

VOL  
1

# Human Rights & Mental Illness

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

**HUMAN RIGHTS  
AND  
MENTAL ILLNESS**

**REPORT OF THE NATIONAL  
INQUIRY INTO THE HUMAN RIGHTS  
OF PEOPLE WITH MENTAL ILLNESS**

**Volume 1**



**HUMAN RIGHTS AND  
EQUAL OPPORTUNITY COMMISSION**

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**Human Rights and  
Equal Opportunity Commission**



*Human Rights Commissioner*

16 September 1993

The Hon Michael Lavarch MP  
Attorney-General  
Parliament House  
CANBERRA ACT 2600

Dear Attorney

We enclose the report of our National Inquiry into Human Rights and Mental Illness. This Inquiry was conducted pursuant to the powers and responsibilities conferred on the Human Rights and Equal Opportunity Commission under Federal law. Given the numerous and serious breaches of human rights which are identified, we respectfully request that the Government give urgent consideration to the report and to the recommendations we have made.

Yours sincerely

BRIAN BURDEKIN  
Federal Human Rights Commissioner

DAME MARGARET GUILFOYLE  
Commissioner

DAVID HALL  
Commissioner



## PREFACE

This report has been made possible by the many thoughtful written and oral submissions received from people affected by mental illness, their carers, members of the public, community organisations, and also Federal, State and Territory governments. The problems which it identifies require responses not only from governments, but from our community and, indeed, each of us as individuals.

A major difficulty in compiling this report has been the lack of relevant research in Australia relating to mental illness – including its incidence, effects and treatments available for those affected. We found many dedicated individuals and organisations working with very little information and very few resources – often unaware of developments elsewhere in Australia that could have assisted them. We have therefore attempted, within the limits of our resources, to include material and to structure this report in such a way that it will have some continuing value as a reference for Australians affected by mental illness and those working with them.

We wish to place on record our appreciation to staff of the Human Rights and Equal Opportunity Commission for their dedication, professionalism and sheer hard work. Many contributed at different times but we wish to thank particularly Anne Plummer, Rebecca Peters, Rana Flowers, Helen Hurwitz, Kim Ross, Kieren Fitzpatrick, Judy Brookman, Ruth Callaghan, Leanne Craze, David Mason, Susan Coles and Nerida Blair.

# NATIONAL INQUIRY CONCERNING THE HUMAN RIGHTS OF PEOPLE WITH MENTAL ILLNESS

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# **Part I**

## **Background, Definitions and Existing Services**

# Chapter 1

## THE INQUIRY PROCESS

Human Rights is about balancing the rights of all of us as individuals within the community, and yet the mentally ill do not seem to have their rights taken into account at all in many cases — let alone balanced.<sup>1</sup>

### Human Rights and Equal Opportunity Commission

Under Federal law the Human Rights and Equal Opportunity Commission<sup>2</sup> (the Commission) has two primary responsibilities:

- To increase the understanding, acceptance and observance of human rights in Australia; and
- To promote a fairer society by protecting human rights and ensuring that Australia complies with its human rights obligations under international law.<sup>3</sup>

To achieve these objectives the federal parliament has given the Commission extensive functions — which include conducting Inquiries, reporting on any laws which should be made, or other action which should be taken by Australia, to properly protect human rights.

### Background to this Inquiry

Evidence outlined in the Commission's earlier report, *Our Homeless Children*,<sup>4</sup> suggested that a disproportionate number of children and young people who ended up on the streets were suffering undiagnosed and untreated mental health problems. Subsequent research clearly established that this failure to protect and appropriately care for those affected by psychiatric disorders was not confined to the young — and that in many areas the human rights of individuals affected by mental illness were being ignored, eroded or seriously violated.

Our preliminary research also suggested a serious failure by governments to provide sufficient resources to protect the fundamental rights of many thousands of Australians affected by mental illness or psychiatric disability. It also revealed:

- Widespread ignorance about the nature and prevalence of mental illness in the community;
- Widespread discrimination against people affected by mental illness;
- Widespread misconceptions about the number of people with a mental illness who are dangerous;
- A widespread belief that few people affected by mental illness ever recover.

