by the Tribunal as near as possible to the time that a forensic patient would have been released if they had been convicted for the offence for which they had been brought before the court. There is also provision for reviews to be initiated by the patient, the Director of Public Prosecutions, the Chief Psychiatrist or anyone else with a genuine concern.

Other functions of the Forensic Review Tribunal include the review of fitness to stand trial and the continuation of a patient's forensic status. The Bill sets out criteria for consideration by the Tribunal in determining whether or not a person should continue to be a forensic patient. The Tribunal has the power to discharge those who became forensic patients because of lack of capacity to understand criminal proceedings<sup>11</sup> or because during a trial they were found to be of unsound mind<sup>12</sup>. However, in relation to those who have been acquitted of criminal charges on account of unsoundness of mind and ordered to be held in strict custody at the Governor's pleasure, the Tribunal may only recommend to the Minister for Health that the Governor be advised that the person should be released.

Replacing existing provisions permitting police to apprehend individuals believed to be mentally ill, the Bill provides for apprehension by the police in more clearly defined circumstances and provides for the diversion of those apprehended from the criminal justice system to the mental health system. The

police are given powers of entry (with necessary force), search and seizure (but the latter is limited to items likely to assist the medical examination of the person or items likely to be used by the person to prejudice their own or another's health or safety or to damage property.)

The Bill contains innovative provisions enabling the Minister to make agreements with any other State or Territory to receive, care for, treat or deal with persons who come under the terms of the Western Australian legislation or to provide reciprocal services to individuals who are covered by the laws of other jurisdictions.

The existing Boards of Visitors appointed to each psychiatric hospital would be replaced under the Bill by one larger Board covering all involuntary and forensic patients and those under continuing care orders. The members, appointed by the Minister, are to be known as official visitors — whose functions are broader than those of the current Boards. Under the proposed arrangements official visitors must ensure that people are informed of their rights and must assist in the making and presentation of applications or appeals under the legislation.

## **Conclusion**

While the provisions of the proposed legislation in both SA and WA are not entirely consistent with the UN Principles, the proposals, and the Western Australian Bill in particular, constitute major improvements on existing legislative provisions. They also acknowledge the necessity for effective arrangements between different jurisdictions with respect to the treatments of those affected by mental illness. It must be emphasised, however, that in both States, at the time of writing, this legislation is not in effect. Both States should move to accord its passage the highest priority.

- 1 This chapter, like the previous one, should be read in conjunction with the Commission's Background Paper *Mental Health Legislation and Human Rights: An Analysis of Australian Mental Health Legislation in Terms of the UN Principles for the Protection of Persons with Mental Illness*, AGPS, December 1992.
- 2 Western Australia has been reviewing its mental health legislation for well over a decade and even passed a new *Mental Health Act* in 1991 without ever proclaiming it. In NSW, debate for many years over reform of the *Mental Health Act* 1958 lead to passage of the *Mental Health Act* 1983 which was only partially proclaimed at different times during the next seven years. It was eventually replaced by the *Mental Health Act* 1990. In the ACT, the Mental Health Review Committee's report - *Balancing Rights* - was published in 1990 but has not yet produced any significant changes to the mental health legislation - although there has been separate legislation establishing a Community Advocate and Guardianship and Management of Property Tribunal.
- 3 See Principles 9 and 16, *Principles For The Protection Of Persons With Mental Illness And For The Improvement Of Mental Health Care*, at Appendix 5.
- 4 The Guardianship and Administration (Mental Capacity) Bill 1992.
- 5 The Public Advocate is to be appointed by the Governor for a term of five years and may only be removed from office by the Governor on specific grounds.
- 6 The Minister may also assign additional functions to the Public Advocate.
- 7 This is to allow specialist advisers or people with specialist expertise to assist the Board in reaching appropriate decisions.
- 8 Mental Health Bill 1992 and Guardianship and Administration (Mental Capacity) Bill 1992
- 9 'a disturbance of thought, mood, volition, perception, orientation or memory that impairs judgement to a significant extent' (clause 3(2)).
- 10 See Principle 16, *Principles For The Protection Of Persons With Mental Illness And For The Improvement Of Mental Health Care*, at Appendix C.
- 11 Under section 631 of the WA *Criminal Code*.
- 12 *ibid*, section 652.



# **Part V**

## **Findings and Recommendations**

## Chapter 30

### LEGISLATION: FINDINGS AND RECOMMENDATIONS

In its background paper — *Mental Health Legislation and Human Rights* — published in December 1992, the Inquiry analysed mental health laws in each State and Territory in terms of the UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (see Appendix 5). Widespread breaches of the standards prescribed by those Principles were identified in the background paper. The findings and recommendations set out in this chapter address the problems identified and the concerns raised in evidence to the Inquiry.

One fundamental problem is the language of most existing laws; both the form and substance of the legislation work against the assertion of rights by people with mental illness. The ACT still relies (in relation to forensic patients) on legislation from last century which uses the terms ‘lunacy’ and ‘insane’. In a number of jurisdictions the criminal law still refers to ‘insanity’ — long after such terminology has been abandoned in the civil sphere. These pejorative terms perpetuate the stigma associated with mental illness. Moreover, the way in which mental health legislation is written, particularly in Queensland and Tasmania, makes it difficult to comprehend — even for those with legal training. The drafting style is turgid, the structure hard to follow and there is insufficient use of clear headings as ‘signposts’. Such laws are not well suited to use in emergency situations; nor do they help service providers or consumers to appreciate or to enforce the rights that the laws confer. Mental health legislation must be expressed in clear and accessible terms and provide procedures that are as simple as possible — especially for emergencies.

The findings and recommendations set out in this chapter relate specifically to changes which should be accorded priority by governments in amending or introducing mental health or related legislation. They should be read in conjunction with the findings and recommendations set out in Chapter 31 — which deal more generally with reforms which are necessary to policies, programs and services to ensure proper protection of the rights of Australians affected by mental illness.

# STATE LEGISLATION

In our view, mental health legislation should start with the principle that it is an extremely serious matter to deprive a person of his liberty. Allowing for that, it should allow for prompt, effective action to provide for the care and control of someone who has become acutely disturbed, allowing them to be taken to a place of safety and evaluated. It should provide some means of protecting those who have become mentally incompetent and it should provide effective means by which individual rights are protected and the actions of those who are placed in control of people who have become incompetent become accountable and able to be monitored. The current legislation fails rather dismally by any test.<sup>1</sup>

## Statutory Objects and Definitions

### Findings:

- Certain jurisdictions (the Northern Territory and Western Australia) have no statements of principles or objectives in their mental health legislation. Laws in other jurisdictions are inadequate in that they give insufficient emphasis to the principle of the 'least restrictive alternative' in relation to the care and treatment of people with mental illness.
- In most jurisdictions mental illness is not defined at all in existing mental health legislation — or is defined in a way that is inadequate in light of modern knowledge. This creates uncertainty over issues that are critical to matters of admission, treatment and discharge. It also provides no basis for consistency among and between Australia's eight different jurisdictions.

### Recommendations:

- Mental health legislation should clearly set out the principles and objects on which it is based and, in particular, should give emphasis to the principle of the least restrictive form of appropriate care and treatment.
- There should be a clear and consistent definition of mental illness in each jurisdiction's mental health Act, providing specific criteria which apply in all jurisdictions.

## Voluntary Admission

The situation which gave rise to the criminal charge occurred shortly after her fifth [unsuccessful] attempt to admit herself as a voluntary patient...<sup>2</sup>

## **Findings:**

- Mental health legislation makes insufficient provision for the rights of voluntary (or informal) patients.
- Most jurisdictions do not provide a right of appeal against refusal of admission as an informal patient.
- The rights of informal patients to discharge themselves are often subject to significant restrictions, and no legislation clearly deals with the rights of voluntary patients to refuse specific forms of treatment.

## **Recommendations:**

- Provision should be made for a right to appeal against refusal to admit an individual as a voluntary patient.
- The right of voluntary patients to discharge themselves should not be limited other than to provide sufficient notice to allow urgent action to detain them if this is justifiable under the provisions for involuntary treatment.
- There should be a clear statement concerning the extent of the rights of voluntary patients to refuse specific forms of treatment.

## **Involuntary Admission**

There are certainly some members of the medical profession who regard the processes and procedures for detaining people in... a cavalier fashion.<sup>3</sup>

## **Findings:**

- The criteria for detention are too broadly defined in most jurisdictions.
- The procedures for involuntary admission in a number of States involve the exercise by police, magistrates and medical practitioners of very wide discretion.
- In most jurisdictions there is insufficient provision for assessment by appropriately independent and expert medical practitioners prior to detention.
- Detention procedures in emergencies are often inappropriately cumbersome.

## **Recommendations:**

- The criteria and procedures for detention in emergencies should be clear and clearly specified. Limits on their application should be clearly defined.
- The criteria for involuntary admission should be specific and should include the requirement that there is no less restrictive form of appropriate treatment available.
- Procedures for involuntary admission should require assessment by independent expert medical practitioners. (In emergencies the initial opinion of more generally qualified health practitioners must be verified or varied by an appropriately qualified expert as quickly as possible.)

## **Review**

In the area of civil commitment of the mentally ill we vest great power in the hands of medical practitioners. No matter how well-intentioned, how humane these people may be, I suggest that it's axiomatic that their daily practices have to be subject to proper external review.<sup>4</sup>

## **Findings:**

- Provisions for review are non-existent or inadequate in a number of jurisdictions.
- Where independent review bodies exist, they are not always required to automatically review patients.
- The intervals for which a person may be detained without review are frequently excessive (many patients are discharged before the statutory time for review has elapsed).

## **Recommendations:**

- Independent specialist review bodies should be established in every jurisdiction.
- These review bodies should be required to conduct an initial review of involuntary patients within a time limit that is less than the average term of detention.

- These review bodies should also be required to review involuntary patients at intervals of no more than six months and voluntary patients at intervals no longer than one year.
- Individuals should be guaranteed a right to apply to the review body for discharge — exercisable by either the person concerned or an authorised relative or friend of the patient.

## **Procedural Safeguards**

A person finds themselves going into a hearing with or without a lawyer, with a state system, a hospital system, which has for ten years been building a case against them... There are clinical files, there are all sorts of diagnoses, labelling, and systems which the psychiatric consumer may in part be familiar with and yet for the most part they will be entirely unaware of... The individual is very poorly resourced to deal with the legal proceedings which are taking place.<sup>5</sup>

### **Findings:**

- Few jurisdictions make statutory provision for personal appearance or legal representation at review hearings.
- In no jurisdiction is there express provision for access to an interpreter.
- Where legislative provision is made for access to information relevant to a case under review, this is not done in sufficiently clear, straightforward terms.

### **Recommendations:**

- Individuals should be given statutory rights to appear in person at review hearings, to have access to an interpreter if necessary, and to be represented by a lawyer or other person with leave of the tribunal.
- Provision should expressly be made guaranteeing the basic elements of natural justice — in particular, access to relevant information.
- Individuals should have a right of appeal from decisions of the review body.

## Treatment

I don't think that medical culture has yet embraced the notion that patients have rights and that people must be seen as more than simply diagnostic labels and vehicles for treatment.<sup>6</sup>

### Findings:

- Few jurisdictions provide for involuntary treatment without detention.
- While some jurisdictions have detailed requirements for administration of ECT and psychosurgery, others have none.
- In all jurisdictions there is inadequate clarity in legislation relating to the requirements for informed consent to general psychiatric treatment of voluntary and involuntary patients.

### Recommendations:

- Legislation in all jurisdictions should make provision for compulsory treatment in the community. Appropriate safeguards must be prescribed to avoid over-use or other forms of abuse.
- Administration of ECT or psychosurgery (where it is permitted) must be subject to stringent and clearly specified requirements for consent by the patient, where this is possible, and independent specialist approval.
- The position of voluntary and involuntary patients regarding consent to general psychiatric treatment must be set out clearly in legislation.

## Confidentiality

### Finding:

- Safeguards against breaches of confidentiality in the mental health system are inadequate.

### Recommendation:

- Every jurisdiction should have penalties for breaches of confidentiality in relation to personal information obtained in the administration of mental health legislation.

# Forensic Patients

Release decisions are made by State Cabinet and, inevitably, it appears political considerations are taken into account.<sup>7</sup>

## Findings:

- Most jurisdictions do not adequately divert from the criminal justice system individuals accused of crimes who require psychiatric treatment.
- In most jurisdictions patients accused or convicted of a criminal offence have lesser rights in relation to matters such as treatment, information, and review than other patients.
- In most jurisdictions, decisions to discharge forensic patients are not made by an independent review body.

## Recommendations:<sup>8</sup>

- Mental health and related legislation must ensure that any person accused or convicted of criminal offences and in need of psychiatric treatment is provided with such treatment in an appropriate environment.
- Forensic patients should be accorded rights equivalent to those of other patients in matters other than leave and discharge.
- Decisions about the discharge of forensic patients should be made by an independent body and not at a political level.

# Legislative Controls

What we really need is an ongoing whistle blower which is independent...and which will be able to go around and constantly bring to public attention any difficulties in standards, in particular, in hospitals.<sup>9</sup>

## Findings:

- While all mental health legislation provides for safeguards and standards in hospitals designated for the involuntary treatment of mental illness, there is not the same systematic control in relation to community treatment facilities.



- There is, in most jurisdictions, a paucity or complete absence of criteria for monitoring standards in psychiatric facilities.
- Most jurisdictions do not have a statutory mechanism for consumer complaints.
- Most jurisdictions do not have an independent advocate monitoring conditions of treatment.

### **Recommendations:**

- Legislation should set out clear criteria for the approval of all psychiatric facilities. It is also recommended that the Commonwealth adopt a monitoring role in this regard.
- Safeguards and controls applicable to compulsory treatment by community facilities should ensure rights at least equivalent to those specified in relation to designated hospitals.
- Consumer complaints should be dealt with by a statutory body with appropriate powers to investigate and either to settle by conciliation or to 'prosecute' where appropriate.
- Each State and Territory should have an independent advocate with statutory power and responsibility to monitor the provision of services and maintenance of standards.

## **Guardianship and Administration**

### **Findings:**

- In some jurisdictions there are no provisions for an independent determination concerning the capacity of individuals with mental illness to make decisions regarding their personal and financial affairs and for appointment of substitute decision-makers.
- While several jurisdictions have provision for enduring powers of attorney, there is not similar provision for self-determination and planning of guardianship.

## **Recommendations:**

- Every State and Territory should have an independent statutory body with power to determine capacity in relation to personal and financial affairs and to appoint substitute decision-makers where appropriate.
- Every jurisdiction should make provision for individuals to appoint a nominee to be their guardian and to specify the conditions they wish to place on such guardianship while they have the capacity to do so.

## **Anti-Discrimination**

### **Finding:**

- In some jurisdictions there is no prohibition in State or Territory legislation (as compared to Federal legislation) against discrimination on the ground of mental illness or psychiatric disability.

### **Recommendation:**

- Discrimination (appropriately defined) on the ground of mental illness or psychiatric disability should be proscribed by law in every jurisdiction.

## **Inter-State Co-operation**

We have eight different jurisdictions and some really very bizarre situations arise... For example...patients from the Northern Territory — the Alice Springs areas — were often moved to South Australia for treatment and you would have a fairly strange situation occurring at Adelaide airport where the Territory authorities would formally hand over to the South Australian authorities and the individual would have to be re-certified. It was like something from a spy novel, a transfer at the Berlin Wall.<sup>10</sup>

### **Finding:**

- Serious difficulties are caused by governments' limiting of recognition of orders and provisions under mental health, guardianship and administration legislation to their own States or Territories. Many individuals affected by mental illness are highly mobile and indeed are sometimes transferred across State borders for treatment.

**Recommendation:**

- Every jurisdiction should have legislative provision for the reciprocal recognition of orders relating to detention, involuntary treatment, guardianship and administration of property.

## FEDERAL LEGISLATION

**Finding:**

- The definition of 'hostel' in the *Aged or Disabled Persons Care Act* specifically excludes an institution exclusively or primarily for people with mental illness and receiving funding from a State government.

**Recommendation:**

- This exclusion should be removed so that the Federal government can fund hostels conducted for people with mental illness regardless of whether the institution also receives some State funding.

**Finding:**

- The criteria in Regulations under the *Aged or Disabled Persons Care Act* governing eligibility for hostel care (in hostels funded under that Act) discriminate against people affected by mental illness.

**Recommendation:**

- The criteria governing eligibility for care in federally funded hostels should be amended to ensure they do not discriminate against those affected by mental illness.

**Finding:**

- Criteria under the *National Health Act* for classification of residents of nursing homes according to the level of personal care they require, do not give sufficient weight to cognitive and/or affective dysfunction. Similar deficiencies exist in relation to criteria governing eligibility for the Domiciliary Nursing Care Benefit.

**Recommendation:**

- These criteria should be amended to give greater weight to the personal care needs of those with cognitive and/or affective dysfunction.

**Finding:**

- The limitation of eligibility for the Domiciliary Nursing Care Benefit under the *National Health Act* to carers who reside in the same homes as those for whom they care is unduly restrictive.

**Recommendation:**

- Eligibility for the Domiciliary Nursing Care Benefit under the *National Health Act* should be extended to carers who live separately from those for whom they care, provided this care is sufficiently intensive and regular.

**Finding:**

- The procedures for obtaining and maintaining eligibility for Disability Pension, Sickness Allowance and Job Search and Newstart Benefits include requirements which are often difficult for people with mental illness to meet.

**Recommendation:**

- Procedural requirements for these Pensions, Allowances and Benefits should be made sufficiently flexible to take account of difficulties that may be encountered in relation to matters such as accommodation and the intermittent nature of much psychiatric disability.

**Finding:**

- The criteria for psychiatric impairment under the *Social Security (Disability and Sickness Support) Amendment Act* are too vague and, in particular, lack specificity as to the frequency of symptoms required.

**Recommendation:**

- These criteria should be amended to make them clearer and more specific.

**Finding:**

- The categories of service for which rebates are available under the *Health Insurance Act* do not cover many 'non-medical' services, such as psychological counselling and stress management, which can be particularly important in preventing mental illness or its recurrence, or promoting effective rehabilitation of those affected.

**Recommendation:**

- The Federal Government should include a broader range of options within the scope of services for which rebates are available — particularly for psychological and counselling services which are important to those affected by mental illness.

1. Dr Ian Sale, Tasmanian Branch, RANZCP. Oral evidence, Hobart 12.11.91, p187.
2. Karen Fryar, ACT Legal Aid Office. Oral evidence, Canberra 18.3.92, p74.
3. Keith Darwin, community representative on the SA Mental Health Review Tribunal. Oral evidence, Adelaide 23.10.91, p382.
4. Neil Rees, President, Victorian Mental Health Review Board. Oral evidence, Melbourne 8.4.91, p21.
5. Steven Hird, solicitor, Mental Health Legal Service. Oral evidence, Melbourne 10.4.91, p427.
6. Rees, op cit, p21.
7. *ibid*, p26.
8. More details relevant to several of these recommendations are provided in Chapter 31.
9. Rees, op cit, p25.
10. Sale, op cit, p193.

## Chapter 31

# GENERAL FINDINGS AND RECOMMENDATIONS

## General Conclusions

- People affected by mental illness are among the most vulnerable and disadvantaged in our community. They suffer from widespread, systemic discrimination and are consistently denied the rights and services to which they are entitled.
- *Individuals with special needs* — children and adolescents, the elderly, the homeless, women, Aboriginal and Torres Strait Islander people, people from non-English speaking backgrounds, those with dual or multiple disabilities, people in rural and isolated areas and prisoners — bear the burden of double disadvantage and seriously inadequate specialist services.
- The level of ignorance and discrimination still associated with mental illness and psychiatric disability in the 1990s is completely unacceptable and must be addressed.
- In general, the savings resulting from deinstitutionalisation have not been redirected to mental health services in the community. These remain seriously underfunded, as do the non-government organisations which struggle to support consumers and their carers. While the movement towards mainstreaming mental health services may alleviate the stigma associated with psychiatric care, there is a serious risk it will not receive the resources it so desperately needs.
- Poor inter-sectoral links, the ambivalent stance of the private sector and a reluctance on the part of government agencies to co-operate in the delivery of services to people with mental illness have contributed to the alarming situation described in this report. While the Inquiry welcomes the initiative recently taken by governments in endorsing a *National Mental Health Policy and Plan*, a major injection of resources will be needed before we are in a position to comply with our international obligations under the UN Principles for the Protection of Persons with Mental Illness.

## **Mental Health Services (Chapter 5)**

### **Findings:**

- The promise of more, and more effective, community-based services following implementation of policies of deinstitutionalisation has not been realised. Most jurisdictions have not substantially redirected funds from expensive inpatient psychiatric institutions to community mental health services.
- New policies of 'mainstreaming' mental health services will not work without a substantial increase in resources and greatly improved coordination between all government and non-government service providers.
- Concerns about mainstreaming are particularly pronounced in relation to specialist services. Specialist public and private mental health services in Australia are inadequate and underfunded; there is a real risk that they will be increasingly marginalised.
- Many psychiatrists in private practice treat few people affected by serious mental illnesses.
- The existing relationship between the public and private psychiatric systems militates against optimum patient care.
- Private inpatient care is virtually unobtainable by people who do not have private health insurance. There is also evidence that certain funds may discriminate against people with mental illness.
- Although levels of funding suggest that the non-government sector is regarded as peripheral to psychiatric treatment and rehabilitation, governments are deliberately relying increasingly on non-government organisations (NGOs). Indeed, evidence to the Inquiry indicated that NGOs are now assisting many people virtually discarded as 'untreatable' by the public psychiatric system.

### **Recommendations:**

- Federal, State and Territory governments should provide increased funding and resources to integrated mental health services as a matter of urgency. In the first instance Governments must give priority to redirecting funding from high cost institutions to such services.
- Governments should accord a high priority to improving inter-agency and inter-sectoral co-operation and coordination.



- Governments should investigate innovative methods of service provision in consultation with non-government organisations and the private health sector. The possibility of leasing beds from the private sector to cater for people with special needs (such as children and adolescents) should be pursued in some areas.
- Private psychiatrists should acknowledge a professional responsibility to treat serious mental illness.
- Links between the public and private psychiatric systems must be strengthened and particular attention given to access by private psychiatrists to the public system.
- Private health funds should ensure eligibility criteria are non-discriminatory.
- All governments must substantially increase funding and resources to non-government services.
- Federal, State and Territory governments should improve access to relevant non-psychiatric programs and services such as HACC, SAAP and public housing programs.
- Governments should encourage the establishment of non-government services in rural and isolated areas.