The Human Rights Commissioner therefore decided to conduct a National Inquiry — based on Australia's human rights obligations.<sup>5</sup>

### Other Inquiries

The need for a **National Inquiry** has been dramatically underlined by the report on Chelmsford Private Hospital in NSW, by the Inquiry into Ward 10B in Townsville, and perhaps also by the Lakeside Inquiry in Ballarat, Victoria. Those inquiries have documented numerous examples of serious violations of the most basic human rights of mentally ill people...

Placed in a human rights context, the treatment meted out to the patients at Chelmsford represents one of the most systematic and sustained gross violations of human rights in this nation's history. It was a disgrace to this country, a disgrace to psychiatry, a disgrace to the governments and bureaucrats who allowed it to happen. Many people lost their lives as is now a matter of public record. It would be comforting to think that what happened there...could not happen anywhere else. It would also, in our view, be extremely naive.<sup>6</sup>

The development of psychiatric facilities and mental health services in Australia has been plagued by controversy.

The first asylum was commissioned by Governor Macquarie, with the instruction that there was to be 'cleanliness, kindness, nutrition, medical attention, recreation and good record keeping.'<sup>7</sup> Disregard for this injunction signalled the beginning of a pattern of neglect which, in some facilities, continues to this day.

As outlined in Chapter 5 — Mental Health Services, the post-war period saw the development of a number of revolutionary treatments for psychiatric disorders which meant that most people affected by mental illness no longer required long term institutional care.<sup>8</sup>

In the intervening years numerous inquiries into institutional care and community mental health services have been undertaken. However, none have

involved carers, consumers and clinicians on a national basis, and their recommendations have frequently been ignored.

An historical review of those Inquiries does not leave one with many precedents for change or with optimism for the future. Governments seem peculiarly immobile in implementing progressive development for the betterment of the mentally ill.<sup>9</sup>

In NSW alone, there have been approximately 40 inquiries into psychiatric facilities and services since the first recorded case of mental illness in 1801. The majority of State and Territory investigations examined issues such as maladministration, under-resourcing, overcrowding, abuse and harassment, and inadequate legislation. The only two which attempted to provide a national perspective<sup>10</sup> essentially ignored the issue of the **rights** of those affected. Nevertheless, the desperate under-resourcing of mental health services and the need for a properly regulated system of accountability and professional peer scrutiny were recurring themes.<sup>11</sup>

These issues acquired a sense of urgency in the 1980s with the revelations of serious abuses in psychiatric facilities in three different States. The NSW Royal Commission into Deep Sleep Therapy at Chelmsford Hospital, the Commission of Inquiry into Ward 10B of Townsville General Hospital, Queensland and the investigation into Lakeside Hospital, at Ballarat in Victoria, provided frightening reminders of the results of 'bureaucratic nonchalance and indifference.'<sup>12</sup>

### **Terms of Reference**

This Inquiry has been conducted in accordance with the following terms of reference:

1. To inquire into the human rights and fundamental freedoms afforded persons who are or have been or are alleged to be affected by mental illness, having due regard to the rights of their families and members of the general community.
2. In particular, to inquire into the effectiveness of existing legislative provisions, legal mechanisms and other measures in protecting and promoting the human rights of such persons.
3. To examine the respective roles and responsibilities of Commonwealth, State and Territory Governments in these areas.

4. Without limiting the generality of the preceding terms, to consider:

- (a) any discrimination on the basis of mental illness in Commonwealth laws or programs;
- (b) any discrimination in employment, occupation, accommodation or access to goods and services on the basis of mental illness;
- (c) human rights in relation to institutional and non-institutional care and treatment of persons with mental illness.

### **The Commissioners**

The Federal Human Rights Commissioner, Mr Brian Burdekin, chaired the Inquiry. He was assisted by Dame Margaret Guilfoyle and Mr David Hall.