## **Health Professionals (Chapter 6)**

### **Findings:**

- The quality of psychiatric care is critical to the welfare of many individuals affected by mental illness.
- Medicare funding is not available for a wide range of services provided in the community.
- The continuing drift of mental health professionals and allied staff from the public sector to the private sector is seriously restricting access by people with mental illness to appropriate services.
- The needs of mental health professionals and allied staff in terms of primary and continuing education and training are not adequately met.

- General practitioners (GPs) have insufficient training in the assessment and treatment of mental illness. This is particularly apparent in specialised areas such as the diagnosis and treatment of psychiatric disorders and mental health problems in the elderly, children and adolescents and other particularly vulnerable groups.
- Mental health professionals and allied staff working both in institutions and the community require education and training in the delivery of community-based services.
- Workers and service providers in other sectors need appropriate training and education to meet the specific needs of people with mental illness.

### **Recommendations:**

- The Federal Government, in consultation with State and Territory Governments, service providers, mental health professionals and allied staff, and people with mental illness should develop and implement national standards concerning the regulation and maintenance of psychiatric care and treatment. These standards should, inter alia, address the issue of appropriate minimum staffing levels to ensure effective treatment.
- The Federal Government, in consultation with State and Territory Governments and service providers should examine and clarify the treatment roles of mental health professionals and allied staff working both in institutions and in the community. In particular, the roles of psychiatrists and clinical psychologists should be carefully assessed to ensure the most effective utilisation of professional services.
- The role of mental health professionals and allied staff in the delivery of community-based services must be adequately recognised by the Federal government in Medicare funding.
- The Federal Government, in consultation with State and Territory Governments, service providers, professional associations, mental health professionals and allied staff should examine options to encourage mental health professionals and allied staff to work in the public sector. Options for expanding the role of mental health professionals and allied staff in the private sector in the treatment of people with chronic mental illness should also be examined.

- The Federal Government, in consultation with State and Territory Governments and professional associations should improve the links between GPs and private and public sector mental health professionals and allied staff. Consultation-liaison psychiatry should be supported.
- Education authorities should examine the mental health education and training system in order to identify deficiencies and clearly define the specific training needs of mental health professionals and allied staff working with people with mental illness
- Major universities should be encouraged to make academic appointments in rehabilitation psychiatry and psychiatric nursing and additional appointments in child and adolescent psychiatry, psycho-geriatrics, co-morbidity, family intervention, and forensic psychiatry.
- State education authorities need to provide appropriate undergraduate, graduate and continuing education programs. In particular, further programs are needed in community-based service delivery skills.
- Governments and medical authorities should investigate the establishment of Institutes of Psychiatric Training in States where these do not exist.
- Training courses should be as accessible as possible. Particular attention must be given to the needs of rural and isolated professionals.
- Health employers should ensure that staff are able to attend continuing education and training programs.
- Compulsory continuing education should be a requirement for re-registration, particularly registration of psychiatrists.
- Trainee psychiatrists and psychiatric registrars must be provided with appropriate clinical supervision and support.
- The training of general practitioners must place greater emphasis on the assessment and treatment of mental illnesses and mental health problems.
- Tertiary-based nurse education programs must accord higher priority to mental health training.

- Government Equal Employment Opportunity plans should provide specifically for the needs of people with mental illness and psychiatric disability.
- Federal, State, Territory and local government employees delivering services to the public should receive appropriate training in the needs of people affected by mental illness.

## **Inpatient Care and Treatment (Chapter 8)**

### **Findings:**

- The lack of crisis teams to assist with psychiatric emergencies sometimes places consumers and their families at serious risk. It also means that the police are often forced to intervene to take seriously ill people to hospital — ‘criminalising’ the process and reinforcing stigma and fear in the community
- The rights of people with mental illness to inpatient care in a safe, therapeutic environment are not being respected. Violations and abuse continue, and the universal right to treatment with humanity, respect and dignity is frequently disregarded.
- Avenues to hear and investigate grievances by inpatients are inadequate. Where such avenues do exist, many people in psychiatric facilities are either unaware of or unable to access them. Patients are afraid of retribution by hospital staff if they make a complaint.
- Some form of long-term institutional care must be retained for the small proportion of people whose psychiatric disability is so severe that they will not be able to live in the community.

### **Recommendations:**

- Health departments should ensure an adequate number of trained psychiatric emergency or crisis teams — on call for 24-hours, seven days a week — in each health region in Australia. In areas where this is impracticable because of distance or small population, alternative mechanisms should be established, using, for example, local general hospital staff, a GP or a community nurse, with telephone access to a consultant psychiatrist.

- Independent hospital visitors (Official Visitors, Community Visitors, Boards of Visitors or their equivalents) should be appointed to oversee patient rights and welfare. They should be given appropriate formal powers of investigation regarding consumers' grievances and a clear line of responsibility to an executive officer with statutory powers, independent of the hospital administration. Jurisdictions without sufficient hospital visitors to undertake this role effectively should rectify this situation. Complaints should initially remain confidential and independent of clinical staff.
- Independent, statutory complaints investigation bodies should be established in each State and Territory.
- The ambulance service should be used wherever possible to transfer a person in an acute state of mental illness (who is unwilling to go by the usual means) to hospital. Police should be called upon as a last resort and, if genuinely required, unmarked police cars should be used, not divisional vans ('paddy wagons'). Police officers likely to be involved in these situations should receive appropriate training and should comply with a special code of practice.
- Where a mentally disturbed or distressed person seeks admission to an inpatient psychiatric facility but does not appear to meet admission criteria, they should be afforded 'asylum' for one night or, at the very least, referred to mental health personnel or an appropriate agency which can provide immediate support. In no circumstances should individuals be turned away without any assistance.
- General hospitals should develop and constantly review their psychiatric admission procedures to ensure the most appropriate assessment and treatment.
- Hospital administrations must ensure that every person admitted to a psychiatric facility receives a full physical health check as soon as possible after admission. Physical health should be monitored for the duration of each person's stay and arrangements made for medical attention where required.
- Staff should provide information to people on admission to hospital, or as soon as they are able to receive it, about their rights and responsibilities, complaint procedures, the names and roles of treating doctors and nurses, hospital rules and procedures, and daily activities.

- Staff must inform patients about medication prescribed in hospital — including its effects, side-effects, duration of administration and frequency of review, anticipated outcome, associated risks, and possible alternatives. Patients should be given an opportunity to express views and ask questions of the prescribing doctor.
- Prescribing doctors must review patient histories to ascertain suitability and effectiveness of specific medications. Medication should be carefully monitored and notations made in patients' files for future reference.
- Medication should only be administered for the welfare of inpatients and to alleviate the symptoms of their illness. Staff in hospitals should never use medication as a 'management tool'.
- Alternatives to medication should be considered wherever appropriate. The views and preferences of the consumer should be considered at all stages of the treatment process.
- Psychiatric facilities should provide a reasonable degree of privacy, room for and access to personal belongings, a comfortable environment, indoor and outdoor recreation space, and separate areas where patients can talk to visitors.
- Hospital administrations should provide inpatients with opportunities for continuing and remedial education.
- Protocols should be established for the use of seclusion. Seclusion should be employed only in the rarest of circumstances and only after all other nursing strategies have been attempted without success. Any seclusion room must have a toilet.
- Attempts must be made to minimise the occurrence of assaults and abuse in hospitals by employing sufficient numbers of skilled psychiatric nurses and other mental health professionals committed to establishing therapeutic relationships with inpatients; by avoiding overcrowding or inappropriate patient mixes in wards; and by working to defuse tension and create a positive living environment.
- All staff should be aware of the procedures for reporting assaults and other serious incidents. Allegations by inpatients should be followed-up immediately.

- A treatment plan should be drawn up for each inpatient as soon as practicable after admission. The plan should be regularly reviewed in consultation with the individual wherever this is possible.
- The preparation of plans for care and treatment after discharge should commence early in the person's hospitalisation and should involve both the individual and appropriate family members, especially if they are to become carers. Community mental health workers and relevant community agency representatives should participate in the discharge planning process at least once before discharge takes place.
- The discharge summary for each patient should include information about diagnosis, history (including previous medication), treatment provided, current status and current medication requirements. The discharge summary should be provided, with the individual's consent, to the person responsible for oversight of the individual's treatment after discharge.
- Inpatient facilities should collect data for service planning purposes regarding the anticipated accommodation arrangements for each person leaving hospital.

## **Community Care and Treatment (Chapter 9)**

### **Findings:**

- The inadequacy of existing community mental health services to treat, care for, and support people with mental illness living in the community is disgraceful. Those services which do exist are grossly underfunded and underdeveloped.
- Very few community mental health services have established systematic follow-up procedures.
- There has been virtually no systematic retraining of psychiatric hospital staff to work with people in a non-institutional setting in the community.
- There is little coordination between mental health services provided to people in inpatient psychiatric facilities and community mental health services.

- Procedures for discharge planning and for co-ordination of services for community treatment and care of people with mental illness are generally inadequate and, in many instances, non-existent.
- There are conflicting views regarding the compulsory administration of anti-psychotic medication to people subject to Community Treatment Orders (CTOs). CTOs offer a form of involuntary treatment which is less restrictive than hospitalisation. If they become too intrusive, however, they are likely to be resisted and additional safeguards may be necessary.

### **Recommendations:**

- Community mental health services should include an appropriate combination of inpatient facilities, crisis services, mobile teams, outpatient services, day programs, community outreach and follow-up, accommodation support, and rehabilitation programs (including social skills, living skills, recreation and health promotion, education, management and budgeting, self esteem building, medication management, where appropriate, and vocational rehabilitation). Non-vocational rehabilitation programs must be provided for those whose disability makes employment unlikely.
- Governments in all jurisdictions should institute procedures to ensure that community mental health services attain levels of mental health care and treatment such as those prescribed in the Area Integrated Mental Health Service Standards.
- Mental health services should not attempt to care for people with serious mental illnesses in the community until it can be demonstrated that appropriate accommodation and sufficient numbers of suitably trained community mental health staff are available to provide adequate care and support for them.
- Governments in all jurisdictions should provide priority funding for psychiatric disability programs (including psychosocial rehabilitation), until funding for these services is at least equivalent to that provided for other categories of disability.
- All departments and agencies involved in the community care of people with mental illness should develop and implement procedures to ensure effective inter-agency collaboration.



- Inter-agency training should be provided to familiarise staff with the needs of people with mental illness and appropriate responses to assist their integration into the general community. Other government and non-government workers who deal with the public should be given basic information about mental illness and the importance of treating consumers with respect.
- Health administrations must allocate funding to retrain psychiatric hospital staff for community work.
- The new Divisions of General Practice should encourage GPs to actively participate in community mental health services for people with mental illness living in the community.
- Inpatient and community mental health service staff should work together to develop a practical management plan for every individual with a mental illness who comes into contact with either community or inpatient mental health services. The individual and appropriate family members should participate in the formulation of the management plan.
- One person should be nominated to oversee the coordination of services for individuals who require access to a range of services. This person should establish and maintain a therapeutic relationship with the individual and ensure that, where appropriate, family members are included in decisions and management.
- Legislation in all jurisdictions should make provision for compulsory treatment in the community. Mental health services should monitor compulsory Community Treatment Orders to evaluate their benefits, disadvantages and overall effectiveness.
- The level of income support for people with chronic mental illness should be increased to provide an acceptable standard of living and to relieve some of the financial burden on carers.
- The Federal Government should examine ways of increasing timely access to new drugs for the treatment of schizophrenia and other serious illnesses.

# **Accommodation, Boarding Houses and Homelessness (Chapters 10, 11 and 18)**

## **Findings:**

- People affected by mental illness face a critical shortage of appropriate and affordable housing. The absence of suitable supported accommodation is the single biggest obstacle to recovery and effective rehabilitation.
- Government housing programs for people with disabilities exclude many Australians with mental illness, due to inflexible criteria and poor coordination between departments and agencies.
- A large proportion of people with mental illness live at home with their families, who urgently need more respite care.
- Homeless shelters, refuges and boarding houses are now functioning, de facto, as a major component of the 'accommodation' provided by our society for thousands of Australians affected by mental illness. This is completely unacceptable.
- Large numbers of Australians affected by mental illness live in boarding houses. Living conditions in many of these establishments are disgraceful — and completely unacceptable for people with disabilities. They rarely have trained mental health workers on staff and generally provide minimal opportunities for rehabilitation.
- Boarding house staff are often involved in dispensing residents' medication, and usually have little or no training for this task.
- The Supported Accommodation Assistance Program (SAAP), the main source of funding for crisis services for homeless people, excludes services specifically for people with mental illness. This is a major problem, given the very large number of homeless people affected by mental illness.
- Some groups of people with mental illness are harder to place in accommodation, due to their age, special needs, personal circumstances, and/or discrimination. These include: Aboriginal people, ex-prisoners and those with a history of violence, young people, women with dependent children and individuals with dual or multiple disabilities.

## **Recommendations:**

- Supported accommodation for people with psychiatric disabilities must be established in all major metropolitan and regional centres. This should include crisis, medium-term and long-term accommodation.
- In allocating places in supported accommodation, priority should be given to accommodating particularly disadvantaged groups (as identified in this report).
- Support staff should be available to provide medical, counselling and life skills support. Their hours and availability should be appropriate to the needs of consumers. This support should be provided to consumers wherever they live, whether in designated special accommodation schemes or in public or private housing.
- Hospital discharge plans should include appropriate accommodation placement. Local accommodation providers should be routinely consulted as part of discharge planning.
- State and Territory housing departments should recognise the urgent needs of homeless people affected by mental illness and accord them priority.
- Housing, health and community services departments should work together to provide supported accommodation which effectively meets the needs of people with disabilities. Each Government should nominate one department as the lead agency responsible for coordination of services.
- People with a mental illness should be permitted to share their housing department accommodation with a carer (as are people with physical disabilities in some States).
- Additional funding must be provided for respite accommodation for mentally ill people being cared for by their families.
- Staff at shelters and refuges should be given appropriate training in dealing with people with mental illness. Some shelters may also wish to employ a mental health professional on staff. This must not be permitted to jeopardise their funding from the Supported Accommodation Assistance Program.

- Hospital discharge summaries must be made available to any medical staff assisting shelters to which patients are referred, and discharge summaries should place greater emphasis on behavioural/ functional disabilities.
- All boarding houses or similar facilities which have mentally ill people among their residents should be subject to stringent licensing and regulation by State governments.
- Boarding house proprietors who fully comply with these regulations should be eligible for appropriate financial assistance.
- One condition of licenses should be that boarding house proprietors must co-operate with community mental health support workers.
- Funds for monitoring and enforcement personnel should be increased so that regulation will actually be effective.
- Training programs should be required (and provided) for hostel and boarding house managers and staff, to improve their ability to care for people with mental illness appropriately.
- As part of the National Evaluation of SAAP the current exclusion relating to people affected by mental illness should be eliminated.
- Before someone affected by a mental illness is discharged from any medical facility, one department or agency should be allocated responsibility for arranging their accommodation.

## **Employment (Chapter 12)**

### **Findings:**

- Vocational rehabilitation for people with a psychiatric disability has been neglected by governments.
- A number of barriers combine to deny most people with a psychiatric disability the opportunity to obtain work commensurate with their abilities and interests. These include lack of access to vocational and educational training, the debilitating effects of psychiatric illness and treatments, job design and negative employer and community attitudes.

- The heterogeneous needs of people affected by mental illness mean that a range of graduated, transitional, vocational and rehabilitation services need to be developed to provide greater access to employment opportunities and more meaningful use of non-working time.

### **Recommendations:**

- The Federal Government should undertake an examination of the vocational and rehabilitation support services it provides in order to: (1) better define the specific vocational needs of people with mental illness and (2) identify current deficiencies and gaps in service provision.
- The Federal Government should develop and expand specific vocational services for people with mental illness. Generic vocational services should be made more accessible by ensuring that eligibility requirements and structures take account of the specific needs of people affected by mental illness.
- The Federal Government should fund the development and publication of guidelines outlining the various forms of 'reasonable accommodation' employers could provide to people with mental illness.
- The Federal Government should investigate the introduction of tax incentives or subsidies for employers who make special provision in the workplace for people affected by mental illness.
- The Federal Government should provide funding for the implementation of an education project aimed at employers and workers, and developed in conjunction with employer and union representatives, to combat negative attitudes and discrimination affecting the employment of people with mental illness.
- In the development and expansion of specific and generic vocational and rehabilitation programs for people affected by mental illness, the following issues should be addressed:
  - a) The goals and preferences of individual participants need to be acknowledged and incorporated into program design. Programs should be flexibly structured to accommodate changes in an individual's illness and personal circumstances.

- b) Programs must be as accessible as possible. Issues such as geographic location, proximity to public transport, flexible operating hours, eligibility criteria and procedures should be taken into account.
- The Federal Government should encourage the development of 'Clubhouse' or other effective programs based on transitional employment schemes. The *Disability Services Act 1986* funding guidelines should be amended to ensure Clubhouse programs access to Commonwealth funds.
  - Services for people with mental illness must include a range of options that cater for both vocational and non-vocational needs. The Federal Government, in consultation with appropriate consumer organisations, should support a range of meaningful non-vocational programs to meet the needs of people with mental illness.

## **Education and Training (Chapter 13)**

### **Findings:**

- Evidence to the Inquiry underlined the importance of education in any effective system of care. In many cases, however, special education programs and services are required to assist people with mental illness achieve their potential. The lack of these services means that those affected by mental illness are denied important opportunities associated with education and training.
- There is a particular lack of educational programs for children and adolescents in hospital or participating in day programs.

### **Recommendations:**

- A working party of Federal and State/Territory education representatives should be established, to clearly define, in consultation with people affected by mental illness, their educational and training needs over the full educational continuum (ranging from pre-school needs to tertiary and vocational studies) and to identify deficiencies in our educational and training system and problems with service delivery.
- The Federal Government should fund an investigation of the practical application of the concept of 'reasonable accommodation' (prescribed in the *Disability Discrimination Act 1992*) as it applies to the

education of students with mental illness. Guidelines outlining the various forms of 'reasonable accommodation' in education services should be developed and publicised.

- State education and hospital authorities should develop appropriate education and day programs for children and adolescents affected by mental illness.
- Educational institutions and authorities should review their access and equity programs to ensure appropriate education, training and support services are made available to people affected by mental illness.
- Education authorities should, in particular, develop and provide appropriate information, career guidance and counselling for students with mental illness.
- Education authorities should also provide appropriate assistance with orientation and enrolments and special assessment and examination provisions for students affected by mental illness.
- Education authorities should make special allowance for those individuals who, because of the onset of illness in early adolescence, lack the necessary 'starter' or eligibility qualifications.
- Educational authorities should offer staff awareness and professional development programs — with particular emphasis on skills development courses for teachers in primary, secondary and tertiary systems in the recognition of mental illness and liaison with appropriate community-based mental health professionals.
- Education authorities should support the expansion of alternative education and training options in TAFE, and the expansion of training options provided by private and community agencies.
- The Federal Government should ensure the provision of appropriate assistance and greater flexibility from DEET and CRS for students with mental illness undertaking tertiary study.

## **Discrimination: The Personal Experience of Mental Illness (Chapter 14)**

### **Finding:**

People with mental illness experience stigma and discrimination in almost every aspect of their lives.

### **Recommendations:**

- Insurance companies and superannuation schemes should ensure that eligibility criteria do not discriminate against people affected by mental illness.
- Other providers of goods and services must be made aware of their legal obligations to people with psychiatric disabilities under Federal disability discrimination legislation.
- Governments and non-government organisations should conduct public education programs to dispel the ignorance and misconceptions associated with mental illness. (See also findings and recommendations for Chapter 27 – Prevention and Early Intervention.)

## **Carers (Chapter 15)**

### **Findings:**

- The serious lack of community mental health services means that carers carry an enormous and unreasonable burden of care for people with mental illness.
- This burden has adverse effects on carers' physical, emotional and mental health and imposes heavy financial strains.
- Carers are denied information and excluded from decisions concerning the care and treatment of people affected by mental illness.



## **Recommendations:**

- Governments must provide appropriate community mental health services (particularly crisis care) to alleviate the onerous burdens borne by carers.
- A range of centre-based, home-based and holiday respite services should be made available for carers and consumers.
- Eligibility criteria for HACC services and DNC benefits should be amended to accommodate the needs of carers.
- Mental health professionals should involve carers in consultations about inpatient treatment and home care and treatment.
- Mental health professionals should provide carers with written and oral information about diagnosis, medication (and its side effects), and proposed treatment.
- Mental health professionals should provide consumers and carers with intensive home support in the first week after discharge from inpatient care.
- Mental health professionals should ensure that carers' knowledge and understanding of the individual affected by mental illness are taken into account in decisions concerning treatment and follow-up.
- Where there is an apparent conflict in the provision of information about an individual's progress and condition, mental health professionals must attempt to balance the rights of the consumer and the carer.
- Governments should provide significant additional funding to carer support groups.

# **Children of Parents with Mental Illness (Chapter 16)**

## **Findings:**

- Mental health professionals and service providers do not routinely inquire about the existence of any dependents when interviewing or admitting an adult with a mental illness.
- As a result, very little is known about what happens to the children of mentally ill parents and their needs are largely ignored. Young people who do not receive appropriate support may be adversely affected for the rest of their lives.
- Child and family support programs are needed urgently.

## **Recommendations:**

- Mental health professionals should seek information about dependent children in cases where people present for treatment for a mental illness. Referrals must be made where necessary.
- Relevant government departments such as health, education, family services and community services should co-operatively plan, develop, fund and implement services which provide a range of family and child support services for parents affected by mental illness and their dependent children.
- Agencies must be resourced to develop programs to meet children's varying needs. These include support during a parent's hospital admission, ongoing support after their discharge, and a range of home-based, centre-based, school-based and community-based activities.
- Education authorities and child and adolescent mental health services should institute or modify school-based programs to provide support for school-age children with mentally ill parents. Authorities should support the programs being conducted on a limited basis by ARAFMI and encourage their expansion.
- Governments should allocate adequate resources to non-government agencies which provide programs for children and family members

where there is a mentally ill parent. Programs provided by both government and non-government agencies should collect usage data and comply with regular review and reporting requirements.

## **Elderly People (Chapter 17)**

### **Findings:**

- General practitioners are the main contact point with the health system for elderly people, yet they often fail to recognise mental disorders in these patients. Depression, in particular, is undiagnosed and therefore untreated in a large number of cases.
- General mental health services frequently fail to recognise and meet the needs of elderly people affected by mental illness.
- Research and training on mental illness in the elderly are seriously deficient.
- Many older people with dementia are being denied their right to treatment in the least restrictive environment:
  - a) Approximately 3000 people with dementia are still confined to psychiatric wards.
  - b) Inadequate support services in the community are forcing older people unnecessarily, or prematurely, into institutional care.
  - c) Outdated, inappropriate design and funding arrangements for nursing homes result in some residents who have dementia being physically restrained or sedated as a method of control.
- These practices frequently constitute serious human rights violations.
- Carers of aged people with mental illness urgently need respite and other support services.

### **Recommendations:**

- All medical students should receive some training specifically relating to psychiatric disorders in old age.

- Increased education and information should be provided to GPs concerning diagnosis and treatment of mental illness in older people.
- At the very least, each health area should have a psychiatrist specialising in mental disorders of the elderly, who is available to teach, assess patients and provide advice to GPs and other mental health professionals.
- A specialist psychogeriatric service should be established in every health area (one team for every 25,000 local residents over 65). Such a specialist service should be multidisciplinary, mobile and community-based. It should coordinate all psychiatric facilities for elderly people in the area, including acute, rehabilitation, outpatient and inpatient care, as well as domiciliary services. The service should co-operate closely with the general geriatric health service, and maintain regular contact with all private psychiatrists, nursing homes, hostels and GPs in the area.
- Area guidelines should be drawn up to clarify the responsibilities of psychogeriatric and general geriatric medical services.
- Nurse education should emphasise training in psychogeriatric skills.
- Funding for research on mental illness in the elderly must be increased.
- Patients with severe ambulant dementia should not be admitted to nursing homes or hostels where the layout cannot accommodate their need to move around. Such homes should modify their facilities or cease to admit these residents.
- The revised formula for the Residential Classification Instrument should be assessed to determine its effect on the chronic problem of underfunding for dementia. If necessary the formula should be reviewed to increase the subsidy for residents with severe ambulant dementia.
- The *Charter of Rights* for Commonwealth-funded nursing homes, and the associated monitoring scheme, should be extended to all State-funded homes.
- Purpose-designed dementia facilities must be supported as a more humane and cost-effective form of accommodation than generic

facilities. Funds should be allocated immediately for the planning and construction of such facilities.

- The support services for dementia sufferers and their carers in each health area should be coordinated through an office where carers can obtain all appropriate information and referrals.
- Governments should provide additional respite care, home help, day centres and other support services for carers of elderly people with mental illness as a matter of urgency.
- The Domiciliary Nursing Care Benefit should be increased and criteria which currently operate to exclude many carers of dementia sufferers should be amended.

## **Women (Chapter 19)**

### **Findings:**

- Some professionals place an over-reliance on symptomatology and purely medical models to the exclusion of psychosocial and environmental factors in diagnosing psychiatric disorders in women.
- The significance of sex-role stereotypes in clinical judgements relating to mental health issues has not yet been sufficiently acknowledged.
- Women are given insufficient information about their illness and proposed treatment.
- The lack of specialised knowledge of Post Natal Depression (PND) and other women's disorders is a major impediment to improving diagnostic and treatment methods.
- Women who have a history of childhood abuse, sexual assault or domestic violence are more likely to be affected by mental illness or mental health problems.
- Allegations of assault and harassment of women inpatients by staff and other patients, or visitors, are common — and require effective complaints mechanisms.

- There is a critical shortage of both emergency and long-term accommodation for women affected by mental illness and their children.

**Recommendations:**

- Pilot early intervention programs should be undertaken to examine:
  - a) the links between violence and abuse and mental illness;
  - b) the efficacy of non-medical treatments for mental illness and mental health problems;
  - c) the aetiology of post natal depression and other psychiatric disorders that affect women;
  - d) the prevalence of sex-role stereotyping and its effect on clinical judgements concerning women's mental health.
- All medical students should receive training in psychiatric disorders and mental health problems in women.
- Additional education and information should be provided to GPs and mental health professionals about the diagnosis and treatment of mental illness in women.
- Greater emphasis should be placed on environmental and psychosocial factors in the diagnostic process.
- GPs and mental health professionals should provide patients with clear and comprehensive information about:
  - a) drugs which are being prescribed (including possible side effects and/or addictive potential);
  - b) alternative non-pharmaceutical treatments.
- Governments should establish specialist PND clinics so that women can remain with their children, wherever possible, during treatment.
- Treatment, counselling and rehabilitation of women who have suffered violence and abuse should address the situation directly and attempt to protect women from further harm.

- Hospital administrations should take appropriate measures to secure the safety of women who have been the victims of abuse during visits by partners. (Complaints procedures should be implemented and allegations of harassment or assault regarded as serious matters and investigated promptly.)
- Governments must provide resources for supported emergency and long-term accommodation for women affected by mental illness who have children.

## **Children and Adolescents (Chapter 20)**

### **Findings:**

- There is an extremely serious shortage of child and adolescent psychiatrists and other child and adolescent mental health professionals in most parts of Australia.
- There are serious deficiencies in the provision of staff, services, facilities and programs for children and adolescents throughout Australia.
- The whole field of child, family and adolescent mental health service provision is grossly underfunded, despite the fact that a third of our population consists of young people and that the average age of onset for the most serious mental illnesses is 16 years.
- There is an alarming lack of knowledge among many mental health, health, education, welfare and juvenile justice professionals about the various psychiatric, behavioural and emotional problems which can affect children and young people.

### **Recommendations:**

- Governments should allocate increased funding for child and adolescent mental health services as a matter of urgency.
- Health departments should allocate significantly increased resources for the establishment or augmentation of adolescent community mental health clinics, drop-in centres for disturbed or mentally ill adolescents, and child and family outreach and home support services.

- Health departments should allocate substantially increased resources to acute inpatient assessment and treatment facilities for children with mental illness or severe emotional or behavioural disturbance. Facilities should not be restricted to children with a diagnosable mental illness.
- All medical students should receive training in child and adolescent mental health.
- Education and information should be provided to GPs and mental health professionals about the diagnosis and treatment of mental illness and other serious disorders in children and adolescents.
- Outpatient and day-patient mental health services for adolescents should be appropriate for the client group.
- Government departments involved in the delivery of services for children, families and adolescents must ensure improved inter-agency coordination of services. Private and non-government service providers such as clinical psychologists, family therapists, GPs and relevant NGOs should be involved in establishing procedures for inter-agency coordination.
- State and Territory mental health services, in collaboration with departments of family and community services, should provide more day programs for child, adolescent and family counselling and therapy and more in-home support. An appropriate campaign should be undertaken to increase awareness of and access to such services for families under stress.
- Where mandatory reporting of suspected child abuse is introduced it must be accompanied by sufficient resources to enable reported cases to be properly followed up.
- Child and family services should develop protocols in consultation with GPs, health services, schools, social workers, police services, and any church or non-government organisations which may be relevant to follow-up action in cases where child abuse is established.
- Teachers should receive special in-service training in identifying children who are at risk; referring children to relevant services; and, where appropriate, integrating children and adolescents with mental illness and emotional or behavioural disturbance into the classroom.



- Education authorities and tertiary institutions should seek to increase the number of school clinical psychologists in training and increase the numbers appointed to schools.
- Education authorities should ensure that schools provide extra support or remedial education to children who have mental, emotional or behavioural problems themselves, or who are known to live in a dysfunctional or violent family.
- Departments of family and community services should provide more appropriate accommodation for children and adolescents in crisis to avoid the placement of these young people in correctional or detention facilities.
- Juvenile justice agencies should ensure that young people with mental illness or severe emotional or behavioural disturbance who are in detention receive specialist psychiatric assessment before being brought before the courts. The psychiatrist's assessment report must be provided to the magistrate or judge prior to determining placement of the young person.
- Juvenile justice agencies should ensure that young people with a mental illness who are already under detention in either the juvenile justice system or the adult corrections system receive appropriate psychiatric assessment, ongoing treatment and regular psychiatric review.
- Education authorities and mental health services should establish protocols for the provision of critical incident ('postvention') counselling programs in schools after a student has committed suicide.
- Those governments which have not already done so should establish a multi-agency youth suicide prevention task force to devise a range of strategies to counter the rising incidence of youth suicide.

# **People with Dual or Multiple Disabilities (Chapter 21)**

## **Findings:**

- Specialist services for the many thousands of Australians affected by mental illness and some other form of disability are almost non-existent.
- People with dual or multiple disabilities are, consequently, shuffled from agency to agency — often without finding anyone who will assume responsibility for their care.
- Service providers lack the specialist training and have insufficient resources to deal with dual or multiple disability. Misdiagnosis is common and treatment often inappropriate. This can have devastating consequences.

## **Recommendations:**

- Disability, mental health and drug and alcohol services should assume joint or collective responsibility, as appropriate, for the assessment, treatment and rehabilitation of people with dual or multiple disabilities.
- Agency workers should receive special training to deal with the particular problems confronting individuals with dual or multiple disabilities.
- Priority should be given to addressing some of the most pernicious aspects of the existing 'system', including:
  - a) The sexual abuse of female inpatients affected by mental illness and intellectual disability;
  - b) The use of medication as a 'management tool', particularly in dealing with people with mental illness and intellectual disability;
  - c) The lack of services to effectively address the prevalence of mental illness and substance abuse among young people and the homeless;
  - d) Misdiagnosis of deaf people affected by mental illness;

- Governments should fund the establishment or expansion of facilities for individuals with dual or multiple disabilities who need intensive inpatient care and treatment.
- Research into the aetiology, prevention, assessment and treatment of all areas of co-morbidity should be accorded a high priority.

## **People in Rural and Isolated Areas (Chapter 22)**

### **Findings:**

- The provision of mental health services in rural and isolated areas is influenced more by economic factors than consideration for the basic rights of consumers.
- The lack of facilities in rural and isolated areas means that people are often transferred to city hospitals or given inappropriate care in a local hospital. Community care is also frequently inadequate.
- There are considerable strains on mental health professionals and GPs working in isolated areas. This makes it difficult to fill even the positions that exist.
- People affected by mental illness (including carers and families) feel particularly isolated and excluded in small rural communities.

### **Recommendations:**

- Health planners should ensure that the rights of people in rural and isolated areas to appropriate mental health services are respected.
- Health departments should ensure that resources for dealing with acute mental illness are available in local hospitals and integrated with community services in rural and isolated areas. This process should include specialised training for nurses and GPs and, in appropriate circumstances, recognition of an expanded role for specially trained nurse practitioners.
- Health departments should expand and upgrade community-based mental health services to provide follow-up care and support for those who do not require hospitalisation.

- Professional networks should be strengthened to keep workers in isolated areas in touch with each other and in contact with city-based colleagues.
- Governments should provide funding and support for self-help and support groups for consumers and carers in rural and isolated areas.
- Greater recognition should be given to the benefits of using 'tele-medicine' techniques to provide people in rural and remote areas with assessments and consultations involving input by city-based specialists. Governments should ensure that available technology can be more widely used.

## **Aboriginal and Torres Strait Islander People (Chapter 23)**

### **Findings:**

- Not enough is known about the incidence or prevalence of mental illness among Aboriginal and Torres Strait Islander people.
- The removal of children from their families, the dispossession of Aboriginal and Torres Strait Islander people and their continuing social and economic disadvantage have contributed to widespread mental health problems. However, mental health services rarely deal with the underlying grief and emotional distress experienced by Aboriginal people.
- Mental health professionals have little understanding of Aboriginal culture and society. This frequently results in misdiagnosis and inappropriate treatment.
- Existing mainstream mental health services are inadequate and culturally inappropriate for Aboriginal people.
- Aboriginal communities do not have access to the knowledge or resources to care appropriately for many of their own people.
- Many Aboriginal and Islander people are denied the right to adequate mental health services because they live in isolated areas.

- The removal of Aboriginal people from remote communities for treatment in town can be extremely destructive to their mental wellbeing. This is particularly so for elderly people.

### **Recommendations:**

- Governments must provide funding and resources to enable Aboriginal community-controlled health services to develop and deliver appropriate mental health services to Aboriginal people.
- Joint research projects should be undertaken by Aboriginal communities and mental health professionals to determine the nature and extent of mental illness among Aboriginal people.
- Governments should ensure that mental health policy, planning and program delivery is developed in consultation with Aboriginal people.
- Tertiary courses for non-Aboriginal mental health professionals (particularly psychiatrists and nurses) should include material on Aboriginal history and contemporary Aboriginal society.
- Mental health professionals should acknowledge the role and significance of traditional healers in certain communities.
- Priority must be given to training Aboriginal health workers and other Aboriginal community-based resource people as mental health workers.
- Health departments should identify positions for Aboriginal mental health workers in areas with significant Aboriginal populations.
- Aboriginal liaison officers should be employed by relevant mainstream service providers to improve communication and consultation at all levels of the mental health system.
- All government and non-government mental health services should provide cross-cultural training for staff.
- Mental health services for Aboriginal people should be expanded to include community development, mental health promotion and primary prevention, and crisis intervention services for individuals and families.

- Mental health workers must consult with family and community members before deciding that any individual affected by mental illness requires care or treatment away from the community. Community members should be kept informed about the treatment, progress and likely return of anyone removed from their community.
- Health and community services departments should, in consultation with Aboriginal representatives, develop guidelines for the care of elderly Aboriginal people in remote communities.

## **People from Non-English Speaking Backgrounds (Chapter 24)**

### **Findings:**

- Mainstream services are not meeting the needs of large numbers of people from non-English speaking backgrounds — particularly women and the elderly.
- People from non-English backgrounds often come into contact with the health system only when their illness has reached the acute stage.
- There is a clear need for transcultural mental health services and specialist programs for individuals with particular needs, such as the survivors of torture and trauma.
- Interpreters are both under-used and used inappropriately.
- There is a dearth of information about the rates of mental illness among different ethnic communities.

### **Recommendations:**

- State and Territory governments should establish transcultural mental health services and, as appropriate, specialist programs in each capital city.
- States and Territories should take cultural issues into account in their mental health policies, program planning and service delivery. The employment of multilingual staff and staff with training in cross cultural issues should be encouraged.

- General practitioners, psychiatrists, nurses and mental health workers should receive appropriate training in cross cultural issues (especially in terms of symptomatology, diagnosis and assessment). The special problems facing women and the elderly should be emphasised.
- The composition of mental health review and guardianship bodies should reflect the multicultural nature of our society.
- Appropriate use of interpreters should be standard procedure in hospitals and community mental health centres.
- Interpreters working in the health system need to receive training in mental health issues and terminology.
- Health departments should prepare information on mental illness and mental health services in consultation with ethnic communities and ensure that it is disseminated appropriately.
- Non-government organisations supporting people from non-English speaking backgrounds who are affected by mental illness should receive adequate funding. Government and non-government services should collect usage data and observe regular review and reporting procedures.

## **Forensic Patients and Prisoners (Chapter 25)**

### **Findings:**

- Mentally ill people detained by the criminal justice system are frequently denied the health care and human rights protections to which they are entitled.
- The denial of treatment to mentally ill prisoners and ex-prisoners often leads to further criminal offending, longer incarceration and aggravation of their mental illness.
- Mental illness does not equate with criminality, nor with a propensity for violence. Persistent criminal behaviour is not an indicator of mental illness.
- Conditions in some Australian prisons and police cells clearly breach our international obligations under the ICCPR and the Standard Minimum Rules for the Treatment of Prisoners. Such conditions are particularly damaging to the health of detainees affected by mental illness or disorder.

- The rate of mental illness or disorder is higher among women prisoners. However, mental health care for them is virtually non-existent. Thus women in prison are doubly disadvantaged.
- Aboriginal and Torres Strait Islander people are massively over-represented in prison and police custody, and incarceration is particularly damaging to their mental health. Yet forensic mental health services are systematically failing to meet their needs.
- Procedures for detecting and treating mental illness and disorder in the Australian criminal justice system are inadequate in all jurisdictions.
- Serious injustice is being done to individuals who are found unfit to be tried or not guilty of an offence on the grounds of insanity. Indeterminate detention 'at the Governor's Pleasure' is a clear breach of human rights.

#### **Recommendations:**

- Mentally ill people in the criminal justice system must be provided with appropriate treatment.
- Seriously mentally ill prisoners should generally be treated in health care facilities, controlled and operated by public health authorities.
- Police and Corrective Services departments should ensure that individuals detained in custody are appropriately assessed for mental illness or disorder. Whenever possible, the assessment should be performed by mental health professionals. People from high-risk groups (eg Aboriginal prisoners, first offenders and young people) must always be assessed, even if they do not appear to be mentally disordered.
- Police and Corrective Services officers should be given training to enable them to recognise the signs of mental illness.
- The general practice of admitting prisoners to hospital only in designated 'forensic' beds should be discontinued. Seriously mentally ill prisoners should be admitted to psychiatric wards in general hospitals or acute care wards in psychiatric hospitals, unless they are medically assessed to be dangerous or pose a serious risk of absconding. Designated forensic beds in psychiatric hospitals should be retained only for those people who cannot be safely treated elsewhere.



- Penal systems which insist on keeping seriously mentally ill inmates in prison should provide separate — and appropriate — treatment facilities for women.
- Mentally ill prisoners who remain in jail must have access to adequate treatment by mental health professionals. These professionals should be consulted before their patients are transferred between prisons, and also notified well in advance of release.
- The health and corrective services sectors must co-operate to ensure that mentally ill offenders on probation or parole receive the treatment they need.
- Mainstream mental health services must not discriminate against people with a forensic history. Selected community mental health centres should receive funding to develop specialist services for ex-prisoners and sentenced offenders living in the community. These centres should co-operate with prison medical services to ensure continuity of care for prisoners on release.
- Periods spent in hospital for the treatment of a psychiatric illness or serious mental disorder during the course of a prison term should be regarded as time served for the purposes of calculating a prisoner's sentence.
- A diagnosis of 'personality disorder' or 'behavioural disturbance' must not be used as an excuse for denying mental health care to individuals who need it.
- Governments should recognise and support the work of community agencies which provide housing and other assistance to ex-prisoners.
- Anyone ordered to be detained in custody after being found unfit to plead, or not guilty on the grounds of mental illness, should be detained in a health facility — not a prison. Administrative arrangements should be made between the courts, health and corrective services departments to ensure that these patients are not forced to wait in prison while a place is found in a health facility.
- Decisions concerning the release of persons found unfit to be tried or not guilty on the grounds of insanity should be made by courts or independent specialist tribunals. These bodies should exercise

determinative powers. The executive branch of government should not have the ultimate responsibility for release decisions.

## **Mental Health Research (Chapter 26)**

### **Findings:**

- Despite the enormous costs of mental illness to our community, funding for mental health research in Australia is woefully inadequate.
- There is an urgent need for research into all aspects of mental illness, and particularly into its impact on the most vulnerable members of our community — children and young people, the elderly, the homeless, women, Aboriginal and Torres Strait Islander people, those from non-English speaking backgrounds, rural Australians and prisoners.
- Australia urgently needs a national database containing information on the prevalence of psychiatric disorders and the disposition and effectiveness of mental health services.

### **Recommendations:**

- General funding for mental health research in Australia should be increased over the next three to five years to 2 percent of the direct costs of psychiatric care. This would necessitate an increase to at least \$32 million per annum. (The increase should be staged and shared between the Commonwealth and the States and Territories.)
- Priority should be given to attracting young graduates to psychiatric research as a career — and to retaining them in this career.
- The augmentation of psychiatric research should occur within existing Australian medical research structures.
- A high quality national data base, incorporating information on the prevalence of psychiatric disorders and the nature and effectiveness of mental health services, must be established. The data base should integrate, to the maximum extent possible, information from the Commonwealth, States and Territories, and from public and private psychiatric treatment facilities.

- Community support for mental health research should be encouraged by public education programs on mental illness and the rights of those affected by it.
- Research into mental illness and psychiatric disability among the special needs groups identified by this Inquiry must be conducted as a matter of urgency.
- Research into the effectiveness of community-based services should be supported.

## **Prevention and Early Intervention (Chapter 27)**

### **Findings:**

- Prevention is possible and productive in many areas of mental health. Much of what we know about prevention, if systematically applied, could make a significant difference in the levels and severity of many mental health problems and the degree of disability associated with some mental illnesses. Unfortunately, this knowledge has not been systematically applied to prevention policies and programs for mental health.
- Although the specific causes of serious mental illness have not yet been fully identified, many elements which increase risk are now understood. It may be possible in many instances to lessen risk by mitigating these factors.
- The community has a poor understanding of mental health issues and generally lacks compassion for those affected by mental illness. The debilitating effects of stigma and discrimination further inhibit timely access to care, limit opportunities for treatment and recovery, and create difficulties in rehabilitation and community living.
- Social disadvantage often increases the difficulties faced by people with mental illness and those who are vulnerable and at risk of mental illness. Socioeconomic disadvantage may also lead to depression, anxiety and other mental disorders.
- Cultural factors influence perceptions and understanding of unusual behaviour, and patterns of response and care. Not only is an understanding of relevant cultural issues essential for the provision of mental health care, but

unless care is provided in culturally appropriate ways additional stresses occur, adding to the burden, illness and disability of those affected.

- All groups with specific requirements — such as elderly Australians, homeless people, women, those with dual and multiple disabilities and forensic patients — face particular difficulties in terms of mental health problems. To be effective, prevention strategies must also address these associated factors.
- There is now significant scientific evidence suggesting the effectiveness of early intervention programs in addressing serious mental illness (eg schizophrenia, bipolar disorder and depression).
- In light of the growing evidence indicating a link between child abuse and the later onset of mental illness, effective child abuse prevention programs and family mediation programs are essential.
- Timely access to care is unnecessarily complicated by a mental health system which continues to focus overwhelmingly on the **treatment** of illness, at the expense of 'pre-crisis' support and care for vulnerable individuals. The 'compartmentalising' of services and the failure of departments to designate (and accept ultimate responsibility for providing), a coordinated response, contributes to the hardship suffered by many individuals.

### **Recommendations:**

**Note:** A number of the findings and recommendations relevant to this chapter (for example, those relating to Aboriginal and Torres Strait Islander people, the elderly, women, children and adolescents, those in rural and isolated areas, people from non-English speaking backgrounds) have been incorporated earlier in the General Findings and Recommendations.

- There should be a nationwide campaign to educate the general community — and specific groups such as young people at school — about mental illness.
- Prevention programs for young people must address youth suicide, depression, conduct disorder and other disruptive behaviour, and take into account the needs of young homeless people, those involved with our 'juvenile justice system', and other groups with special needs.
- Education, support, and respite must be provided for those who care for people with schizophrenia, dementia or other serious illness.

- Education of general practitioners, physicians and those who care for the elderly is a critical aspect of prevention. Much distress and suffering among elderly people can be ameliorated by better diagnostic skills and more appropriate care.
- Programs for vulnerable women should include prevention counselling, stress management, development of support networks, self care, relaxation and assertiveness skills.
- It is critical that women have access to preventive counselling programs after experiencing violence, such as rape, to prevent psychiatric disorder and long term morbidity.