Dame Margaret Guilfoyle, DBE LLB, is President of the Royal Melbourne Hospital, and is currently the Deputy Chair of the Victorian Mental Health Research Institute. Her career has included 16 years as Senator for Victoria, during which time she was Federal Minister for Education in 1975, Minister for Social Security from 1975 to 1980, and Minister for Finance from 1980 to 1983. Dame Margaret is a Director of several charitable trusts and a Member of the Council of Deakin University.

David Hall is the Executive Director of the Richmond Fellowship of Victoria, and the first convenor of the National Coalition of Mental Health and Psychiatric Disability Groups. Mr Hall has an extensive background in social welfare work, including responsibility for the coordination of welfare services with a number of government departments at both Federal and State level.

Professor Beverley Raphael acted as special adviser to the Inquiry. Professor Raphael, who heads the Department of Psychiatry at the University of Queensland, was formerly President of the Royal Australian and New Zealand College of Psychiatrists and is currently a member of the National Mental Health Working Party for the Australian Health Ministers' Conference. She also chairs the National Health and Medical Research Council's Mental Health Committee.

Professor Neil Rees, Dean of Law, University of Newcastle, Professor David Copolov, Director, Victorian Mental Health Research Institute and Mr Simon Champ, Schizophrenia Fellowship of NSW, also provided substantial advice and assistance in reviewing sections of the material included in this report.

The Commission has received hundreds of submissions, and thousands of letters and phone calls from those affected by mental illness and their families. This report is a testimony to their courage and determination.

## **Procedure of the Inquiry**

Commissioner Burdekin formally announced the Inquiry in June 1990. Several strategies were developed to ensure the involvement of a large number of Australians directly affected by mental illness.

### **Confidentiality**

Because of the stigma and discrimination still frequently associated with psychiatric disability, the Inquiry was careful to protect the identities of those witnesses who requested confidentiality. Private hearings were convened as necessary throughout the Inquiry and those wishing to make confidential written submissions were able to do so.

The number of witnesses who requested anonymity is disturbing testimony to the stigma and discrimination which still surround mental illness.

### **Hearings**

Public hearings commenced in Melbourne on 8 April 1991, and over the next 15 months were convened in a representative selection of cities and regional centres across Australia.

In addition to witnesses from cities in which the hearings were convened, arrangements were made for people wishing to give evidence to travel from smaller centres in every State and Territory.

The Inquiry considered evidence from 456 witnesses during its formal hearings. (A list of individuals and the organisations they represented is included at Appendix 1.)



## Location of Hearings

Location	State	Date
Melbourne	VIC	8,9,10 April 1991
Ballarat	VIC	11 April 1991
Sydney	NSW	17,18,19,20,21 June 1991
Sydney	NSW	8 July 1991
Newcastle	NSW	9 July 1991
Orange	NSW	11 July 1991
Cairns	QLD	9 August 1991
Townsville	QLD	12,13 August 1991
Brisbane	QLD	14,15,16 August 1991
Port Lincoln	SA	18 October 1991
Adelaide	SA	21,22,23 October 1991
Hobart	TAS	11,12,13 November 1991
Devonport	TAS	4 November 1991
Perth	WA	10,11,12 February 1992
Albany	WA	14 February 1992
Canberra	ACT	18,19 March 1992
Darwin	NT	21 July 1992
Alice Springs	NT	23 July 1992

*Table 1*

### *Public Forums*

Public forums were convened in conjunction with several of the hearings. These enabled people affected by psychiatric disability, their families and carers to provide information to the Inquiry in a more informal setting. Over 300 people participated in these open sessions.

### *Private Hearings*

During the forums, Commissioners and members of the Inquiry's staff also conducted private hearings with individuals wishing to make a confidential submission to the Inquiry. (Over 60 people preferred to provide information in this way.)

### *Informal Consultations*

Members of the Inquiry conducted informal consultations with individuals affected by mental illness, consumer and carer organisations, and mental health professionals.

Commissioner Burdekin and Inquiry staff conducted consultations with Aboriginal groups in the Northern Territory during 1992 (in addition to taking evidence from Aboriginal representatives and mental health workers in each State).