## **Accountability (Chapter 28)**

### **Findings:**

- Controls and safeguards to protect the rights of people with mental illness and ensure that they receive appropriate care vary considerably in different States and Territories. Procedures are inconsistent and mechanisms for monitoring compliance with standards are lacking. Many mental health facilities have not been accredited by independent accreditation bodies.
- While some jurisdictions have statutory advocates to promote and protect the rights of people with disabilities, advocates do not always have adequate powers or resources to effectively protect people with psychiatric disabilities and do not exist at all in several jurisdictions.

### **Recommendations:**

- The Federal Government must ensure there is a consistent set of basic controls and standards in every jurisdiction in Australia.
- Health departments must apply minimum outcome standards, based on nationally consistent criteria, to all mental health services.
- Health departments must develop optimal clinical standards and ensure they are applied in all areas of mental health practice.
- Procedures for quality assurance should be coordinated to ensure that universal coverage and a level of consistency are assured.

- The RANZCP and other professional bodies responsible for mental health should develop substantive and procedural guidelines for peer review.
- Monitoring mechanisms should be strengthened and incentives provided for compliance with national service standards.
- Every State and Territory should have statutory advocates with powers extending to the protection of people affected by mental illness.

**APPENDIX 1  
WITNESSES APPEARING BEFORE THE INQUIRY**

<b>DATE</b>	<b>HEARINGS<sup>1</sup></b>
<b>WITNESS</b>	
<b>8/4/91</b>	<b>Melbourne</b>
Mr N Rees	President, Victorian Mental Health Board
Ms J Luntz	President, Coalition of Child and Adolescent Mental Health Professionals
Ms E Anderson	Secretary, Coalition of Child and Adolescent Mental Health Professionals
Dr I Siggins	Victorian Health Services Commissioner
Dr D Copolov	Director, Mental Health Research Institute of Victoria
Dr M Leggatt	Secretary, Schizophrenia Australia Foundation and Executive Director, Schizophrenia Fellowship of Victoria
Mr D Eldridge	Associate Director, Crossroads
Mr P McDonald	Program Director, Crossroads
Ms J Plant	Supported Accommodation Network, Crossroads
Ms M Hamley	Policy & Planning Director, Crossroads
Ms B Horwood	Representative, Melbourne District Health Council
Ms T Bates	Director, Victorian Community Managed Mental Health Services (VICSERV)
Mr M El Hag	Sector Development Project Worker, VICSERV
Ms L Walsh	Consumer
Mr T Calabro	Administrator, Epistle Post Release Centre
Ms K Lancefield	Welfare Worker, Epistle Post Release Centre
<b>9/4/91</b>	<b>Melbourne</b>
Mr D Sandor	Youth Worker
Snr Const H Adams	Community Policing Squad, Victorian Police
Mr T Lawson	President, Guardianship Board
Prof G Burrows	Chairman, Mental Health Foundation of Australia, President, Mental Health Foundation of Victoria, Professor of Psychiatry, University of Melbourne
Ms L Brophy	President, Association of Mental Health Social Workers
Prof B Tonge	Head, Monash University Centre for Developmental Psychiatry and President, Australian Society of Adolescent Psychiatry
Ms M Thorpe	Coordinator, Victorian Aboriginal Mental Health Network
Dr J McKendrick	Melbourne University Dept of Psychiatry, St Vincent's Hospital
Ms M Ray MP	Chairperson, Social Development Committee, Parliament of Victoria

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<sup>1</sup> Witnesses from other cities and towns also attended hearings in regional centres to present evidence. (For example, at the Ballarat hearings there were witnesses from Bendigo, Warrnambool and Hamilton — in addition to those from Ballarat itself.)

Mr D Plant	Research Officer, Social Development Committee, Parliament of Victoria
Mr T Melbourne	Coordinator, Victorian Mental Illness Awareness Council
Ms J Robinson	Hon Secretary, Victorian Mental Illness Awareness Council
Mr R Salvage	Advocacy Worker, Victorian Mental Illness Awareness Council
Mr J Hughes	Consumer
Fr P Nordan	Brosnan Centre Youth Service, Catholic Prison Ministry
Mr B Geary	Director, Brosnan Centre Youth Service
Prof B Singh	Head, Dept of Psychiatry, University of Melbourne
Mr A Papakotsias	Australian Greek Welfare Association
Mr G Malageorgiou	Action on Disabilities Within Ethnic Communities
Ms S Bailey	Aboriginal Issues Unit of the Royal Commission into Aboriginal Deaths in Custody

**10/4/91**

**Melbourne**

Dr D Leonard	Director, Clinical Services, Royal Park Psychiatric Hospital and Representative, Royal Australian and New Zealand College of Psychia- trists (RANZCP), Victorian Branch
Dr M Duke	Representative (RANZCP), Victorian Branch
Ms J Player	Coordinator and two members, Association of Relatives and Friends of the Emotionally and Mentally Ill (ARAFEMI)
Ms E Field	Secretary, Victorian Branch, Australian Psychological Society
Ms M McMahon	Member, Victorian Branch Executive, Australian Psychological Society
Ms M Vidovich	Assistant Federal Secretary, Australian Nurses' Federation
Ms N Horton	Coordinator, Council to Homeless Persons (CHP)
Ms C Allison	Coordinator, George Street Outreach, and member, CHP
Ms M Campbell	Health & Welfare Coordinator, Hanover Day Centre, and member, CHP
Ms C Meese	Assessment and Referral Team Ozanam House, and member, CHP
Mr B Hagedorn	Social Worker, Hanover Access Centre, and member, CHP
Mr F Hytten	Chairperson, Mental Health Legal Service
Mr P Johnson	Solicitor, Mental Health Legal Service
Mr S Hird	Solicitor, Mental Health Legal Service
Ms T Smith	President, Post and Ante-Natal Depression Association
Ms J Rogers	Secretary, Post and Ante-Natal Depression Association
Ms J Ross	Consumer
Mr R Johnson	Researcher, TAFE
Mr R MacLellan MP	Member, Social Development Committee, Parliament of Victoria
Ms M Rowan	Coordinator, Boomerang Club
Ms T Quinn	Community Worker, Boomerang Club
Ms J McNamara	Social Worker, Boomerang Club

**11/4/91**

**Ballarat**

Mr J O'Neill	Administrator, Lakeside Hospital
Mr P Faulkner	Project Officer assisting Mr O'Neill
Mr P Humphreys	Social Worker, Commonwealth Rehabilitation Service
Mr K Burnett	Senior Social Worker, Community Mental Health Service, Warrnambool
Mr D Smith	Regional Manager, Commonwealth Rehabilitation Service, Hamilton
Mr D Pugh	Coordinator, Bendigo Community Support Service



Dr D Wells	Head, Forensic Medicine and Police Surgeon
Ms P McFadyen	Aged & Disability Development Officer, Bendigo Councils
Ms W Leslie	Carer
Mr G Hoogenboom	Psychiatric Nurse, Bendigo Psychiatric Centre
Ms J Atkinson	Consumer

**17/6/91**                      **Sydney**

Prof B Waters	Professor of Child and Adolescent Psychiatry, University of NSW
Ms J Said	Executive Director, Aftercare Association
Prof G Andrews	Professor of Psychiatry, University of NSW and Director of Health Services Research Group, Clinical Research Unit for Anxiety Disorders, St Vincent's Hospital
Dr J Ellard	Director, Northside Clinic
Ms R Gurr	President, New South Wales Council of Social Services
Ms M Smith	Coordinator, Manic Depression and Depression Association
Mr E Nimri	Executive Officer, Mental Health Coordinating Council
Dr E Bernardi	Representative, RANZCP, NSW Branch
Dr Campbell	Representative, RANZCP, NSW Branch
Dr S Einfeld	Representative, RANZCP, NSW Branch
Ms J Meagher	Consumer

**18/6/91**                      **Sydney**

Dr N Buhrich	Acting Director, Dept of Psychiatry, St Vincent's Hospital
Ms P Lowrey	Policy Officer, Consumers' Health Forum of Australia
Ms T Benson	Chairperson, Mental Health Task Force
Ms A Davis	Executive Officer, Association for the Relatives and Friends of the Mentally Ill (ARAFMI)
Ms N James	Consumer
Mr J Lizzio	National Administrator, GROW
Mr W King	National Program Coordinator, GROW
Mr J Gillies	Member, GROW
Dr T Williams	Director, Institute of Psychiatry, NSW
Dr M Dudley	Psychiatrist, Avoca Clinic, Prince of Wales Hospital
Mr D Gisz	Consumer
Mr S Champ	Consumer
Dr R Gurr	Clinical Director of Psychiatry, Blacktown Community Health Centre
Mr L Ridoutt	Research Consultant
Ms A Filis	Research Consultant
Dr J Rey	Director, Rivendell Child, Adolescent and Family Services, Royal Prince Alfred Hospital
Mr P Bioletti	President, Mental Illness and Nervous Disorders Society (MINDS)
Mr A Nettleton	Member, MINDS

**19/6/91**

**Sydney**

Prof H Brodaty      State & Federal President, Alzheimer's Association  
Ms P Jones          Executive Director, Alzheimer's Association  
Ms T Waddell        Carer  
Ms S Gentry         Carer  
Ms P Jones          Chairperson, NSW Association for Mental Health  
Ms M Bull          Vice-President, NSW Association for Mental Health  
Mr A Charles Wood   Consumer  
Ms A Newham        Executive Director, Alliance for Mentally Ill Australia (AMI)  
Ms J Cant            Member, AMI  
Mr R Ramjam        Coordinator, Planning, Schizophrenia Fellowship of NSW  
Ms M Walton         Director, Complaints Unit, NSW Dept of Health  
Mr B Hart            Chelmsford Victims Action Group  
Ms M Como          Chelmsford Victims Action Group  
Dr A Rosen          Director, Area Integrated Mental Health Services Project  
Ms W Weir          Area Coordinator for Mental Health Services,  
Northern Sydney Area Health Service  
Private Hearing      Carers

**20/6/91**

**Sydney**

Dr J Hoult          Director, Clinical Psychiatry, Glebe Community Care  
Dr R Barr            Consultant Forensic Psychiatrist  
Ms M Lukes          Founder of ARAFMI  
Ms M Cunningham   Director of Service for the Treatment and Rehabilitation of Torture and  
Trauma Survivors (STARTTS)  
Ms R Becker         Clinical Director of STARTTS  
Prof I Webster        Professor of Community Medicine, University of NSW and  
President, NSW Association for Mental Health  
Mr T Benjamin      Lecturer, School of Health Services Management, University of NSW  
Ms J Brown          Carer  
Dr M Bashir         Director, Dept of Community Health,  
Central Sydney Area Health Service  
Prof J Snowdon      School of Community Medicine, University of NSW  
Ms A Greener        Consumer

**21/6/91**

**Sydney**

Sr P Swan            Public Health Coordinator, Aboriginal Medical Service, Redfern  
Dr E Hunter         Psychiatrist, Aboriginal Medical Service, Redfern  
Ms M Smith          Disability Council of NSW  
Ms M Sargent        Disability Council of NSW  
Mr T Elligett        Chief Executive, Psychiatric Rehabilitation Association  
Mr S Maller         Program Director, Psychiatric Rehabilitation Association  
Prof D Silove        Professor of Psychiatry, University of NSW,  
Director of Mental Health Services, South Western Sydney Area Health  
Service and Macquarie Clinic, Liverpool Hospital  
Ms P Douglas        Consumer  
Ms C Kendall        Coordinator, LINK-UP (NSW) Aboriginal Corporation

Mr S Bowden                   Member, LINK-UP (NSW) Aboriginal Corporation  
Mr S Houston                 Chief Executive Officer of Tharawal Aboriginal Corporation  
Dr C McLeod                 PALA

**8/7/91                   Sydney**

Ms J Eastgate               National President, Citizens Commission on Human Rights  
Dr H Jolly                   Consultant Psychiatrist, NSW Department of Corrective Services  
Dr Y Skinner                 Consultant Psychiatrist, NSW Department of Corrective Services  
Ms L Cox                     Clinical Nurse Specialist in Mental Health  
Dr R Milton                 Forensic Psychiatrist

**9/7/91                   Newcastle**

Prof R Morice               Chief Executive Officer, Mental Health Services,  
Hunter Area Health Service  
Ms J Young                 Hamilton South Community Housing  
Ms F Rothero               Hamilton South Community Housing  
Ms J Mulluley               Hamilton South Community Housing  
Prof V Carr                 Head, Discipline of Psychiatry, Department of Medicine, Newcastle  
University, Newcastle Mater Hospital  
Ms M Sumner               Member, ARAFMI  
Private Hearing             Member, ARAFMI  
Private Hearing             Consumer  
Mr B Herring               Consumer  
Ms J Brown                 Secretary, Newcastle's Own Physically Handicapped  
Ms L Mason                 Manager, Newcastle's Own Physically Handicapped  
Ms L de Castro Lopo       Acting Area Coordinator, Migrant Health Service,  
Hunter Area Health Service  
Mr R McDonald             Ethnic Project Officer, Migrant Health Service,  
Hunter Area Health Service  
Dr S Tycehurst             Psychogeriatrician, Morrisset and James Fletcher Hospitals  
Ms N Hodgson             Social Work Department, Hunter Area Mental Health Service  
Mr A Rose                 Social Work Department, Hunter Area Mental Health Service  
Private Hearing             Carer  
Ms M Wilson               Aboriginal Health Worker, Aboriginal Medical Service  
Mr S Griffin               Researcher, Aboriginal Rehabilitation Survey,  
Newcastle Commonwealth Rehabilitation Service Office  
Private Hearing             Consumer

**12/7/91                 Orange**

Mr P Fanning               Chief Executive Officer, Orange Health Service and  
Director of Psychiatric Services, Central Western Health Region  
Dr J Hoskin                Medical Superintendent, Bloomfield Hospital  
Mr M Harris                Team Leader, Mental Health Services, Dubbo  
Mr B Melvin                Director, Mental Health Services, Orana and Far West Region  
Sr M Trainer                Chaplain, Bloomfield Hospital  
Dr I Shochet                Clinical Psychologist, Australian Psychological Society

Mr N Rowlands	Clinical Psychologist, Australian Psychological Society
Mr R Wortley	Clinical Psychologist, Australian Psychological Society
Sr P Linnane	Official Visitor, Bloomfield Hospital

**9/8/91**

**Cairns**

Mr C O'Brien	Consumer
Mr R Stewart	Outreach Worker, Youth Link
Ms B Miller	Coordinator, Aboriginal Coordinating Council
Dr J Rigano	Psychiatrist in private practice
Mr G Holland	Senior Community Psychiatric Nurse, Cairns Community Psychiatry Centre
Dr J Wooldridge	Psychiatrist, Cairns Community Psychiatry Centre
Dr T Garrone	Director of Psychiatry, Cairns Base Hospital
Sr K O'Neill	Housing Support Worker, St Vincent de Paul Society
Ms M Knight	Psychiatric Nurse and Crisis Counsellor, Ruth Women's Shelter
Dr M West	Psychiatrist, Flecker House, Cairns
Ms M Kilpatrick	President, ARAFMI, Atherton Tableland
Ms J Lawrence	Secretary, ARAFMI, Atherton Tableland
Ms E Colbert	Carer and Member, ARAFMI, Atherton Tableland
Dr D Boyle	Deputy Mayor and Chairperson of the Regional Health Authority
Ms J Andrews	Far North Queensland Families' and Prisoners' Support
Ms G Ellis	Social Worker, Community Advice & Information Centre, Innisfail
Dr J Hiddlestone	Representative, Allied Health Professionals for the Peninsula Region

**12/8/91**

**Townsville**

Ms M Gibson	Coordinator, Migrant Resource Centre
Ms S Bandaranaike	Chairperson, Migrant Resource Centre
Prof B James	Chairman, Mental Health Association, Chairman, Queensland Country Psychiatrists' Association and Professor of Psychiatry, James Cook University
Ms M Barra	Carer
Ms P Lang	Friends for the Mentally Ill
Private Hearing	Consumer
Private Hearing	Carer
Private Hearing	Coordinator, NGO
Ms S Hale	'Concerned Citizens' Group
Mr R Thompson	'Concerned Citizens' Group
Senator M Reynolds	Senator for Queensland
Ms M Herring	President, Schizophrenia Fellowship of North Queensland
Mr M Drew	Barrister

**13/8/91**

**Townsville**

Prof J Reser	Department of Psychology, James Cook University
Private Hearing	Consumer
Dr P Mildenhall	Psychiatrist

14/8/91

**Brisbane**

Ms M Broad	Consumer
Dr W Middleton	Psychiatrist, RANZCP, Queensland Branch
Private Hearing	Carer
Private Hearing	Psychiatrist
Ms S Tonkin	Co-convenor, Mental Health Sub-committee, Queensland Council for Civil Liberties
Mr J Thompson	Chairperson, Mental Health Sub-Committee, Queensland Council for Civil Liberties
Ms C Davies	Coordinator, Mental Health Action Group
Ms J Graham	Consumer
Ms C Kerr	Occupational Therapist
Ms D Pollard	Occupational Therapist
Ms J Trevan-Hawke	President, Queensland Assoc of Occupational Therapists
Ms V Meyers	Carer
Ms J McLaughlin	President, ARAFMI - Sunshine Coast
Private Hearing	Consumer
Private Hearing	Carers
Private Hearing	Carers
Private Hearing	Carer
Mr C Braddon	Consumer
Mr P Swan	Schizophrenia Fellowship Social Club

15/8/91

**Brisbane**

Ms A Gulash	Voluntary Worker, Aboriginal & Islander Community Welfare Service
Mr T Watson	President, Incarcerated Peoples Cultural and Heritage Aboriginal Corporation (IPCHAC)
Ms S Thorpe	Community Welfare Worker, Aboriginal & Islander Community Health Service
Mr Tony Marrows	Social Worker, Aboriginal & Islander Community Health Service
Mr B Lowah	President, INNA, Torres Strait Islander Corporation
Ms L Hallihan	Community Worker, Queensland Advocacy Inc
Mr J Ward	Lawyer, Queensland Advocacy Inc
Mr T Wade	Sub-committee Convenor, Queensland Association for Mental Health
Ms B Johnson	Coordinator, LINK-UP (Queensland) Aboriginal Corporation
Dr W Bor	Member, Faculty of Child Psychiatry, Queensland Branch, RANZCP
Sr C Hefferan	National Coordinator, Committee for People with Mental Illness, St Vincent de Paul Society
Mr J O'Regan	Consultant, St Vincent de Paul Society
Ms J Gray	President, Schizophrenia Fellowship of South Queensland
Mr O Hodgson	Past President, Schizophrenia Fellowship of South Queensland
Mr A Bowler	Management Committee, Schizophrenia Fellowship of South Queensland
Dr C Alroe	Psychiatrist, Rockhampton

**16/8/91**

**Brisbane**

Mr S Hamlyn-Harris Barrister, Legal Aid Office, Queensland  
Ms E Bacon Member, ARAFMI  
Ms A Whitehead President, ARAFMI, Queensland  
Dr A Urquhart Director, Department of Psychiatry, Mater Children's Hospital  
Mr D Cheetham Consumer  
Mr R Williams Queensland Wattle League for the Disabled  
Private Hearing Consumer  
Private Hearing Carer  
Private Hearing Carer  
Dr J Lawrence Associate Professor, Department of Psychiatry, Royal Brisbane Hospital  
Ms M Lucas GROW  
Ms J Withel GROW  
Ms M Graham Welfare worker, Inala Community House  
Private Hearing Consumer  
Private Hearing Consumer  
Private Hearing Nurse

**18/10/91**

**Port Lincoln**

Ms V Gould Social Worker, Family and Community Services Department  
Ms M Shannon Administrator, Lower Eyre Peninsula Children's Emergency Hostel  
Ms M Brewster GROW  
Ms M Parsons Community Mental Health Nurse, Colbrook House  
Mr C Lowings Community Mental Health Nurse, Colbrook House  
Ms S Pearce Clinical Nurse Consultant, Whyalla Hospital  
Mr B Haynes Regional Training Officer, St John Ambulance Service  
Ms B Water Mental Health Projects Officer,  
Australian Nursing Federation, SA Branch  
Ms R Smith Social Worker, Geriatric Assessment Team,  
Department of Social Work, Port Lincoln Hospital  
Ms R Kinslow Social Worker, Central Clinic, Port Augusta Hospital  
Ms R Breen Manager, Accommodation Services, Excell Enterprises

**21/10/91**

**Adelaide**

Ms C Caust Executive Administrator,  
Southern Child & Adolescent Mental Health Service (CAMHS)  
Dr S Allison Consultant Psychiatrist, Southern CAMHS and Flinders Medical Centre  
Ms P Mead Senior Community Mental Health Nurse, Southern CAMHS  
Mr S Cornelissen Senior Community Mental Health Nurse, Southern CAMHS  
Mr P Mulhearn Social Worker, Child Protection Service of South Australia  
Dr G Martin Psychiatrist, Southern CAMHS and Flinders Medical Centre  
Dr J Clay Director, Mental Health Research and Evaluation Unit,  
SA Health Commission  
Mr D Meldrum Director, Mental Health Unit, SA Health Commission  
Mr R Perkins Chairman, South Australian Mental Health Services Board,  
SA Health Commission

Prof S McFarlane	Foundation Professor of Rehabilitation Psychiatry, University of Adelaide
Mr L Mell	Consumer
Ms D Gatoudis	Consumer
Prof R Kosky	Professor of Child Psychiatry, University of Adelaide, and Adelaide Children's Hospital
Ms T Hatchett	Consumer

**22/10/91                      Adelaide**

Ms L Dalston	Director, Mental Health Association Resource Centre
Ms M Heaton	Manager, Disability Complaints Unit
Ms L Wightman	Consumer Advocacy Program
Dr D Ben-Tovin	Associate Professor of Psychiatry, Director of Mental Health Services
Ms A Burgess	Chief Project Officer, Mental Health Unit, South Australian Health Commission
Mr R Barry	Chief Executive Officer, Guardianship Board
Sr A Gregory	Administrator, Catherine House Inc
Sr M Tulley	Deputy Administrator, Catherine House Inc
Mr R Chapman	Social Worker, Southern Branch Community Accommodation Support Service (CASS)
Ms B Fox	Director, Panic Anxiety Disorder Association
Dr M Battersby	Psychiatrist, Flinders Medical Centre
Mr R Woon	Director and Chairman, Mental Health Action Group; Director, Self-Help MDP (Mood Disorders Prevention)
Ms J Felus	Administrator, Irene Women's Shelter
Ms T Grime	Coordinator, Domestic Violence Outreach Service
Ms J Nelson	Social Worker, Irene Women's Shelter
Mr K Rainsford	Program Coordinator, GROW
Mr B Mannock	Consumer
Ms M Dobson	Coordinator, Schizophrenia Fellowship
Ms I Towler	Executive Director, Schizophrenia Fellowship,
Private Hearing	NGO Representative
Private Hearing	NGO Representative
Private Hearing	NGO Representative
Private Hearing	NGO Representative
Private Hearing	NGO Representative