### **Submissions**

Advertisements were placed in national, state and territory newspapers inviting interested persons and organisations to make written submissions.

More than 820 written submissions were received from individuals affected by mental illness, carers, other family members, organisations, mental health professionals and government authorities. (This figure is closer to 900 if multiple submissions from a number of individuals and organisations are taken into account — see Appendix 2).

Table 2 provides a breakdown of evidence received from mental health professionals, church groups, professional associations, government and non-government groups, carers and consumers. (Witnesses who gave evidence 'in camera' are identified only as consumer, carer, or mental health professional.)

Description	Witnesses	Submissions
Psychiatrists	70	52
General Practitioners	1	3
Psychologists	7	12
Social, Youth, Welfare Workers	25	23
Nurses	14	20
Professional Associations		
- Psychiatrists	11	4
- Social/Welfare Workers	2	5
- Occupational Therapists	3	2
- Nurses	4	5
- Psychologists	5	2
Church Related Organisations	13	15
Consumers	44	206
Carers	26	136
Concerned Citizens		68
Federal, State or Local Government representatives	73	60
NGO representatives	159	185
Others		28
<b>Total witnesses: 456</b>		
<b>Total submissions: 826</b>		
(Excluding multiple submissions from individuals or organisations.)		

Table 2

### *Visits to Facilities*

The Inquiry inspected psychiatric facilities and mental health services throughout Australia (see Appendix 3). Informal discussions with staff and patients were conducted during these visits.

## Scope of the Inquiry

This Inquiry was conceived and conducted on the premise that individuals affected by mental illness have the same rights as other members of our community.

In considering the scope of the Inquiry, we were confronted with a number of difficult definitional issues. (Particular problems associated with defining the term 'mental illness' are examined in Chapter 3 — Definitions and Conceptions of Mental Illness.) Given the complexity of the issues, it was decided not to define mental illness restrictively in the terms of reference for the Inquiry, but to adopt an approach which would allow Commissioners to hear a representative range of relevant views — unimpeded by the limitations of existing legal and clinical definitions (which to a significant extent still reflect ignorance rather than insights into illnesses of the mind).

The Inquiry's primary concern in the preparation of this report has been to carefully consider the evidence received. In doing so, emphasis has necessarily been given to the experiences of those affected by the more severe forms of mental illness. However, other matters have been included where the evidence indicates an abuse or neglect of human rights. The Inquiry did not investigate individual complaints (but, where appropriate, did arrange assistance for a number of individuals who wished to pursue particular problems).

The Inquiry has given careful consideration to the needs of particularly vulnerable or disadvantaged groups of Australians affected by mental illness or serious mental health problems. The problems of children and adolescents have been examined in the light of evidence that many serious psychiatric disorders have their onset in adolescence — a situation which can have devastating effects if ignored or treated inappropriately.

One of the most difficult but important conclusions of this Inquiry is the necessity to avoid clinical definitions precluding appropriate responses for those who urgently need care. While this report primarily focusses on services for those who are affected by mental illness, the evidence established that in relation to some of our most vulnerable young people (including those in prisons or remand centres) an overly meticulous reliance on clinical definitions (particularly those relating to 'mental illness' and 'personality disorder') is not only unhelpful — it is one of the problems.

Special attention has also been given to the human rights of elderly people with mental illness. In this context, the Inquiry has included evidence concerning those suffering from Alzheimer's disease and other forms of dementia. The

Inquiry recognises that the classification of dementia as a mental illness is, in some quarters, a contentious issue. However, this report reflects an extensive body of evidence received from carers and community organisations concerning serious violations of the rights of thousands of elderly Australians.

## **Outline of the Report**

This report addresses the terms of reference in five parts.

Part I examines the existing social, legal, medical and institutional frameworks within which care of people with a psychiatric disability takes place. Chapter 1 outlines the scope of the Inquiry, while Chapter 2 describes the substantial body of international human rights law relevant to the care and protection of those affected by mental illness. Chapter 3 outlines the various legal definitions and medical conceptions of mental illness. Chapter 4 provides a comprehensive analysis of existing mental health and related legislation in Australia. Chapter 5 summarises the range of inpatient, community and specialist services available in the government, private and non-government sectors and Chapter 6 provides an overview of the role and training of professionals working in these services. Part I concludes with a summary acknowledging significant developments which have occurred since the Inquiry began in June 1990.