**23/10/91                      Adelaide**

Dr F Hawker	Psychiatrist in private practice
Mr L Cheers	Director, Outback Health Service, Port Augusta Hospital
Name withheld	Carer
Ms I Berzins	Chairperson, Mental Health Review Tribunal
Mr K Darwin	Community Representative, Mental Health Review Tribunal
Mr C Symes	Solicitor
Mr F Camatta	Solicitor
Ms U Dahl	Human Services Consultant
Ms D Price	Chair, Management Assessment Panel for the Behaviourally Disordered
Private Hearing	Consumer

11/11/91

**Hobart**

Dr S Pridmore Director, Division of Psychiatric Services,  
Tasmanian Health Department  
Dr J Tooth President, Alzheimer's Association of Tasmania  
Mr J Leary Senior Policy Officer, Tasmanian Health Department  
Ms M Blackwood Regional Director, Southern Region Mental Health Services  
Dr S Morgan Consultant Psychiatrist, Clare House, Child and Adolescent Service  
Ms C Muskett Psychiatric Nurses' Committee, Australian Nurses' Federation (ANF)  
Mr J Pyrke Executive Director, Richmond Fellowship of Tasmania  
Mr C Pollard Director, Oasis Community Centre  
Ms M Nielsen Executive Officer, Langford House

12/11/91

**Hobart**

Dr R Pargiter Chairman, Ethics Committee, RANZCP  
Ms K Stanick Senior Social Worker, Gavitt House,  
Northern Suburbs Community Psychiatric Service  
Ms R Laver Clinical Psychologist, Australian Psychological Society, Tasmanian  
Branch  
Mr S Pinkus Clinical Psychologist, Clare House Child and Adolescent Service  
Mr P Donnelly Chairman, Steering Committee, National Carers' Association  
Dr I Sale Chairman, Tasmanian Branch, RANZCP  
Mr R Redom President, Australian National Association for Mental Health (ANAMH)  
and Board Member, Royal Derwent Hospital, Tasmania  
Mr B Mansell Tasmanian Aboriginal Centre  
Ms A Kelly Researcher, Alzheimer's Disease and Related Disorders Society  
Ms J Allie Member, ROPES Self Help Group  
(Reaching Out to People with Emotional Stress)  
Ms P Elwell Member, ROPES  
Ms J Sherrington Consumer, and Founder Member, Breakthrough Manic Depression  
Support Group  
Ms P Ingram Member, ARAFMI, Hobart  
Ms B O'Halloran Member, ARAFMI, Hobart  
Ms G Stocks Member, ARAFMI, Hobart

13/11/91

**Hobart**

Dr J Matthews Senior Psychiatrist and Head of Service,  
Woodhouse Centre Psychogeriatric Service  
Ms E O'Brien Advocacy Worker, Home & Community Care Funded Program,  
Migrant Resource Centre  
Ms Z Pakulski Project Worker, Migrant Resource Centre  
Ms I Matthews Social Worker, Migrant Resource Centre  
Ms P Bourke GROW  
Ms F Gillespie Consumer  
Ms T Evans Chairperson, Domestic Violence Action Group  
Ms L Hodgson Member, Domestic Violence Action Group  
Ms B Mitchell Member, Domestic Violence Action Group



14/11/91

**Devonport**

Dr M Roberts	Psychiatrist in private practice
Ms K Linahan	Coordinator, Community Options Service, Launceston
Ms E Holmes	Chairperson, Migrant Resource Centre, Launceston
Dr R Buttfield	General Manager, NW Regional Health Board
Dr R Schneider	Director, Psychiatric Services, Northern Region
Sr C Long	Clinical Nurse Consultant, Acute Psychiatric Ward, Launceston General Hospital
Private Hearing	Carer
Dr B Kerr	Director, Psychiatric Services, North-West Region, Tasmanian Health Department
Ms D Gora	Member, ARAFMI, Devonport
Ms A Bourchier	Member, ARAFMI, Devonport
Ms G Evans	Member, ARAFMI, Devonport
Dr T Avery	Psychiatrist in private practice
Prof I Jones	Professor of Psychiatry, University of Tasmania
Mr D Paine	Save Our Hospital Organisation
Mr P Johnson	Member, ARAFMI
Ms J West	Outreach Worker, ARAFMI Home Care Service Pilot Project
Ms C Phillips	Field Worker, GROW
Mr M Brakey	Principal, Ulverstone High School
Ms J McCulloch	School Crisis Intervention Worker, Ulverstone High School

10/2/92

**Perth**

Dr J Dingle	Assistant Director, Dept of Psychiatry, Princess Margaret Hospital for Children, and Secretary, Faculty of Child Psychiatry, RANZCP
Dr J Leavelsey	Chairman, Board of Visitors, Heathcote Hospital
Ms M Leach	Manager, Support Services, Outcare Civil Rehabilitation Council of WA
Mr C Cooper	Coordinator, Community Accommodation Support Program
Ms L MacLeod	State Secretary, Psychiatric Nurses' Association
Mr P Marwick	Senior Social Worker, Warwick Child and Adolescent Clinic
Mr G Covich	President, Schizophrenia Fellowship of Western Australia

11/2/92

**Perth**

Dr I Campbell	Associate Professor, School of Law, University of Western Australia
Dr D Lord	Representative, RANZCP, WA Branch and Consultant Psychiatrist, Fremantle Hospital
Ms A Wearne	Researcher and Lecturer, School of Social Work, Curtin University
Dr S Kostov	Senior Consultant Psychiatrist, Multicultural Psychiatric Centre
Dr D Jacobs	Psychiatric Superintendent, Graylands Hospital
Ms B Harris	Coordinator, Emmanuel Centrecare
Ms P Vanderwal	Coordinator, Mentally Ill Need Defending (MIND)
Mr T Fowke	President, Mental Health Association of WA
Private Hearing	Psychiatric Nurse
Ms E Hansen	Chairman, Social Issues Team, Country Women's Association of WA
Ms P Carberry	Director, ARAFMI
Ms A White	ARAFMI
Ms M Harries	Vice President, Australian Association of Social Workers (WA Branch)

12/2/92

**Perth**

Mr K Wyatt	Senior Policy Officer, Aboriginal Health Policy Unit, Health Dept
Ms P Dudgeon	Head, Centre for Aboriginal Studies, Curtin University
Dr H Pickett	Psychologist, Centre for Aboriginal Studies, Curtin University
Dr M Roberts	Psychiatrist in private practice
Ms L Chester	President, Alzheimer's Association of WA
Ms R Gripton	Co-ordinator of Volunteers, Alzheimer's Association of WA
Mr P McHale	Administrator, Lefroy Hostel
Dr N Hills	Consultant Psychogeriatrician, Selby Lodge
The Hon K Wilson	WA Minister for Health
Dr G Smith	Director of Policy & Planning, Mental Health Services, WA Health Dept
Ms L Newby	Director, Legislation Development Branch, WA Health Dept

14/2/92

**Albany**

Dr D Smith	Regional Director, Great Southern Health Region, WA Health Dept
Ms L Hayden	Representative, Southern Aboriginal Corporation
Mr D Coyne	Chairperson, Albany Aboriginal Corporation
Ms J Hansen	Aboriginal Field Officer, Narrogin
Ms T O'Neill	Co-ordinator, Albany Community Mental Health Team
Mr P Goode	Manager, Milgrey House
Mr C Ging	Community Mental Health Nurse, South West Region (Bunbury) WA Health Department
Private Hearing	Carer
Private Hearing	Carer

18/3/92

**Canberra**

Dr A Jorm	Social Psychiatry Research Unit, Australian National University
Ms L Steeper	Convenor, Mental Health Task Force, ACT Council of Social Services (ACTCOSS)
Dr T Heins	Psychiatrist, Phillip Child and Adolescent Service
Dr J Cubis	Liaison Psychiatrist, Woden Valley Hospital
Mr R Gale	Co-ordinator, Mental Health Resource
Ms M Cooper	Representative, Schizophrenia Fellowship, Canberra
Ms P Daniel	Secretary, Mental Health Foundation and Secretary, Manic Depressive Support Group
Mr C Staniforth	Chief Executive Officer, Legal Aid Commission of the ACT
Ms K Fryar	Assistant Executive Officer, Legal Aid Commission of the ACT
Dr S Rosenman	Director, Psychiatric Ward, Woden Valley Hospital
Mr B I'Anson	President, Mental Health Foundation
Mr B Aldcroft	Ainslie Village Limited
Ms R Croton	Ainslie Village Limited
Ms C Stuart	Legal Researcher

19/3/92

**Canberra**

Mr B Bailey                   Acting Community Advocate  
Mr K Horsham               General Manager, Housing & Community Services Bureau,  
                                  ACT Corrective Services Department  
Ms R Nairn                   Social Worker, Phillip Child and Adolescent Service  
Dr B Hughson               Executive Director, Mental Health Services, ACT Board of Health  
Dr Andy Butlin               Director, Alcohol & Drug Service, ACT Board of Health

21/7/92

**Darwin**

Dr B Tyler                    President, NT Association for Mental Health  
Ms J Huck                   Senior Vice-President, NT Association for Mental Health  
Ms L Palfy                   President, NT Alzheimer's Association  
Ms D Hall                    Community Dementia Worker,  
                                  NT Department of Health and Community Services  
Ms D Marshall               Assistant Manager, Keefe Centre for Homeless Men  
Mr B McMahon               St Vincent de Paul Society and NT Association for Mental Health  
Ms G Payne                   Co-ordinator, GROW  
Kirsty                        GROW member  
Ms C Scally                 Management Committee, DAWN House  
Ms S Fogarty                Director, DAWN House  
Ms S Ross                    Director, Danila Dilba Aboriginal Medical Service  
Ms G Lawton                 Aboriginal Health Worker, Danila Dilba Aboriginal Medical Service  
Mr G Norris                 Psychiatric Nurse, NT Department of Health and Community Services  
Ms C Darling                 Aboriginal Mental Health Worker,  
                                  NT Department of Health and Community Services  
Mr J Lawrence               Solicitor, North Australian Aboriginal Legal Aid Service  
Dr M San Pedro              Medical Officer in Charge, Migrant Mental Health,  
                                  NT Department of Health and Community Services  
Ms W Carrington            Social Worker, Migrant Mental Health,  
                                  NT Department of Health and Community Services  
Ms C Beaver                 Manager, Darwin Urban Mental Health Service  
Mr P Mels                    Manager, Forensic Team, NT Mental Health Services  
Dr J Ridley                   Director, NT Mental Health Services

23/7/92

**Alice Springs**

Dr Ohn Kyaw                 Director of Psychiatry,  
                                  Alice Springs Hospital and Alice Springs and Barkly Districts  
Mr J Hopkins                Co-ordinator, Disability Services of Central Australia (DISCA)  
Ms Jo Harrison              Project Officer, Central Australian Advocacy Service  
Ms M Collins                Administrator, Central Australian Advocacy Service  
Dr L Barnes                 General Practitioner, Alice Springs  
Mr T Cox                     Senior Psychologist, NT Department of Health and Community Services,  
                                  Alice Springs and Barkly Districts  
Ms S de la Hunt             Regional Manager, Southern Region,  
                                  Commonwealth Rehabilitation Service  
Mr D Stradling              Social Worker, Vocational Unit for Psychiatric Rehabilitation,  
                                  Commonwealth Rehabilitation Service

**Mr P Warren**

**Occupational Therapist, Mental Health Services,  
Alice Springs Hospital and Community House**

**Ms S Jefford**

**Director of Psychiatric Nursing, Mental Health Services,  
Alice Springs Hospital and Community House**

**APPENDIX 2**  
**WRITTEN SUBMISSIONS**

**GLOSSARY:**

NGO	Non Government Organisation (including support organisations of consumers, relatives and friends)
CRO	Church Related Organisation
Govt	Government
Prof Assoc	Professional Association
ISOH	Independent Statutory Office Holder

The classification system used in this appendix is, of necessity, arbitrary. It is included to give an indication of the range of individuals and organisations that took the trouble to prepare written submissions to the Inquiry and to acknowledge their extremely important contribution.

**VICTORIA**

<u>NO</u>	<u>NAME</u>	<u>CLASSIFICATION</u>
1.	Ms H Adams	Police Officer
2.	Action on Disabilities within Ethnic Communities	NGO
3.	Prof R Adler	Psychiatrist
4.	Name withheld	Consumer
5.	Mr D Anderson	Consumer
6.	Ms L Anthony	Consumer
7.	Association of Relatives and Friends of the Emotionally and Mentally Ill (ARAFEMI)	NGO
8.	Australian Nursing Federation	Prof Assoc
9.	Mr H Baginski	Consumer
10.	Ms T Bates, Victorian Community Managed Health Services (VICSERV)	NGO
11.	Ms G Bell	Consumer
12.	Mr R Bell	Concerned Citizen
13.	Mr S Biondo, Fitzroy Legal Service	NGO
14.	Mr M Blandin de Chalain, Sunshine/Keilor Mental Health Forum	NGO
15.	Name withheld	Consumer
16.	Ms M Blythman	Carer
17.	Ms V Boston, St Kilda City Council	Local Govt
18.	Mrs M Bramall	Carer
19.	Mr R Bridges	Consumer
20.	Mr J Briggs	Carer
21.	Name withheld	Consumer
22.	Ms E Burnell	Concerned Citizen
23.	Ms L Brophy, Association of Mental Health Social Workers	Prof Assoc
24.	Ms A Brown, Melbourne District Health Council	NGO
25.	Mr J Caldwell	Consumer
26.	Ms J Cameron, Port Melbourne Baptist Church	CRO

27.	Mr C Campbell, Citizens' Commission on Human Rights	NGO
28.	Ms M Carmody	Consumer
29.	Mr F Carnegie	Consumer
30.	Mr P Chambers	Consumer
31.	Name withheld	Consumer
32.	Dr J Clarke, Prahran City Parish Mission	CRO
33.	Mr H Clausen (on behalf of a number of psychologists)	Psychologist
34.	Ms J Clements	Carer
35.	Dr P Cook, Kororoit Community Mental Health Service	Psychologist
36.	Dr D Copolov, Mental Health Research Institute of Vic	Research Psychiatrist
37.	Ms H Cousland	Psychiatric Nurse
38.	Name withheld	Consumer
39.	Ms P Crosthwaite	Carer
40.	Ms P Dasic	Carer
41.	Ms R Dawson, Port Melbourne Baptist Church	CRO
42.	Ms A Deveson, Schizophrenia Australia Foundation	NGO
43.	Mr D Dixon	Consumer
44.	Ms D Dowell	Consumer
45.	Name withheld	Carer
46.	Doyle, Considine	Solicitors
47.	Mr I Eames, Wodonga Moodswing Self Help Group	NGO
48.	Dr P Eisen, Office of Psychiatric Services, Victorian Health Dept	Govt
49.	Ms E Field, Australian Psychological Society	Prof Assoc
50.	Fintry Bank Supported Accommodation Project	NGO
51.	Mr J Flynn, Victorian Deaf Society	NGO
52.	Name withheld	Consumer
53.	Name withheld	Carer
54.	Ms J Gee, Mental Health Legal Centre	NGO
55.	Name withheld	Consumer
56.	Dr F W Grahame	Psychiatrist
57.	Ms M Guthrie, People Against Power Abuse	NGO
58.	Dr S Hacker	Psychiatrist
59.	Ms M Hage, Alcohol Related Brain Injury Assessment, Accommodation Support Inc	NGO
60.	Mrs E Halley	Carer
61.	Ms B Harrison, Association for the Support of Psychiatric Services	NGO
62.	Health Department of Victoria	Govt
63.	Mr B Healy, Dept of Social Work La Trobe University	Academic
64.	Ms L Hepburn, Inner City School Support Centre	NGO
65.	Dr H Herrman, Senior Lecturer, Monash University	Psychiatrist, Academic
66.	Mr G Hoogenboom	Psychiatric Nurse
67.	Mr P Horan	Carer
68.	Ms P Horner, Ballarat Psychiatric Fellowship	NGO
69.	Ms N Horton, Council to Homeless Persons	NGO
70.	Ms N Hotchin	Carer
71.	Mr P Humphries, Commonwealth Rehabilitation Service	Govt
72.	Mr W Issell, Out Doors Inc	NGO
73.	Dr H Jackson	Psychologist
74.	Ms R James, Western Region Women's Response Group	NGO
75.	Dr R Jamieson, Bendigo CAE	Academic
76.	Mr G R Johnston, Northern Metropolitan College of TAFE	Academic

77.	Mr P Kaye	Consumer
78.	Dr B Kenny, RANZCP	Prof Assoc
79.	Mr J Klement	Consumer
80.	Ms K Lancefield, Epistle Post Release Service	CRO
81.	Ms J Lane	Consumer
82.	Mrs J Lawrence & Mrs M Robinson	Carers
83.	Dr M Leggatt, Schizophrenia Fellowship	NGO
84.	Mrs W Leslie	Carer
85.	Mrs L Light, Uniting Church Ballarat, Central Parish Mission Outreach Centre	CRO
86.	Mrs J Lococo, Support Group for Relatives of People with a Psychiatric Disability	NGO
87.	Ms J Luntz, Coalition of Child & Adolescent Mental Health Professionals	Prof Assoc
88.	Name withheld	Consumer
89.	Mr R McCaig	Consumer
90.	Mr S McGrath	Consumer
91.	Mrs M McCutcheon	Consumer
92.	Ms P McFadyen, Bendigo Sub-Region Aged & Disability Services Development Committee	NGO
93.	Dr P McGorry, Early Psychosis Research Centre	Research Psychiatrist
94.	Mr A Mackenzie	Carer
95.	The Hon R Maclellan, MLA	Member of Parliament
96.	Ms M McQueenie, Australian National Association for Mental Health	NGO
97.	Mrs R Mahar	Consumer
98.	Ms V Mancini, Ethnic Communities & Mental Health Issues Sub-Committee of VICSERV	NGO
98.	Mr D Mandic	Consumer
99.	Mr B Martyn	Concerned Citizen
100.	Mrs V Mason	Consumer
101.	Mr M Mead, Outer East Council for Developing Services in Mental Illness	NGO
102.	Mr T Melbourne, Victorian Mental Illness Awareness Council	NGO
103.	Mr G Merry	Consumer
104.	Dr H Minas, Victorian Transcultural Psychiatry Unit	Psychiatrist
105.	Ms S Mortimer	Consumer
106.	Mr V Mouradian	Consumer
107.	Name withheld	Carer
108.	Mr T Nicholson, Hanover Welfare Services	NGO
109.	Ms M O'Donoghue, Changing Attitudes Towards Schizophrenia	NGO
110.	Ms L Oke, Australian Association of Occupational Therapists	Prof Assoc
111.	Mr O O'Flynn	Community Visitor
112.	Mr P O'Leary	Carer
113.	Mr G Ooi	Consumer
114.	Dr J Opie, Australian Catholic Health Care Assoc	CRO
115.	Outdoors Inc	NGO
116.	Dr W Orchard, Prince Henry's Hospital	Psychiatrist
117.	Mr G Overton, The Melbourne Clinic	Manager, Private Clinic
118.	Mr A Papakotsias, North Eastern Alliance for the Mentally Ill	NGO
119.	Dr C Paul, Royal Children's Hospital	Psychiatrist

120.	Mr M Pavone, Australian Catholic Health Care Assoc	CRO
121.	Ms V Peacock	Speech Pathologist
122.	Mr E Place	Consumer
123.	Mrs J Player, ARAFMI	NGO
124.	Mr D Pugh, Community Support Program	NGO
125.	Mrs J Rainbow	Consumer
126.	Name withheld	Consumer
127.	Mr R Reynolds	Consumer
128.	Name withheld	Consumer
129.	Richmond Fellowship of Victoria	NGO
130.	Mrs M Roberts	Consumer
131.	Name withheld	Consumer
132.	Ms P Ronnau, Victorian Advisory Council on Recreation for People with Disabilities	NGO
133.	Ms J Ross	Consumer
134.	Mr D Sandor	Youth Worker
135.	Mr S Sarma	Consumer
136.	Mr B Scates	Concerned Citizen
137.	Dr I Siggins, Health Services Commissioner, Victoria	ISOH
138.	Ms T Smith, Post and Ante-Natal Depression Association	NGO
139.	Mrs V Smith	Carer
140.	Ms G Snaauw	Consumer
141.	Mrs J Stjepovic	Carer
142.	Mr H Strnad, Humanist Society of Victoria	NGO
143.	Ms T Swanborough, Royal District Nursing Service	Psychiatric Nurse
144.	Ms C Taylor, Health Services Commissioner's Office	ISOH
145.	Ms C Taylor	Consumer
146.	Mr I Taylor, Marjorie Oke Rooming House	NGO
147.	Ms M Thorpe, Koori Mental Health Network/Victorian Aboriginal Health Service Co-operative	NGO
148.	Mr R Trowbridge, Dept of Leisure Studies, Phillip Institute of Technology	Academic
149.	Ms S Turale, Ballarat University College	Nurse, Academic
150.	Ms S Vernon, North West Community Resource Exchange	NGO
151.	Mr G Walker, Australian Guidance & Counselling Association	Prof Assoc
152.	Ms L Walsh	Consumer, Student
153.	Mr M Warnock	Consumer
154.	Dr D Wells, Director of Forensic Medicine and Police Surgeon	Govt
155.	Mr R Wiggins, Daily Activity for Self Help	NGO
156.	Mrs J Willman	Carer
157.	Ms C Wilson, St Kilda Community Health Centre	Govt
158.	Name withheld	NGO
159.	Ms M Wynne, Macaulay Community Support Program	NGO
160.	Mr F Wright, Executive Director, Outer East Council for Developing Services in Mental Health	NGO
161.	Mr G Yates	Concerned Citizen
162.	Victorian Government	Govt



NEW SOUTH WALES

<u>NAME</u>	<u>CLASSIFICATION</u>
163. Prof G Andrews, Director, Clinical Research Unit for Anxiety Disorders	Psychiatrist
164. Name withheld	Social Worker
165. Mr R Bailey	Consumer
166. Mr K Baker	Concerned Citizen
167. Dr R Barr	Psychiatrist
168. Name withheld	Carer
169. Mr C Beaumont	Concerned Citizen
170. Ms M Bell, Volunteer Centre of NSW	NGO
171. Mr T Benjamin	Academic
172. Dr R Beran	Neurologist
173. Mr P Bioletti, Mental Illness and Nervous Disorders Society (MINDS)	NGO
174. Mrs D Blenman	Carer
175. Ms A Blitz	Psychotherapist
176. Name withheld	Consumer
177. Dr B Boettcher	Psychiatrist
178. Ms M Bowles	Consumer
179. Name withheld	Carer
180. Name withheld	Carer
181. Name withheld	Carer
182. Mr P Bright	Consumer
183. Dr H Brodaty, President, Alzheimers Disease and Related Disorders Assoc (ADARDS)	NGO
184. Mr G Brown	Consumer
185. Name withheld	Consumer
186. Mrs J Brown	Carer
187. Mr D Bryson-Taylor, Alliance for the Mentally Ill, Australia	NGO
188. Dr N Buhrich, Psychiatric Department, St Vincents Hospital and Inner City Mental Health Service	Psychiatrist
189. Name withheld	Consumer
190. Mrs J Cant	Carer
191. Prof V Carr, Dept of Psychiatry, Newcastle University and Mater Hospital, Newcastle	Psychiatrist
192. Ms F Carr-Boyd	Carer
193. Sir John Carrick	Concerned Citizen
194. Mr S Champ	Consumer
195. Name withheld	Consumer
196. Name withheld	Consumer
197. Ms J Clements	Consumer
198. Ms E Clough	Consumer
199. Ms C Coad	Carer
200. Mr R Coady, Unemployed People's Embassy	NGO
201. Ms L Cole, Mental Health Co-ordinating Council	NGO
202. Mr A Collins	Concerned Citizen
203. Rev P Collins	Concerned Citizen
204. Ms M Como, Chelmsford Victims Action Group	NGO
205. Ms L Cox	Psychiatric Nurse

206.	Name withheld	Consumer
207.	Ms M Cunningham, Service for the Treatment and Rehabilitation of Torture and Trauma Survivors	Govt
208.	Mr G Curry, Faculty of Nursing, Kuring-Gai CAE	Academic
209.	Ms H Cusack	Consumer
210.	Ms J Dilli, Ballina District Community Services Association	NGO
211.	Name withheld	Consumer
212.	Ms P Douglas	Consumer
213.	Name withheld	Psychiatrist
214.	Dr M Dudley, Avoca Clinic, Prince of Wales Hospital	Psychiatrist
215.	Mr J Du Ross	Carer
216.	Ms J Eastgate, Citizen's Commission on Human Rights	NGO
217.	Name withheld	Consumer
218.	Dr J Ellard, Director, Northside Clinic	Psychiatrist
219.	Mr T Elligett, Psychiatric Rehabilitation Association	NGO
220.	Ms V Eyles	Concerned Citizen
221.	Mr M Fabre	Concerned Citizen
222.	Name withheld	Carer
223.	Ms M Fernandes	Consumer
224.	Ms C Flynn, Mental Health Co-ordinating Council	NGO
225.	Ms J Fraser, Disability Council of NSW	NGO
226.	Mrs A Gabeler	Carer
227.	Name withheld	Carer
228.	Mr D Gisz	Consumer
229.	Name withheld	Consumer
230.	Name withheld	Consumer
231.	Ms M Graden	Consumer
232.	Mr I Graham	Consumer
233.	Ms M Graham	Social Work Student Concerned Citizen
234.	Mrs E Gray	Concerned Citizen
235.	Ms R Greene, Association of Relatives and Friends of the Mentally Ill (ARAFMI)	NGO
236.	Ms A Greener	Consumer, Social Worker
237.	GROW	NGO
238.	Ms R Gurr, NCOSS	NGO
239.	Name withheld	Consumer
240.	Mr N Hampton	Concerned Citizen
241.	Mr C Harbaum, Federation of Ethnic Communities Councils of Australia	NGO
242.	Mr M Harris, Mental Health Services, Dubbo	Govt
243.	Name withheld	Consumer
244.	Mr B Hart	Consumer
245.	Sr P Hartley, Bloomfield Hospital	Psychiatric Nurse
246.	Ms J Hawley, Psychiatric Rehabilitation Association	NGO
247.	Ms P Haylen	Concerned Citizen
248.	Mr A Helman	Nurse
249.	Rev H Herbert, Uniting Church in Australia	CRO
250.	Mr B Herring	Consumer
251.	Mr B Hill, Schizophrenia Fellowship	NGO

252.	Mrs J Hodgess, Association of Relatives and Friends of the Mentally Ill (ARAFMI)	NGO
253.	Name withheld	Consumer
254.	Ms N Hodgson	Social Worker
255.	Mr A Hogan	Concerned Citizen
256.	Mrs L Holland	Carer
257.	Name withheld	Carer
258.	Name withheld	Carer
259.	Dr J Hoult, Clinical Director of Psychiatry, Glebe Community Care	Psychiatrist
260.	Dr C Howe, Hunter Medical Association	Prof Assoc
261.	Mr D Hunt	Consumer
262.	Dr E Hunter, Psychiatrist, Redfern Aboriginal Medical Service	NGO
263.	Mr G Hutchison	Carer
264.	Mr C Jacob	Consumer
265.	Name withheld	Consumer
266.	Ms P Jockel	Consumer
267.	Names withheld	Carers
268.	Ms P Jones, Alzheimer's Association	NGO
269.	Mr P Joyce	Consumer
270.	Name withheld	Carer
271.	Mr D Kashyap	Carer
272.	Mr D Kavanagh	Clinical Psychologist
273.	Mr P Kelly	Consumer
274.	Ms C Kendall, LINK-UP	NGO
275.	Mr V Kenny	Consumer
276.	Mr A Keogh	Concerned Citizen
277.	Mr S Kinkead, New Horizons Disability Services	NGO
278.	Mr B Lane	Concerned Citizen
279.	Dr J Lennane	Psychiatrist
280.	Mr A Lewis	Concerned Citizen
281.	Mr A Lisle	Concerned Citizen
282.	Ms M Long	Consumer
283.	Mr M Longhurst, Ryde-Hunters Hill Mobile Treatment Team	Govt
284.	Name withheld	Carer
285.	Mr K Lovett, Gay Solidarity Group	NGO
286.	Mrs M Lukes, ARAFMI	NGO
287.	Mr D McDonald, Forestry and Mining Employees Union	Trade Union
288.	Name withheld	Carer
289.	Mr J McLenaghan, Life Insurance Federation of Australia	Prof Assoc
290.	Ms S McLoughlin	Consumer
291.	Mr R Malcolm	Concerned Citizen
292.	Mrs I Mack	Consumer
293.	Ms L Macpherson, Family Association for Mental Health Support	NGO
294.	Ms M Maher	Consumer
295.	Ms B Marks	Carer
296.	Mr B Marsh	Concerned Citizen
297.	Ms J Martin	Concerned Citizen
298.	Ms P Martyn, Mental Health Services North Coast Region, NSW Health Department	Govt
299.	Name withheld	Consumer
300.	Ms C Miller	Consumer

301.	Name withheld	Carer
302.	Name withheld	Consumer
303.	Mr A Nettleton	Consumer
304.	Mrs E Nettleton	Carer
305.	Ms A Newham, Alliance for the Mentally Ill, Australia	NGO
306.	Mr T Newlands, Manic Depressive Group in the Hunter	NGO
307.	Mr T Nicholls, GROW	NGO
308.	Mr E Nimri, Mental Health Co-ordinating Council	NGO
309.	Ms J Noble	Concerned Citizen
310.	Mrs H Nolan	Consumer
311.	NSW Association for Mental Health	NGO
312.	NSW Health Department	Govt
313.	Ms L O'Brien, Hornsby Ku-ring-gai Association - Action for Mental Health	NGO
314.	Dr P O'Neill	Medical Practitioner
315.	Mr G Page	Concerned Citizen
316.	Prof G Parker, Dept of Psychiatry, University of NSW	Psychiatrist
317.	Mr T Paynter	Consumer
318.	Mr M Peacock, Country Freedom Group	NGO
319.	Ms D Peck, GROW, Hunter/Central Coast Region	NGO
320.	Mr H Peck	Concerned Citizen
321.	Name withheld	Carer
322.	Mrs J Pickering	Concerned Citizen
323.	Ms M Pinervia, ARAFMI	NGO
324.	Ms M Podnieks, CENTACARE	CRO
325.	Ms H Pountney, Association of Self Help Organisations	NGO
326.	Ms J Prigg	Consumer
327.	Mr B Rainey	Consumer
328.	Dr C Reading	Psychiatrist
329.	Dr J Rey, Rivendell Child Adolescent and Family Psych Services	Psychiatrist
330.	Ms J Roberts	Psychiatric Nurse
331.	Mrs M Robinson	Consumer
332.	Dr S Robinson, Hunter Area Community Mental Health Service	Psychiatrist
333.	Dr A Rosen, Area Integrated Mental Health Standards Project	Psychiatrist
334.	Name withheld	Consumer
335.	Name withheld	Carer
336.	Dr A Ryan	Medical Practitioner
337.	Ms J Said, After Care Association of NSW	NGO
338.	Mr P Scollay	Clinical Psychologist
339.	Name withheld	Carer
340.	Name withheld	Consumer
341.	Mr J Shewan	Consumer
342.	Mr G Shoebridge	Consumer
343.	Ms J Short	Concerned Citizen
344.	Ms J Short	Carer
345.	Ms N Short	Carer
346.	Mr P Sievert	Consumer
347.	Prof D Silove, South West Sydney Area Health Service	Psychiatrist
348.	Mr J Simpson, Croydon Living Skills Centre	Govt
349.	Mrs P Simpson, ARAFMI	NGO
350.	Mr D Skinner, Mental Illness and Nervous Disorders Society (MINDS)	NGO

351.	Dr Y Skinner	Psychiatrist
352.	Ms M Smith, Depressive & Manic Depressive Association	Consumer, NGO
353.	Mr B Smout	Concerned Citizen
354.	Prof J Snowden, University of NSW, Prince Henry Hospital	Psychogeriatrician
355.	St Vincent de Paul Society, National Council	CRO
356.	Mrs J Steel	Consumer
357.	Name withheld	Consumer
358.	Name withheld	Consumer
359.	Ms J Sulima, SOMA, Health Association of Australia	NGO
360.	Name withheld	Carer
361.	Mr D Swain, Mental Health Advocacy Service	NGO
362.	Ms P Taylor	Psychiatric Nurse
363.	Dr J Thompson, Forensic Study Group, RANZCP	Psychiatrist
364.	Transitional Enterprises Inc	NGO
365.	Ms W Turner	Concerned Citizen
366.	Mr G Udy, Lifeline	CRO
367.	Mr R Van Wegen, Australian Community Action Network	NGO
368.	Mr C Vowles, United Nations' Association of Australia	NGO
369.	Ms M Walton, Complaints Unit, NSW Department of Health	Govt
370.	Name withheld	Consumer
371.	Mr R Weaver	Concerned Citizen
372.	Prof I Webster, NSW Association for Mental Health	NGO
373.	Ms W Weir	Occupational Therapist
374.	Mr E Wellman	Concerned Citizen
375.	Name withheld	Carer
376.	Ms P Williams	Concerned Citizen
377.	Ms M Wilson	Social Worker
378.	Mr N Wilson	Concerned Citizen
379.	Name withheld	Consumer
380.	Ms J Woodruff, NSW Women's Co-ordination Unit	Govt
381.	Mr A York	Nurse
382.	Mr J Young, Hamilton South Community Group	NGO
383.	Name withheld	Consumer
384.	Mr W Zyla, Community Mental Health Services, Orange	Govt
385.	Name withheld	Consumer

**QUEENSLAND**

<u>NAME</u>	<u>CLASSIFICATION</u>
386. Mr C Ackerman	Concerned Citizen
387. Dr C Alroe	Psychiatrist
388. Mr T Atkin, Schizophrenia Fellowship of South Qld	NGO
389. Mrs E Bacon	Carer
390. Mrs L Bailey	Consumer
391. Names withheld	Carers
392. Mr R Batt	Consumer
393. Mr A Beesley	Consumer
394. Mrs H Binns	Consumer
395. Name withheld	Consumer
396. Mrs J Booth	Carer
397. Name withheld	Consumer
398. Mr T Breadsell, Concerned Citizens & Supported Accommodation Options	NGO
399. Mrs M Broad	Carer
400. Dr F Bryant, Queensland Country Psychiatrists' Assoc	Prof Assoc
401. Mrs F Bubb	Consumer
402. Mr & Mrs Burey	Carers
403. Ms A Campbell, West Moreton Regional Office, Dept of Health	Govt
404. Dr C Cantor, Suicide Research & Prevention Program, Dept of Health	Govt
405. Mr D Cheetham, Brisbane Manic Depressive Support Group	NGO
406. Mr G Christmas, ARAFMI	NGO
407. Mr J Clarke, Central Qld Multidisciplinary Psychiatric Team	Govt
408. Mr J Cockerill, Public Trust Office	Govt
409. Mrs D Conway	Consumer
410. Mr N Cunningham	Consumer
411. Dr J Cutbush, Queensland Branch, RANZCP	Prof Assoc
412. Mr C Davies, Mental Action Group	NGO
413. Mrs M Dearer	Consumer
414. Ms G Deordas	Consumer
415. Mrs C Doherty	Carer
416. Mrs A Ellis	Carer
417. Prof L Evans, Anxiety Disorder Clinic, University of Queensland	Psychiatrist
418. Mrs E Ferriday	Consumer
419. Ms C Fischer, Independent Advocacy in the Tropics	NGO
420. Mr M Free and Ms H Ravenscroft	Psychologists
421. Mr J Fry	Consumer
422. Mr M Galligan	Consumer
423. Mr R Garvey	Consumer
424. Mrs J Graham	Consumer
425. Mrs I Gray	Carer
426. The Hon W Goss, Premier	Govt
427. Mr B Green, John Oxley Memorial Hospital	Social Worker
428. Mr P Gregory, Advocacy for the Aged Association Inc	NGO
429. Mrs G Griffiths	Consumer
430. Mr J Hammett	Concerned Citizen
431. Mr P Halpin	Consumer

432.	Mr S Hamlyn-Harris, Legal Aid Office	Govt
433.	Ms D Hanson	Concerned Citizen
434.	Mrs C Healy	Consumer
435.	Mrs C Healy	Carer
436.	Sr C Hefferan, St Vincent de Paul Society	CRO
437.	Ms M Herring, Schizophrenia Fellowship of Nth Qld	NGO
438.	Mr R Hilsdon, Queensland Deaf Society	NGO
439.	Mr O Hodgson, Schizophrenia Fellowship	NGO
440.	Name withheld	Carer
441.	Name withheld	Carer
442.	Mrs J Holdway	Consumer
443.	Mrs P Hutchins, ARAFMI, Sunshine Coast	NGO
444.	Ms B Innis	Social Worker
445.	Mrs I Isaacs	Carer
446.	Prof B James, Director of Psychiatry, James Cook University at Townsville General Hospital	Psychiatrist
447.	Ms N Jessop, Fortitude Valley Community Mental Health Centre	Govt
448.	Mr D Jones, Queensland Nurses Union	Prof Assoc
449.	Mr P Jones, Safe Accommodation For Everyone (SAFE)	NGO
450.	Ms C Kerr	Occupational Therapist
451.	Mrs M Kilpatrick	Concerned Citizen
452.	Ms A Lamprecht	Carer
453.	Ms P Lang, Friends for the Mentally Ill	NGO
454.	Prof J Lawrence, University of Queensland at Royal Brisbane Hospital	Psychiatrist
455.	Mrs J Lawrence	Carer
456.	Ms E Leah	Consumer
457.	Ms K Lean	Consumer
458.	Names withheld	Carers
459.	Ms H Low	Consumer
460.	Ms M Lucas, GROW	NGO
461.	Name withheld	Psychiatric Nurse
462.	Name withheld	Consumer
463.	Mr D McLaughlin, ARAFMI	NGO
464.	Ms J McLaughlin, ARAFMI	NGO
465.	Mrs S McLoughlin	Consumer
466.	Mr G McMahon	Consumer
467.	Ms J Magub, Qld Association for Mental Health	NGO
468.	Names withheld	Carers
469.	Ms M Makin	Consumer
470.	Mr D Maroevic, Migrant Resource Centre	NGO
471.	Ms C Mercer, Marlish Aftercare Home	Private Hostel
472.	Mrs V Meyers	Carer
473.	Miami Special Interest Mental Health Group	NGO
474.	Mr W Milfull	Consumer
475.	Ms B Miller, Aboriginal Co-ordinating Council	NGO
476.	Mrs M Milne	Consumer
477.	Mrs J Muir	Carer
478.	Mrs A Miscovich	Carer
479.	Mrs Y Murray	Carer
480.	Mrs J Nicol, Schizophrenia Fellowship	NGO
481.	Mrs J Nicol	Carer

482.	Mr P O'Brien, Brisbane Psychiatric Social Workers Interest Group	Prof Assoc
483.	Mr V O'Donnell, Roma & District Community Support Association	NGO
484.	Mrs M O'Neill	Consumer
485.	Mrs K Payne	Carer
486.	Ms V Peisker	Consumer
487.	Mrs F Pownall, Caring Committee for the Mentally Ill	NGO
488.	Mr E Priddle	Psychiatric Nurse
489.	Queensland Government	Govt
490.	Mr J Quinn	Psychiatric Nurse
491.	Mr J Raine	Carer
492.	Ms S Raine	Carer
493.	Mr C Regan	Consumer
494.	Name withheld	Carer
495.	Mrs J Rocker	Carer
496.	Mrs J Roy	Carer
497.	Mr J Russell	Concerned Citizen
498.	Name withheld	Consumer
499.	Mr R Schluter	Consumer
500.	Ms M Schroder, Queensland Advocacy Inc	NGO
501.	Mr N Segal	Carer
502.	Mrs H Selinger	Carer
503.	Mr J Skelton, SOMA	NGO
504.	Name withheld	Consumer
505.	Mr H Smith	Consumer
506.	Fr J Smith, Catholic Psychiatric Pastoral Care	CRO
507.	Name withheld	Carer
508.	Mr P Stanley, Qld Dept of Health	Govt
509.	Mrs L Teallaj	Consumer
510.	Mrs M Tebbitt	Carer
511.	Name withheld	Consumer
512.	Mrs M Thomas	Carer
513.	Mr N Thompson	Consumer
514.	Ms S Tonkin, Queensland Council for Civil Liberties	NGO
515.	Dr P Tucker	Psychiatrist
516.	Name withheld	Carer
517.	Dr A Urquhart, Director, Psychiatry, Mater Children's Hospital	Psychiatrist
518.	Mrs M Vance	Consumer
519.	Mr T Wade, Australian National Association for Mental Health	NGO
520.	Ms S Wadley, National Carers' Association	NGO
521.	Mrs B Wainman	Consumer
522.	Mrs M Walsh, Australian Parent Advocacy	NGO
523.	Rev C Ware	Carer
524.	Mr D Warth	Consumer
525.	Dr P Watson	Anthropologist
526.	Names withheld	Carers
527.	Ms R Westbrook	Consumer
528.	Mrs D Wheeler	Carer
529.	Mrs M Whiting	Carer
530.	Mrs E Wilcox	Carer



- |      |   |                   |
|------|---|-------------------|
| 531. | Ms S Wilkie, Field Worker, Aboriginal & Islander Community Health Service | Govt              |
| 532. | Name withheld   | Consumer          |
| 533. | Mr R Williams, Queensland Wattle League for the Disabled                  | NGO               |
| 534. | Name withheld   | Psychiatric Nurse |

## WESTERN AUSTRALIA

<u>NAME</u>	<u>CLASSIFICATION</u>
535. Dr L Achimovich, Fremantle Hospital	Psychiatrist
536. Name withheld	Consumer
537. Ms T Antill, Psychiatric Occupational Therapists' Group, Osborne Park Hospital	Prof Assoc
538. Mr M Austen	Consumer
539. Mrs Laylmore	Carer
540. Mrs M Bellman	Consumer
541. Mrs H Berill	Consumer
542. Ms N Bertinshaw, Health Department, South West Region	Govt
543. Dr G Boranga, Multicultural Psychiatric Centre	Psychiatrist
544. Mrs D Borlase	Consumer
545. Ms E Brackenreg, Health Department, North East Metropolitan Region	Govt
546. Name withheld	Advocate
547. Mrs H Buckley	Carer
548. Mr W Burong	Carer
549. Ms R Butcher	Consumer
550. Mrs H Byles Drage	Psychologist
551. Mrs P Carberry, ARAFMI	NGO
552. Mr F Collard	Concerned Citizen
553. Mr C Coopes, Accommodation Support Program, WA Health Dept	Govt
553a. Mr G Covich, Schizophrenia Fellowship	NGO
554. Sr B Daly	Prison Visitor
555. Name withheld	Carer
556. Name withheld	Carer
557. Ms P Dudgeon	Psychologist
558. Ms J Dye, Milgrey House	NGO
559. Mr B Edwards	Consumer
560. Mrs M English	Carer
561. Ms D Fergusson-Stewart, Caring Services, Anglican Homes	CRO
562. Mr H French	Concerned Citizen
563. Mr J Gardiner	Clinical Psychologist
564. Ms J Geary	Consumer
565. Dr J Godfrey	Carer
566. Mr B Gooley	Concerned Citizen
567. Mr E Gosney	Consumer
568. Mr N Gregory, Australian Congress of Mental Health Nurses	Prof Assoc
569. Mr P Hammond	Concerned Citizen
570. Mr G Hancy	Concerned Citizen
571. Ms M Harries, Australian Association of Social Workers	Prof Assoc
572. Ms B Harris, Emmanuel Centrecare	CRO
573. Ms E Hayden, Southern Aboriginal Corporation	NGO
574. Mr R Hetherington	Concerned Citizen
575. Dr Neville Hills	Psychogeriatrician
576. Name withheld	Consumer
577. Dr D Jacobs, RANZCP	Prof Assoc
578. Ms M Johnson, Drug Adverse Reaction Information Centre	NGO