Part II of the report deals with evidence concerning psychiatric care and treatment — both in institutional settings and in the community. The reality of living with mental illness and the difficulties involved in securing adequate housing are described in Chapter 10 (Accommodation) and Chapter 11 (Boarding Houses). Chapters 12-16 analyse the personal experiences of those affected by mental illness and their carers and family members, and examine the discrimination suffered by consumers in terms of employment, education and training.

Part III of the report examines the position of several vulnerable or particularly disadvantaged groups — concentrating on difficulties faced by children and adolescents, elderly people, women, Aboriginal and Torres Strait Islander people, the homeless, forensic patients and prisoners, people from non-English speaking backgrounds, people in rural and isolated areas and people with dual and multiple disabilities.

Part IV addresses the importance of prevention and early intervention services and the need for a substantially enhanced research program. Other chapters examine the effectiveness of accountability measures (notably, quality assurance and accreditation, minimum standards and monitoring mechanisms, patient

advocacy and complaints procedures) and analyse legislative proposals being considered by several State Governments at the time of writing.

Part V of the report presents the Inquiry's findings and recommendations for change.

Many of the endnotes in each chapter contain important supplementary information. They should be read in conjunction with the body of the report.

### **A Note on Language Use**

People affected by mental illness frequently suffer discrimination and stigmatisation based on ignorance, labelling and inaccurate stereotypes. The Inquiry consulted widely about terminology and has attempted to use language which is both accurate and appropriate throughout this report.

In response to advice from numerous individuals and support groups, the term 'consumer' is generally used to refer to an individual with a psychiatric disability.

Individuals affected by mental illness are frequently 'labelled' according to their illness — rather than being seen as individuals with particular disabilities. The Inquiry therefore considers the use of terms such as 'a schizophrenic' or 'a manic depressive' to be both inappropriate and inherently discriminatory. They have not, therefore, been used in this report.

## **Incidence of Mental Illness**

The incidence of mental illness in Australia has not been established definitively. The lack of epidemiological studies and the absence of a comprehensive data base (including information regarding the level of disability associated with major mental illness) are regrettable.<sup>13</sup> However, it is clear that:

Mental illness touches all socioeconomic groups in Australia, and there is growing evidence that its morbidity is greatest in the most productive working years when family responsibilities are also at their peak.<sup>14</sup>

It is also certain that the number of people affected is far higher than is generally recognised. At least 250,000 Australians (approximately 1.5 percent of the population) suffer from major mental illnesses<sup>15</sup> and approximately one in five adults have, or will develop, some form of mental disorder.<sup>16</sup> Although these figures are only estimates they illustrate the magnitude of the problem.<sup>17</sup>

Studies also indicate that despite the fact that approximately 20 percent of Australians are likely to be affected by a mental illness or disorder, only a small percentage (estimated at around 3 percent of those who become ill) ever come to the attention of specialist mental health services. (Of these, approximately two-thirds will be treated by the public health system.<sup>18</sup>)

Approximately 1 percent of the population (170,000 Australians) suffers from schizophrenia.<sup>19</sup> Schizophrenia therefore affects more Australians than many other better known illnesses.<sup>20</sup> Twenty to thirty percent of people who experience an episode of schizophrenia recover without ever needing to be re-hospitalised; approximately 40 percent suffer recurrent episodes over several years; and approximately 35 percent will be affected throughout their lives. In any one year, one in five people affected by schizophrenia will require hospitalisation.<sup>21</sup>

Depressive disorders also constitute a major mental health problem in Australia, with up to 10 percent of adults affected. (The incidence of other forms of mental illness and disorder is addressed in various chapters throughout the report).

### **Disability**

It is also important to note that while the severity and duration of different forms of mental illness vary substantially, the resulting disability may effect the individual for long periods of time.