579.	Name withheld	Consumer
580.	Name withheld	Psychiatric Nurse
581.	Ms C Kneebone, Albany Schizophrenia Fellowship	NGO
582.	Dr S Kostov, Multicultural Psychiatric Centre	Psychiatrist
583.	Ms M Leach, Outcare, Civil Rehabilitation Council of WA	NGO
584.	Name withheld	Consumer
585.	Dr J Leavesley, Heathcote Board of Visitors	ISOH
586.	Ms E Lenz, Resource Centre for Personal Development	NGO
587.	Dr John Lindsay, Former Director, Ward 10B, Townsville	Psychiatrist
588.	Dr J Lister	Psychiatrist
589.	Dr D Lord, RANZCP	Prof Assoc
590.	Mr R Mace	Concerned Citizen
591.	Ms L MacLeod, WA Psychiatric Nurses' Association	Prof Assoc
592.	Ms M MacPherson	Social Worker
593.	Ms L Maddison	Psychiatric Nurse
594.	Mr J Manners, Institute of Private Clinical Psychologists	Prof Assoc
595.	Mr J and Mrs P Marsh	Carers
596.	Name withheld	Consumer
597.	Mr N Mhen	Psychiatric Nurse
598.	Mr W O'Brien	Psychiatric Nurse
599.	June O'Connor Centre	NGO
600.	Ms B Other-Gee, WACOSS	NGO
601.	Name withheld	Consumer
602.	Names withheld	Carers
603.	Ms V Rowney, Country Women's Association of WA	NGO
604.	Mrs I Sales	Consumer
605.	Name withheld	Carer
606.	Name withheld	Consumer
607.	Mrs H Sharp, Albany Schizophrenia Fellowship	NGO
608.	Mr N Sharp	Concerned Citizen
609.	Ms J Sinclair	Welfare Officer
610.	Dr D Smith, South-West Health Region, WA Health Department	Psychiatrist
611.	Name withheld	Consumer
612.	Ms P Stone	Social Worker
613.	Name withheld	Consumer
614.	Mr P Thompson	Carer
615.	Mr J & Mrs J Tracey	Carers
616.	Ms T Vanderwal, Mentally Ill Need Defending (MIND)	NGO
617.	Ms A Wearne	Social Worker, Academic
618.	Ms C White	Concerned Citizen
619.	Ms J Winch, Marr Mooditj Foundation, Aboriginal Health Worker College	Academic
620.	Mr K Wyatt, Aboriginal Health Policy Unit, Health Dept of WA	Govt
621.	Ms C O'Farrell, Regional Director, Kimberley Health Region	Govt
622.	Mr P O'Hara, Social Work Supervisor, Graylands Hospital	Social Worker
623.	Ms B Pondaag, Pilbara Region, WA Health Department	Govt
624.	Name Withheld	Consumer
625.	Western Australian Government	Govt
626.	The Hon Keith Wilson MLA, WA Minister for Health	Govt

## NORTHERN TERRITORY

<u>NAME</u>	<u>CLASSIFICATION</u>
627. Mr J Arrand, NT Council on the Ageing	NGO
628. Ms S Capes	Consumer
629. Ms E Carter, Central Australian Aboriginal Congress	NGO
630. Mrs M Crabbe	Concerned Citizen
631. Ms D Hall, NT Dept of Health and Community Services	Govt
632. Ms J Harrison, Central Australian Advocacy Service	NGO
633. Dept of Health and Community Services	Govt
634. Name withheld	Carer
635. Mr J Hopkins, Disability Services of Central Australia	NGO
636. Ms S de la Hunt, Commonwealth Rehabilitation Service	Govt
637. Name withheld	Consumer
638. Mr J Lawrence, North Australian Aboriginal Legal Service	NGO
639. Mr W McMahon, NT Association for Mental Health	NGO
640. Mr W McMahon, St Vincent de Paul Society	NGO
641. Ms A Mitchell	Social Worker
642. Mr G Norris	Psychiatric Nurse
643. Mr M Owen, Miwatj Health Aboriginal Corporation	NGO
644. Mr F Panaia, Secretary, NT Assoc for Mental Health	NGO
645. Ms G Payne, GROW	NGO
646. Ms J Pendlebury, Dawn House Women's Shelter	NGO
647. Mrs M Pere	Carer
648. The Hon M Perron MP, Chief Minister	Govt
649. Name withheld	Consumer
650. Ms B Shaw, Tangentyere Council	NGO
651. Dr P Thorn	Medical Practitioner
652. Mr J Torkington	Concerned Citizen
653. Dr B Tyler, NT Mental Health Association	NGO
654. Mr R Wesley-Smith	Concerned Citizen

ACT

<u>NAME</u>	<u>CLASSIFICATION</u>
655. ACT Government	Govt
656. Mr B Aldcroft, Ainslie Village	NGO
657. Dr M Anderson	Concerned Citizen
658. Mr B Bailey, Acting Community Advocate	Govt
659. Mr L Barr	Consumer
660. Name withheld	Carer
661. Names withheld	Carers
662. Ms J Braithwaite, ACROD	NGO
663. Ms G Burnett	Consumer
664. Name withheld	Concerned Citizen
665. Mr P Chivers, Adult Corrective Services, ACT Housing and Community Services Bureau	Govt
666. Name withheld	Carer
667. Name withheld	Consumer
668. Ms K Fryar, Legal Aid Office	Govt
669. Names withheld	Carers
670. Ms D Gordon, Australian Association of Social Workers	Prof Assoc
671. Name withheld	Consumer
672. Commonwealth Department of Health, Housing and Community Services	Govt
673. Mr P Hinchliffe, Ainslie Village Residents Association	NGO
674. Mr B I'Anson, Mental Health Foundation	NGO
675. Dr T Jorm, Social Psychiatry Research Unit, ANU and NHMRC	Research Psychiatrist
676. Mr B Lloyd	Law Student
677. Mr P Lowe	Concerned Citizen
678. Ms P Lowrey, Mental Health Task Force, Consumers' Health Forum	NGO
679. Mr D McIver	Consumer
680. Name withheld	Carer
681. Ms R Nairn, Child and Adolescent Unit, ACT Mental Health Services	Govt
682. Ms L O'Donoghue, Citizens' Committee on Human Rights	NGO
683. Dr S Rosenman, Director of Psychiatry, Woden Valley Hospital	Psychiatrist
684. Mr B Shaw, Consumers' Health Forum	NGO
685. Ms L Steeper, ACTCOSS Mental Health Task Force	NGO
686. Ms C Stuart	Legal Researcher
687. Ms K Sutinen, Self-Supporting Schizophrenia Sufferers	NGO
688. Mr J Templeman	Carer
689. Name withheld	Consumer
690. Name withheld	Consumer

## SOUTH AUSTRALIA

<u>NAME</u>	<u>CLASSIFICATION</u>
691. Ms J Anderson, SA Association of Mental Health Social Workers	Prof Assoc
692. Ms B Arnold, Community Accommodation Support Services	Govt
693. Australian Nursing Federation	Prof Assoc
694. Name withheld	Consumer
695. Mr J Blassky	Concerned Citizen
696. Ms E Bleby	Social Worker
697. Mr R Bruggeman, Intellectual Disability Services Council	NGO
698. Name withheld	Carer
699. Ms C Caust, Child and Adolescent Mental Health Services	Govt
700. Mr R Chapman, Community Accommodation Support Service	Govt
701. Mr A Cielens	Concerned Citizen
702. Dr J Clayer, SA Health Commission Mental Health Research & Evaluation Centre	Govt
703. Mr D Crawley	Social Worker
704. Dr A Czechowicz, Carramar Clinic	Psychiatrist
705. Ms L Dalston, Mental Health Association and Resource Centre	NGO
706. Ms W Danforth, Murray Mallee Health & Social Welfare Council	NGO
707. Ms P Donoughue	Consumer
708. Mr M Dougherty, Housing and Disability Forum	NGO
709. Mr D Dowling	Consumer
710. Ms R Downing, Anorexia & Bulimia Nervosa Assoc	NGO
711. Ms A Draper, Management Assessment Panel for Behaviourally Disordered Persons	Govt
712. Ms M Dugon, Disability Complaints Service	NGO
713. Mr K Duke, Community Accommodation Support Service	Govt
714. Name withheld	Consumer
715. Dr R Elzinga, Hillcrest Hospital	Psychiatrist
716. Ms B Fox, Agoraphobia Assoc of SA	NGO
717. Ms S Fryar	Concerned Citizen
718. Name withheld	Consumer
719. Ms T Hart, Community Accommodation Support Service	Govt
720. Ms A Holmes	Social Worker
721. Mr R Holmes	Student
722. Irene Women's Shelter	NGO
723. Mr L James	Concerned Citizen
724. Dr N James, Chief Executive Officer, Hillcrest Hospital	Govt
725. Mr P John, Invicta Sheltered Workshops	Private Establishment
726. Mr D Jones	Consumer
727. Name withheld	Consumer
728. Ms B Kilernen	Concerned Citizen
729. Name withheld	Consumer
730. Prof R Kosky, University of Adelaide at Adelaide Children's Hospital	Psychiatrist
731. Name withheld	Consumer
732. Ms B Lazarus, Judith House	NGO
733. Mr H Lindquist	Consumer
734. Mr H Lucke, Semaphore Residents Assoc	NGO

735.	Ms S Madex	Consumer
736.	Dr G Martin, Southern Child and Adolescent Mental Health Service	Psychiatrist
737.	Sr J Mead, Adelaide Day Centre for Homeless Persons	CRO
738.	Mr D Meldrum, Mental Health Unit, SA Health Commission	Govt
739.	Mr L Mell	Academic
740.	Mr D Neville	Consumer
741.	Panic Anxiety Disorder Assoc of SA	NGO
742.	Ms S Pearce, Whyalla Hospital	Nurse
743.	Mr I Pitcher	Concerned Citizen
744.	Mr M Potter	Concerned Citizen
745.	Dr R Powrie	Concerned Citizen
746.	Mr K Rainsford, GROW	NGO
747.	Mr R Rana	Concerned Citizen
748.	Name withheld	Consumer
749.	Mrs J Sherry	Concerned Citizen
750.	Mr C Slocabe, Obsessive Compulsive Neurosis Support Group	NGO
751.	Name withheld	Consumer
752.	Name withheld	Consumer
753.	Name withheld	Carer
754.	Name withheld	Carer
755.	Name withheld	Carer
756.	Mrs F Towill	Consumer
757.	Mrs I Towler, Schizophrenia Fellowship of SA	NGO
758.	Mrs R Tucker	Carer
759.	Ms M Van Der Byl	Academic
760.	T J Wayne	Consumer
761.	Dr C Wilson, National Police Research Unit	Govt
762.	Mr R Woon, Self-Help Mood Disturbance Prevention (MDP)	NGO
763.	Ms D Wright, Central Clinic, Port Augusta	Govt

## TASMANIA

<u>NAME</u>	<u>CLASSIFICATION</u>
764. Dr T Avery	Psychiatrist
765. Name withheld	Psychiatric Nurse
766. Ms P Berkery, Domestic Violence Action Group	NGO
767. Mr T Blackwell, Co-ordinator, The Link, Youth Health Service	NGO
768. Ms M Blackwood, Southern Region Mental Health Service, Department of Health	Govt
769. Name withheld	Carer
770. Ms P Bourke, GROW	NGO
771. Mrs V Bradley	Carer
772. Name withheld	Carer
773. Mr C de Bills	Consumer
774. Dr N Cochrane, Department of Health	Psychologist
775. Ms T Evans, Domestic Violence Action Group	NGO
776. Ms M Fawdry, Tas Community Health Association	Psychiatric Nurse
777. Name withheld	Consumer
778. Ms S Goiser	Interpreter
779. Ms J Harwood	Carer
780. Ms E Holmes, Migrant Resource Centre	NGO
781. Mr P Johnson, ARAFMI	NGO
782. Names withheld	Concerned Citizens
783. Prof I Jones, Professor of Psychiatry, University of Tasmania	Psychiatrist
784. Dr W Kerr, Director of Psychiatric Services, Northwest Region	Govt
785. Mr F Kitson	Concerned Citizen
786. Mrs N Kuilenburg, Jireh House Assoc	NGO
787. Ms R Laver, Australian Psychological Society	Prof Assoc
788. Mr J Leary, Department of Health	Govt
789. Name withheld	Consumer
790. Ms K Linahan, Migrant Resource Centre	NGO
791. Name withheld	Carer
792. Ms J McCulloch	Itinerant Teacher
793. Ms G May	Community Worker
794. Name withheld	Carer
795. Ms M Nielsen, Community Hostels Assoc	NGO
796. Dr R Pargiter, Chairman, Ethics Committee, RANZCP	Prof Assoc
797. Mr S Pinkus, Clare House Child and Adolescent Mental Health Service	Govt
798. Psychiatric Services Division, Tasmanian Health Dept	Govt
799. Ms R Raward, ARAFMI	NGO
800. Dr S Pridmore, Psychiatric Services Division, Department of Health	Govt
801. Mr R Redom, Australian National Assoc for Mental Health	NGO
802. Name withheld	Carer
803. Mr I Ribic	Consumer
804. Dr M Roberts	Psychiatrist
805. Name withheld	Carer
806. Ms K Stanick	Social Worker
807. Ms J Tanner	Youth Worker
808. Name withheld	Consumer



809.	Tasmanian Government	Govt
810.	Mrs S Taylor	Social Worker
811.	Dr J Tooth, President, Alzheimer's Assoc	Psychogeriatrician
812.	Name withheld	Consumer

## MISCELLANEOUS

<u>NAME</u>	<u>CLASSIFICATION</u>
813. Alison	Carer
814. Anonymous	Consumer
815. Anonymous	Consumer
816. Anonymous	Carer
817. Anonymous	Consumer
818. Anonymous - SA	Consumer
819. Anonymous - TAS	Consumer
820. Anonymous - WA	Consumer
821. Anonymous - WA	Carer
822. Mr T Avery — NSW	Concerned Citizen
823. Mr M Carter	Concerned Citizen
824. People Against Power Abuse (Vic)	NGO
825. Mr G Matena	Social Worker
826. Name withheld	Consumer

**APPENDIX 3****FACILITIES VISITED BY INQUIRY**

All hospitals listed in this appendix are psychiatric hospitals. Psychiatric wards or units, however, are located in general hospitals.

<b>July 1991</b>	Newcastle	<ul style="list-style-type: none"><li>● Morisset Hospital</li><li>● Banksia House Rehabilitation Program</li><li>● Lake Macquarie Community Mental Health Team</li><li>● Residential Services Team, Mayfield</li></ul>
	Orange	<ul style="list-style-type: none"><li>● Bloomfield Hospital</li><li>● Arcadia House Community Mental Health Service</li><li>● SHIPS Program (Satellite Housing Integrated Programmed Support): Endeavour House and Kallara</li></ul>
<b>August 1991</b>	Townsville	<ul style="list-style-type: none"><li>● Psychiatric Unit (formerly Ward 10B), Townsville General Hospital</li><li>● Vincent Community Mental Health Centre</li></ul>
	Brisbane	<ul style="list-style-type: none"><li>● Royal Brisbane Hospital: Ward 3A and Ward B</li><li>● Rosemount Hospital</li><li>● John Oxley Hospital</li><li>● Wolston Park Hospital</li></ul>
<b>October 1991</b>	Adelaide	<ul style="list-style-type: none"><li>● Hillcrest Hospital</li><li>● James Nash House (Forensic Unit)</li><li>● Glenside Hospital</li><li>● Southern Child and Adolescent Mental Health Service (CAMHS), Flinders Medical Centre</li></ul>

**November 1991** Hobart

- Royal Derwent Hospital
- Risdon Prison Forensic Unit
- Flagstaff Gully Dementia Home
- Richmond Fellowship
- Peacock Hospital (Residential, Day and Respite Care)

**February 1992** Perth

- Lefroy Hostel (Dementia Care)
- Graylands Hospital
- Heathcote Hospital
- Royal Perth Hospital Psychiatric Unit
- Fremantle Hospital
- Fremantle Clinic
- Hillview Terrace Child and Family Clinic
- Hillview Terrace Hospital
- Selby Lodge
- Avro Clinic
- June O'Connor Drop-In Centre

Albany

- Milgrey House

**May 1992** Sydney

- Arndell Child and Adolescent Unit, Macquarie Hospital

**July 1992** Darwin

- Psychiatric Ward, Royal Darwin Hospital

Sydney

- Dementia Unit, Rozelle Hospital

**APPENDIX 4**

**DECLARATION ON THE RIGHTS OF DISABLED PERSONS**

*Proclaimed by General Assembly Resolution 3447 (XXX) of 9 December 1975*

*The General Assembly*

*Mindful* of the pledge made by Member States, under the Charter of the United Nations; to take joint and separate action in co-operation with the Organisation to promote higher standards of living, full employment and conditions of economic and social progress and development,

*Reaffirming* its faith in human rights and fundamental freedoms and in the principles of peace, of the dignity and worth of the human person and of social justice proclaimed in the Charter,

*Recalling* the principles of the Universal Declaration of Human Rights, the International Covenants on Human Rights, the Declaration of the Rights of the Child and the Declaration on the Rights of Mentally Retarded Persons, as well as the standards already set for social progress in the constitutions, conventions, recommendations and resolutions of the International Labour Organisation, the United Nations Educational, Scientific and Cultural Organisation, the World Health Organisation, the United Nations Children's Fund and other organisations concerned,

*Recalling* also Economic and Social Council resolution 1921 (LVIII) of 6 May 1975 on the prevention of disability and the rehabilitation of disabled persons,

*Emphasising* that the Declaration on Social Progress and Development has proclaimed the necessity of protecting the rights and assuring the welfare and rehabilitation of the physically and mentally disadvantaged,

*Bearing in mind* the necessity of preventing physical and mental disabilities and of assisting disabled persons to develop their abilities in the most varied fields of activities and of promoting their integration as far as possible in normal life,

*Aware* that certain countries, at their present stage of development, can devote only limited efforts to this end,

*Proclaims* this Declaration on the Rights of Disabled Persons and calls for national and international action to ensure that it will be used as a common basis and frame of reference for the protection of these rights:

- 1 The term 'disabled person' means any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capabilities.
- 2 Disabled persons shall enjoy all the rights set forth in this Declaration. These rights shall be granted to all disabled persons without any exception whatsoever and without distinction or discrimination on the basis of race, colour, sex, language, religion, political or other opinions, national or social origin, state of wealth, birth or any other situation applying either to the disabled person himself or herself or to his or her family.
- 3 Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible.
- 4 Disabled persons have the same civil and political rights as other human beings; paragraph 7 of the Declaration on the Rights of Mentally Retarded Persons applies to any possible limitation or suppression of those rights for mentally disabled persons.
- 5 Disabled persons are entitled to the measures designed to enable them to become as self-reliant as possible.
- 6 Disabled persons have the right to medical, psychological and functional treatment, including prosthetic and orthotic appliances, to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the process of their social integration or reintegration.
- 7 Disabled persons have the right to economic and social security and to a decent level of living. They have the right, according to their capabilities, to secure and retain employment or to engage in a useful, productive and remunerative occupation and to join trade unions.

- 8 Disabled persons are entitled to have their special needs taken into consideration at all stages of economic and social planning.
- 9 Disabled persons have the right to live with their families or with foster parents and to participate in all social, creative or recreational activities. No disabled person shall be subjected, as far as his or her residence is concerned, to differential treatment other than that required by his or her condition or by the improvement which he or she may derive therefrom. If the stay of a disabled person in a specialised establishment is indispensable, the environment and living conditions therein shall be as close as possible to those of the normal life of a person of his or her age.
- 10 Disabled persons shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature.
- 11 Disabled persons shall be able to avail themselves of qualified legal aid when such aid proves indispensable for the protection of their persons and property. If judicial proceedings are instituted against them, the legal procedure applied shall take their physical and mental condition fully into account.
- 12 Organisations of disabled persons may be usefully consulted in all matters regarding the rights of disabled persons.
- 13 Disabled persons, their families and communities shall be fully informed, by all appropriate means, of the rights contained in this Declaration.

**APPENDIX 5**

**PRINCIPLES FOR THE PROTECTION OF PERSONS WITH MENTAL ILLNESS AND FOR THE IMPROVEMENT OF MENTAL HEALTH CARE**

**APPLICATION**

These principles shall be applied without discrimination of any kind such as on grounds of disability, race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, legal or social status, age, property or birth.

**DEFINITIONS**

In these Principles:

‘counsel’ means a legal or other qualified representative;

‘independent authority’ means a competent and independent authority prescribed by domestic law;

‘mental health care’ includes analysis and diagnosis of a person’s mental condition, and treatment, care and rehabilitation for a mental illness or suspected mental illness;

‘mental health facility’ means any establishment, or any unit of an establishment, which as its primary function provides mental health care;

‘mental health practitioner’ means a medical doctor, clinical psychologist, nurse, social worker or other appropriately trained and qualified person with specific skills relevant to mental health care;

‘patient’ means a person receiving mental health care and includes all persons who are admitted to a mental health facility;

‘personal representative’ means a person charged by law with the duty of representing a patient’s interests in any specified respect or of exercising specified rights on the patient’s behalf, and includes the parent or legal guardian of a minor unless otherwise provided by domestic law;



'the review body' means the body established in accordance with Principle 17 to review the involuntary admission or retention of a patient in a mental health facility.

## **GENERAL LIMITATION CLAUSE**

The exercise of the rights set forth in these Principles may be subject only to such limitations as are prescribed by law and are necessary to protect the health or safety of the person concerned or of others or otherwise to protect public safety, order, health or morals or the fundamental rights and freedoms of others.

### **Principle 1**

#### **FUNDAMENTAL FREEDOMS AND BASIC RIGHTS**

1. All persons have the right to the best available mental health care, which shall be part of the health and social care system.
2. All persons with a mental illness, or who are being treated as such persons, shall be treated with humanity and respect for the inherent dignity of the human person.
3. All persons with a mental illness, or who are being treated as such persons, have the right to protection from economic, sexual and other forms of exploitation, physical or other abuse and degrading treatment.
4. There shall be no discrimination on the grounds of mental illness. 'Discrimination' means any distinction, exclusion or preference that has the effect of nullifying or impairing equal enjoyment of rights. Special measures solely to protect the rights, or secure the advancement, of persons with mental illness shall not be deemed to be discriminatory. Discrimination does not include any distinction, exclusion or preference undertaken in accordance with the provisions of these Principles and necessary to protect the human rights of a person with a mental illness or of other individuals.
5. Every person with a mental illness shall have the right to exercise all civil, political, economic, social and cultural rights as recognised in the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and in other relevant instruments such as the

**Declaration on the Rights of Disabled Persons and the Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment.**

6. Any decision that, by reason of his or her mental illness, a person lacks legal capacity, and any decision that, in consequence of such incapacity, a personal representative shall be appointed, shall be made only after a fair hearing by an independent and impartial tribunal established by domestic law. The person whose capacity is in issue shall be entitled to be represented by a counsel. If the person whose capacity is in issue does not himself or herself secure such representation it shall be made available without payment by that person to the extent that he or she does not have sufficient means to pay for it. The counsel shall not in the same proceedings represent a mental health facility or its personnel and shall not also represent a member of the family of the person whose capacity is in issue unless the tribunal is satisfied that there is no conflict of interest. Decisions regarding capacity and the need for a personal representative shall be reviewed at reasonable intervals prescribed by domestic law. The person whose capacity is in issue, his or her personal representative, if any, and any other interested person shall have the right to appeal to a higher court against any such decision.
  
7. Where a court or other competent tribunal finds that a person with mental illness is unable to manage his or her own affairs, measures shall be taken, so far as is necessary and appropriate to that person's condition, to ensure the protection of his or her interests.

**Principle 2**

**PROTECTION OF MINORS**

Special care should be given within the purposes of these Principles and within the context of domestic law relating to the protection of minors to protect the rights of minors, including, if necessary, the appointment of a personal representative other than a family member.

**Principle 3**

**LIFE IN THE COMMUNITY**

Every person with a mental illness shall have the right to live and work, as far as possible, in the community.

## **Principle 4**

### **DETERMINATION OF MENTAL ILLNESS**

1. A determination that a person has a mental illness shall be made in accordance with internationally accepted medical standards.
2. A determination of mental illness shall never be made on the basis of political, economic or social status, or membership of a cultural, racial or religious group, or any other reason not directly relevant to mental health status.
3. Family or professional conflict, or non-conformity with moral, social, cultural or political values or religious beliefs prevailing in a person's community, shall never be a determining factor in diagnosing mental illness.
4. A background of past treatment or hospitalisation as a patient shall not of itself justify any present or future determination of mental illness.
5. No person or authority shall classify a person as having, or otherwise indicate that a person has, a mental illness except for purposes directly relating to mental illness or the consequences of mental illness.

## **Principle 5**

### **MEDICAL EXAMINATION**

No person shall be compelled to undergo medical examination with a view to determining whether or not he or she has a mental illness except in accordance with a procedure authorised by domestic law.

## **Principle 6**

### **CONFIDENTIALITY**

The right of confidentiality of information concerning all persons to whom these Principles apply shall be respected.

### **Principle 7**

#### **ROLE OF COMMUNITY AND CULTURE**

1. Every patient shall have the right to be treated and cared for, as far as possible, in the community in which he or she lives.
2. Where treatment takes place in a mental health facility, a patient shall have the right, whenever possible, to be treated near his or her home or the home of his or her relatives or friends and shall have the right to return to the community as soon as possible.
3. Every patient shall have the right to treatment suited to his or her cultural background.

### **Principle 8**

#### **STANDARDS OF CARE**

1. Every patient shall have the right to receive such health and social care as is appropriate to his or her health needs, and is entitled to care and treatment in accordance with the same standards as other ill persons.
2. Every patient shall be protected from harm, including unjustified medication, abuse by other patients, staff or others or other acts causing mental distress or physical discomfort.

### **Principle 9**

#### **TREATMENT**

1. Every patient shall have the right to be treated in the least restrictive environment and with the least restrictive or intrusive treatment appropriate to the patient's health needs and the need to protect the physical safety of others.
2. The treatment and care of every patient shall be based on an individually prescribed plan, discussed with the patient, reviewed regularly, revised as necessary and provided by qualified professional staff.

3. Mental health care shall always be provided in accordance with applicable standards of ethics for mental health practitioners, including internationally accepted standards such as the Principles of Medical Ethics adopted by the United Nations General Assembly. Mental health knowledge and skills shall never be abused.
4. The treatment of every patient shall be directed towards preserving and enhancing personal autonomy.

### **Principle 10**

#### **MEDICATION**

1. Medication shall meet the best health needs of the patient and shall be given to a patient only for therapeutic or diagnostic purposes and shall never be administered as a punishment, or for the convenience of others. Subject to the provisions of paragraph 15 of Principle 11, mental health practitioners shall only administer medication of known or demonstrated efficacy.
2. All medication shall be prescribed by a mental health practitioner authorised by law and shall be recorded in the patient's records.

### **Principle 11**

#### **CONSENT TO TREATMENT**

1. No treatment shall be given to a patient without his or her informed consent, except as provided for in paragraphs 6, 7, 8, 13 and 15.
2. Informed consent is consent obtained freely without threats or improper inducements after appropriate disclosure to the patient of adequate and understandable information in a form and language understood by the patient on:
  - (a) The diagnostic assessment;
  - (b) The purpose, method, likely duration and expected benefit of the proposed treatment;
  - (c) Alternative modes of treatment, including those less intrusive; and

- (d) Possible pain or discomfort, risks and side-effects of the proposed treatment.
3. A patient may request the presence of a person or persons of the patient's choosing during the procedure for granting consent.
  4. A patient has the right to refuse or stop treatment except as provided for in paragraphs 6, 7, 8, 13 and 15. The consequences of refusing or stopping treatment must be explained to the patient.
  5. A patient shall never be invited or induced to waive the right to informed consent. If the patient should seek to do so, it shall be explained to the patient that the treatment cannot be given without informed consent.
  6. Except as provided in paragraphs 7, 8, 12, 13, 14 and 15 a proposed plan of treatment may be given to a patient without a patient's informed consent if the following conditions are satisfied:
    - (a) The patient is, at the relevant time, held as an involuntary patient;
    - (b) An independent authority, having in its possession all relevant information, including the information specified in paragraph 2, is satisfied that, at the relevant time, the patient lacks the capacity to give or withhold informed consent to the proposed plan of treatment or, if domestic legislation so provides, that, having regard to the patient's own safety or the safety of others, the patient unreasonably withholds such consent; and
    - (c) The independent authority is satisfied that the proposed plan of treatment is in the best interests of the patient's health needs.
  7. Paragraph 6 does not apply to a patient with a personal representative empowered by law to consent to treatment for the patient; but except as provided in paragraphs 12, 13, 14 and 15 treatment may be given to such a patient without his or her informed consent if the personal representative, having been given the information described in paragraph 2, consents on the patient's behalf.
  8. Except as provided in paragraphs 12, 13, 14 and 15 treatment may also be given to any patient without the patient's informed consent if a qualified mental health practitioner authorised by law determines that it is urgently necessary in order to prevent immediate or imminent harm to

the patient or to other persons. Such treatment shall not be prolonged beyond the period which is strictly necessary for this purpose.

9. Where any treatment is authorised without the patient's informed consent, every effort shall nevertheless be made to inform the patient about the nature of the treatment and any possible alternatives, and to involve the patient as far as practicable in the development of the treatment plan.
10. All treatment shall be immediately recorded in the patient's medical records, with an indication of whether involuntary or voluntary.
11. Physical restraint or involuntary seclusion of a patient shall not be employed except in accordance with the officially approved procedures of the mental health facility and only when it is the only means available to prevent immediate or imminent harm to the patient or others. It shall not be prolonged beyond the period which is strictly necessary for this purpose. All instances of physical restraint or involuntary seclusion, the reasons for them, and their nature and extent shall be recorded in the patient's medical record. A patient who is restrained or secluded shall be kept under humane conditions and be under the care and close and regular supervision of qualified members of the staff. A personal representative, if any and if relevant, shall be given prompt notice of any physical restraint or involuntary seclusion of the patient.
12. Sterilisation shall never be carried out as a treatment for mental illness.
13. A major medical or surgical procedure may be carried out on a person with mental illness only where it is permitted by domestic law, where it is considered that it would best serve the health needs of the patient and where the patient gives informed consent, except that, where the patient is unable to give informed consent, the procedure shall be authorised only after independent review.
14. Psychosurgery and other intrusive and irreversible treatments for mental illness shall never be carried out on a patient who is an involuntary patient in a mental health facility and, to the extent that domestic law permits them to be carried out, they may be carried out on any other patient only where the patient has given informed consent and an independent external body has satisfied itself that there is genuine informed consent and that the treatment best serves the health needs of the patient.

15. Clinical trials and experimental treatment shall never be carried out on any patient without informed consent, except that a patient who is unable to give informed consent may be admitted to a clinical trial or given experimental treatment but only with the approval of a competent, independent review body specifically constituted for this purpose.
16. In the cases specified in paragraphs 6, 7, 8, 13, 14 and 15, the patient or his or her personal representative, or any interested person, shall have the right to appeal to a judicial or other independent authority concerning any treatment given to him or her.

### **Principle 12**

#### **NOTICE OF RIGHTS**

1. A patient in a mental health facility shall be informed as soon as possible after admission, in a form and a language which the patient understands, of all his or her rights in accordance with these Principles and under domestic law, which information shall include an explanation of those rights and how to exercise them.
2. If and for so long as a patient is unable to understand such information, the rights of the patient shall be communicated to the personal representative, if any and if appropriate, and to the person or persons best able to represent the patient's interests and willing to do so.
3. A patient who has the necessary capacity has the right to nominate a person who should be informed on his or her behalf as well as a person to represent his or her interests to the authorities of the facility.

### **Principle 13**

#### **RIGHTS AND CONDITIONS IN MENTAL HEALTH FACILITIES**

1. Every patient in a mental health facility shall, in particular, have the right to full respect for his or her:
  - (a) Recognition everywhere as a person before the law;
  - (b) Privacy;



- (c) Freedom of communication which includes freedom to communicate with other persons in the facility; freedom to send and receive uncensored private communications; freedom to receive, in private, visits from a counsel or personal representative and, at all reasonable times, from other visitors; and freedom of access to postal and telephone services and to newspapers, radio and television;
  - (d) Freedom of religion or belief.
2. The environment and living conditions in mental health facilities shall be as close as possible to those of the normal life of persons of similar age and in particular shall include:
- (a) Facilities for recreational and leisure activities;
  - (b) Facilities for education;
  - (c) Facilities to purchase or receive items for daily living, recreation and communication;
  - (d) Facilities, and encouragement to use such facilities, for a patient's engagement in active occupation suited to his or her social and cultural background, and for appropriate vocational rehabilitation measures to promote reintegration in the community. These measures should include vocational guidance, vocational training and placement services to enable patients to secure or retain employment in the community.
3. In no circumstances shall a patient be subject to forced labour. Within the limits compatible with the needs of the patient and with the requirements of institutional administration, a patient shall be able to choose the type of work he or she wishes to perform.
4. The labour of a patient in a mental health facility shall not be exploited. Every such patient shall have the right to receive the same remuneration for any work which he or she does as would, according to domestic law or custom, be paid for such work to a non-patient. Every such patient shall in any event have the right to receive a fair share of any remuneration which is paid to the mental health facility for his or her work.

## **Principle 14**

### **RESOURCES FOR MENTAL HEALTH FACILITIES**

1. A mental health facility shall have access to the same level of resources as any other health establishment, and in particular:
  - (a) Qualified medical and other appropriate professional staff in sufficient numbers and with adequate space to provide each patient with privacy and a program of appropriate and active therapy;
  - (b) Diagnostic and therapeutic equipment for the patient;
  - (c) Appropriate professional care; and
  - (d) Adequate, regular and comprehensive treatment, including supplies of medication.
2. Every mental health facility shall be inspected by the competent authorities with sufficient frequency to ensure that the conditions, treatment, and care of patients comply with these Principles.

## **Principle 15**

### **ADMISSION PRINCIPLES**

1. Where a person needs treatment in a mental health facility, every effort shall be made to avoid involuntary admission.
2. Access to a mental health facility shall be administered in the same way as access to any other facility for any other illness.
3. Every patient not admitted involuntarily shall have the right to leave the mental health facility at any time unless the criteria for his or her retention as an involuntary patient, as set forth in Principle 16, apply, and he or she shall be informed of that right.

## **Principle 16**

### **INVOLUNTARY ADMISSION**

1. A person may (a) be admitted involuntarily to a mental health facility as a patient; or (b) having already been admitted voluntarily as a patient, be retained as an involuntary patient in the mental health facility, if and only if a qualified mental health practitioner authorised by law for that purpose determines, in accordance with Principle 4, that that person has a mental illness and considers:
  - (i) That, because of that mental illness, there is a serious likelihood of immediate or imminent harm to that person or to other persons; or
  - (ii) That, in the case of a person whose mental illness is severe and whose judgement is impaired, failure to admit or retain that person is likely to lead to a serious deterioration in his or her condition or will prevent the giving of appropriate treatment which can only be given by admission to a mental health facility in accordance with the principle of the least restrictive alternative.

In the case referred to in subparagraph (ii), a second such mental health practitioner, independent of the first, should be consulted where possible. If such consultation takes place, the involuntary admission or retention may not take place unless the second mental health practitioner concurs.
2. Involuntary admission or retention shall initially be for a short period as specified by domestic law for observation and preliminary treatment pending review of the admission or retention by the review body. The grounds of the admission shall be communicated to the patient without delay and the fact of the admission and the grounds for it shall also be communicated promptly and in detail to the review body, to the patient's personal representative, if any, and, unless the patient objects, to the patient's family.
3. A mental health facility may receive involuntarily admitted patients only if the facility has been designated to do so by a competent authority prescribed by domestic law.

## **Principle 17**

### **REVIEW BODY**

1. The review body shall be a judicial or other independent and impartial body established by domestic law and functioning in accordance with procedures laid down by domestic law. It shall, in formulating its decisions, have the assistance of one or more qualified and independent mental health practitioners and take their advice into account.
2. The review body's initial review, as required by Principle 16.2, of a decision to admit or retain a person as an involuntary patient shall take place as soon as possible after that decision and shall be conducted in accordance with simple and expeditious procedures as specified by domestic law.
3. The review body shall periodically review the cases of involuntary patients at reasonable intervals as specified by domestic law.
4. An involuntary patient may apply to the review body for release or voluntary status, at reasonable intervals as specified by domestic law.
5. At each review the review body shall consider whether the criteria for involuntary admission set out in Principle 16.1 are still satisfied, and, if not, the patient shall be discharged as an involuntary patient.
6. If at any time the mental health practitioner responsible for the case is satisfied that the conditions for the retention of a person as an involuntary patient are no longer satisfied, he or she shall order the discharge of that person as such a patient.
7. A patient or his personal representative or any interested person shall have the right to appeal to a higher court against a decision that the patient be admitted to, or be retained in, a mental health facility.

## **Principle 18**

### **PROCEDURAL SAFEGUARDS**

1. The patient shall be entitled to choose and appoint a counsel to represent the patient as such, including representation in any complaint procedure or appeal. If the patient does not secure such services, a counsel shall be

made available without payment by the patient to the extent that the patient lacks sufficient means to pay.

2. The patient shall also be entitled to the assistance, if necessary, of the services of an interpreter. Where such services are necessary and the patient does not secure them, they shall be made available without payment by the patient to the extent that the patient lacks sufficient means to pay.
3. The patient and the patient's counsel may request and produce at any hearing an independent mental health report and any other reports and oral, written and other evidence that are relevant and admissible.
4. Copies of the patient's records and any reports and documents to be submitted shall be given to the patient and to the patient's counsel except in special cases where it is determined that a specific disclosure to the patient would cause serious harm to the patient's health or put at risk the safety of others. As domestic law may provide, any document not given to the patient should, when this can be done in confidence, be given to the patient's personal representative and counsel. When any part of a document is withheld from a patient, the patient or the patient's counsel, if any, shall receive notice of the withholding and the reasons for it and it shall be subject to judicial review.
5. The patient and the patient's personal representative and counsel shall be entitled to attend, participate and be heard personally in any hearing.
6. If the patient or the patient's personal representative or counsel requests that a particular person be present at a hearing, that person shall be admitted unless it is determined that the person's presence could cause serious harm to the patient's health or put at risk the safety of others.
7. Any decision whether the hearing or any part of it shall be in public or in private and may be publicly reported shall give full consideration to the patient's own wishes, to the need to respect the privacy of the patient and of other persons and to the need to prevent serious harm to the patient's health or to avoid putting at risk the safety of others.
8. The decision arising out of the hearing and the reasons for it shall be expressed in writing. Copies shall be given to the patient and his or her personal representative and counsel. In deciding whether the decision shall be published in whole or in part, full consideration shall be given to the patient's own wishes, to the need to respect his or her privacy and

that of other persons, to the public interest in the open administration of justice and to the need to prevent serious harm to the patient's health or to avoid putting at risk the safety of others.

### **Principle 19**

#### **ACCESS TO INFORMATION**

1. A patient (which term in this Principle includes a former patient) shall be entitled to have access to the information concerning the patient in his or her health and personal records maintained by a mental health facility. This right may be subject to restrictions in order to prevent serious harm to the patient's health and avoid putting at risk the safety of others. As domestic law may provide, any such information not given to the patient should, when this can be done in confidence, be given to the patient's personal representative and counsel. When any of the information is withheld from a patient, the patient or the patient's counsel, if any, shall receive notice of the withholding and the reasons for it and it shall be subject to judicial review.
2. Any written comments by the patient or the patient's personal representative or counsel shall, on request, be inserted in the patient's file.

### **Principle 20**

#### **CRIMINAL OFFENDERS**

1. This Principle applies to persons serving sentences of imprisonment for criminal offences, or who are otherwise detained in the course of criminal proceedings or investigations against them, and who are determined to have a mental illness or who it is believed may have such an illness.
2. All such persons should receive the best available mental health care as provided in Principle 1. These Principles shall apply to them to the fullest extent possible, with only such limited modifications and exceptions as are necessary in the circumstances. No such modifications and exceptions shall prejudice the persons' rights under the instruments noted in Principle 1.5.

3. Domestic law may authorise a court or other competent authority, acting on the basis of competent and independent medical advice, to order that such persons be admitted to a mental health facility.
4. Treatment of persons determined to have a mental illness shall in all circumstances be consistent with Principle 11.

### **Principle 21**

#### **COMPLAINTS**

Every patient and former patient shall have the right to make a complaint through procedures as specified by domestic law.

### **Principle 22**

#### **MONITORING AND REMEDIES**

States shall ensure that appropriate mechanisms are in force to promote compliance with these Principles, for the inspection of mental health facilities, for the submission, investigation and resolution of complaints and for the institution of appropriate disciplinary or judicial proceedings for professional misconduct or violation of the rights of a patient.

### **Principle 23**

#### **IMPLEMENTATION**

1. States should implement these Principles through appropriate legislative, judicial, administrative, educational and other measures which they shall review periodically.
2. States shall make these Principles widely known by appropriate and active means.

## **Principle 24**

### **SCOPE OF PRINCIPLES RELATING TO MENTAL HEALTH FACILITIES**

These Principles apply to all persons who are admitted to a mental health facility.

## **Principle 25**

### **SAVING OF EXISTING RIGHTS**

There shall be no restriction upon or derogation from any existing rights of patients, including rights recognised in applicable international or domestic law, on the pretext that these Principles do not recognise such rights or that they recognise them to a lesser extent.



## **APPENDIX 6**

# **GLOSSARY**

<b>AASW:</b>	<b>Australian Association of Social Workers</b>
<b>ABS:</b>	<b>Australian Bureau of Statistics</b>
<b>ACHS:</b>	<b>Australian Council on Healthcare Standards</b>
<b>ACOSS:</b>	<b>Australian Council of Social Service</b>
<b>ADARDS:</b>	<b>Alzheimer's Disease and Related Disorders Society</b>
<b>ADEC:</b>	<b>Australian Drug Evaluation Committee.</b>
<b>AGPS:</b>	<b>Australian Government Publishing Service.</b>
<b>AHMAC:</b>	<b>Australian Health Ministers' Advisory Council</b>
<b>AIDS:</b>	<b>Acquired Immune-Deficiency Syndrome</b>
<b>AIMHS:</b>	<b>Area Integrated Mental Health Service</b>
<b>AMA:</b>	<b>Australian Medical Association</b>
<b>AMI:</b>	<b>Alliance for the Mentally Ill, Australia</b>
<b>ANAMH:</b>	<b>Australian National Association for Mental Health</b>
<b>ANF:</b>	<b>Australian Nursing Federation</b>
<b>APS:</b>	<b>Australian Psychological Society</b>
<b>ARAFMI:</b>	<b>Association for the Relatives and Friends of the Mentally Ill</b>
<b>ARAFEMI:</b>	<b>Association for the Relatives and Friends of the Emotionally and Mentally Ill</b>
<b>ATSI:</b>	<b>Aboriginal and Torres Strait Islander</b>
<b>CAAC:</b>	<b>Central Australian Aboriginal Congress</b>
<b>CAAS:</b>	<b>Central Australian Advocacy Service</b>
<b>CADE:</b>	<b>Residential facility especially designed for the care of confused and disturbed elderly people in NSW.</b>
<b>CAMHS:</b>	<b>Child and Adolescent Mental Health Service</b>
<b>CAT:</b>	<b>Care and Assessment Team.</b>

CATT:	Care, Assessment and Treatment Team.
CASS:	Community Accommodation Support Service (SA)
CCO:	Community Counselling Order
CES:	Commonwealth Employment Service
CETAP:	Commonwealth Employment, Training and Placement
CHASP:	Community Health Accreditation Standards Project
CMHC:	Community Mental Health Centre
CMHS:	Community Mental Health Service
CRISP:	Client Registration/Individual Service Plan
CRS:	Commonwealth Rehabilitation Service
CTO:	Community Treatment Order
DEET:	Department of Employment, Education and Training (Commonwealth)
DNCB:	Domiciliary Nursing Care Benefit.
DISCA:	Disability Services of Central Australia
DSM:	Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R edition revised)
DSS:	Department of Social Security (Commonwealth)
ECT:	Electro Convulsive Therapy
GAT:	Geriatric Assessment Team.
GP:	General Practitioner
HACC:	Home and Community Care Program (Commonwealth)
HREOC:	Human Rights and Equal Opportunity Commission
ICCPR:	International Covenant on Civil and Political Rights.
ICD:	International Classification of Diseases
MIND:	Mentally Ill Need Defending (WA)
MINDS:	Mental Illness and Nervous Disorders Society (NSW)
NACON:	National Anglican Caring Associations Network

<b>NAPCAN:</b>	<b>National Association for the Prevention of Child Abuse and Neglect</b>
<b>NGO:</b>	<b>Non-Government Organisation</b>
<b>NH&amp;MRC:</b>	<b>National Health and Medical Research Council</b>
<b>PaNDa:</b>	<b>Post and Ante-Natal Depression Association</b>
<b>PBS:</b>	<b>Pharmaceutical Benefits Scheme</b>
<b>PECU:</b>	<b>Psychiatric Emergency Care Unit (WA).</b>
<b>PET:</b>	<b>Psychiatric Emergency Team (WA).</b>
<b>PMS:</b>	<b>Prison Medical Service</b>
<b>PND:</b>	<b>Post-Natal Depression</b>
<b>PRA:</b>	<b>Psychiatric Rehabilitation Association</b>
<b>RANZCP:</b>	<b>Royal Australian and New Zealand College of Psychiatrists</b>
<b>RCI:</b>	<b>Resident Classification Index</b>
<b>SAAP:</b>	<b>Supported Accommodation Assistance Program</b>
<b>SANS:</b>	<b>Supported Accommodation Network St Kilda (Vic).</b>
<b>SAYRAC:</b>	<b>South Australian Youth Remand and Assessment Centre</b>
<b>SEP:</b>	<b>Supported Employment Program</b>
<b>SHIPS:</b>	<b>Satellite Housing Integrated Programmed Support</b>
<b>STARTTS:</b>	<b>Service for the Treatment and Rehabilitation of Torture and Trauma Survivors (NSW).</b>
<b>TAFE:</b>	<b>Technical and Further Education (Colleges)</b>
<b>VMIAC</b>	<b>Victorian Mental Illness Awareness Council</b>
<b>VICSERV</b>	<b>Victorian Community-Managed Services</b>
<b>VMO:</b>	<b>Visiting Medical Officer</b>
<b>WHO:</b>	<b>World Health Organisation</b>



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