The manifestations of mental illness are diverse, range in severity and are inextricably linked with quality of life issues, employment opportunities, social and family relationships, general health, economic factors and community participation.<sup>22</sup>

### **Children and Adolescents**

Evidence presented to the Inquiry also indicated that approximately 15 percent of adolescents experience some form of mental health problem and more than 1 percent have serious psychiatric disorders which warrant specialist intervention.<sup>23</sup> (The urgent need for appropriate programs and facilities for young people is discussed in Chapter 20.)

### **Elderly People**

The rapid increase in Australia's 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 and approximately 20 percent of those over 80 are afflicted. At present, 100-140,000 Australians are estimated to be suffering moderate to severe dementia; this number is expected to exceed 200,000 within the next ten years.
- Approximately 50 percent of elderly people have at least one symptom of depression.<sup>24</sup> Estimates vary, but a recent study found major depression in over 10 percent of those over 65.<sup>25</sup> (One measure of this is that the suicide rate for men 70-79 years is the highest for any age group.<sup>26</sup>) Some studies are identifying increasing rates of depression in women.

## Conclusion

It is clear from the evidence presented in this report that the cost of mental illness in terms of human lives and suffering is enormous. In addition to the pain suffered by consumers, these costs include disruption to family life, and sometimes unbearable pressures on other family members who feel powerless to assist the person who is ill.

Estimating the financial costs — both to the individual and to society — is a complicated task because of the differing degrees of disability experienced by consumers and the lack of data available in this area.<sup>27</sup>

But the costs of our current neglect in terms of violations of the most fundamental rights of Australians affected by mental illness are clearly documented in this report. They demand an urgent, concerted and effective response.



1. Brian Burdekin, Federal Human Rights Commissioner and Chair of the Inquiry. Opening address, Darwin hearings, 23.7.92.
2. The Commission is a permanent independent statutory authority with responsibility for the following Acts of Parliament:

- *Human Rights and Equal Opportunity Commission Act 1986*
- *Racial Discrimination Act 1975*
- *Sex Discrimination Act 1984*
- *Privacy Act 1988*
- *Disability Discrimination Act 1992*

These Acts incorporate or otherwise give effect to the following international instruments which Australia has ratified or to which it has otherwise committed itself:

- International Covenant on Civil and Political Rights
- Declaration of the Rights of the Child
- Convention on the Rights of the Child
- Declaration on the Rights of Mentally Retarded Persons (sic)
- International Labour Organisation Convention Concerning Discrimination in Respect of Employment and Occupation (ILO Convention 111)
- Declaration on the Rights of Disabled Persons
- Convention on the Elimination of All Forms of Racial Discrimination
- Convention on the Elimination of All Forms of Discrimination against Women
- Organisation for Economic Co-operation and Development Guidelines for the Protection of Privacy and Transborder Flows of Personal Data
- Declaration on the Elimination of All Forms of Intolerance and of Discrimination Based on Religion or Belief.

See Chapter 2 for more detailed discussion of the relevant human rights provisions.

3. s.11, *Human Rights and Equal Opportunity Commission Act 1986*.
4. Human Rights and Equal Opportunity Commission, *Our Homeless Children*, AGPS, Canberra 1989.
5. In addition to the rights laid down in the International Covenant on Civil and Political Rights, the Declaration of the Rights of Disabled Persons provides that disabled people — including those with a psychiatric disability — have the right to treatment, rehabilitation, education, training and other services to develop their skills and capabilities to the maximum. The recently adopted United Nations Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care also clearly stipulate that it is not acceptable to have lower standards or fewer resources for mental health care than the rest of the health care system.
6. Commissioner Burdekin, Opening address, Sydney 17.6.91, p1.
7. Cited in *Sydney Gazette*, 1 June 1811.
8. M Lewis, *Managing Madness — Psychiatry and Society in Australia 1788-1980*, AGPS, Canberra 1980.
9. J Lawrence, 'Inquiries into psychiatry: Chelmsford and Townsville,' *Medical Journal of Australia*, v155 Nov 1991, p654.
10. A Stoller and K W Ascott, *Mental Health Facilities and Needs of Australia*, Government Printing Office, Canberra, 1955; P Eisen and K Wolfenden, *A National Mental Health Services Policy, Report of the Consultancy to advise Commonwealth, State and Territory Health Ministers*, AGPS, Canberra 1988.

11. Some of the more recent reviews were:

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12. Commissioner W J Carter Q.C., *Commission of Inquiry into the Care and Treatment of Patients in the Psychiatric Unit of Townsville General Hospital (Ward 10B)*, v1 and 2, Brisbane 1991.
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16. According to Gavin Andrews in *The Tolkien Report: A Description of a Model Health Service*, Sydney 1991, 16 percent of the population 'meet the criteria for a mental disorder', although only about 3 percent would have sought treatment for the disorder. Richmond, op cit, p17, estimates that 18-23 percent of the population suffer from a 'significant psychological disorder.'
17. In addition, mortality rates are generally higher for those affected by psychiatric disability than for other individuals. For example, it is estimated that suicide claims the lives of approximately one in ten individuals hospitalised for depression; the lives of those affected by schizophrenia are reduced by approximately ten years; and the mortality rate for those affected by neurosis is twice that of their peer groups. In G Andrews, 'Psychiatry Circa 1990', Unpublished paper.
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24. NHMRC, op cit.
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27. Chapter 26, *Mental Health Research*, gives more detailed information on the substantial economic costs associated with psychiatric disability.

## Chapter 2

# RELEVANT HUMAN RIGHTS PROVISIONS AND INTERNATIONAL LAW

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...<sup>1</sup>

### Introduction

Australia, through successive Federal Governments, has committed itself to honour a range of international standards on human rights developed by the United Nations since 1945.

These standards fulfil part of the mandate of the United Nations under its Charter (which Australia helped draft) to promote universal recognition and respect for human rights. The Charter was, in large part, adopted in response to the atrocities committed by the Nazi regime and others leading up to and during the Second World War. The groups subjected to these atrocities included mentally ill people and others affected by disabilities.

In 1948 the United Nations adopted the Universal Declaration of Human Rights, which proclaimed fundamental rights to which ‘everyone’ should be entitled without discrimination. The Declaration was intended as a common standard of attainment for all nations. It was not, however, seen at the time as imposing binding legal obligations on governments (although many international lawyers have concluded that the Declaration now has substantial legal force). Moreover, it proclaimed rights only in general terms — rather than setting out in detail how those rights should be translated into law and practice.

In the last forty years development of more detailed instruments has therefore continued. Standards have been developed, in particular, to address specific types of discrimination and concerning the human rights of particularly vulnerable groups. These standards are set out in a series of Covenants, Conventions<sup>2</sup>, Declarations, Principles and Rules. Some of these instruments are binding on Australia as a matter of international law. Others, while not strictly binding in international law, set out agreed international standards, to which Australian governments have committed themselves in a variety of ways — including, in some cases, by incorporating them in Australian legislation.<sup>3</sup>

## **Human Rights of People with Mental Illness**

People with mental illness are human beings with human rights. This simple and fundamental point, which unfortunately still needs to be stressed, has been one of the fundamental tenets of this Inquiry.

The international law of human rights explicitly recognises rights which apply to 'everyone' or to 'all individuals'. Further, the rights recognised in the various international human rights instruments are required to be respected and ensured to all individuals 'without any discrimination'.<sup>4</sup> It is clear then, as a matter of international law, that individuals with mental illness are entitled without discrimination to the full range of human rights.

This does not mean that the law or government policy may not make special provision for people with mental illness in some circumstances — including services to provide for special needs, or legal provisions referring to questions of capacity to make decisions. The principle of non-discrimination does not require that everyone be treated alike. Distinctions should not be regarded as discriminatory if they are not arbitrarily made and do not have the purpose or effect of denying or restricting the equal enjoyment of human rights. The international human rights instruments clearly provide that special measures to cater for special needs are not included in the definition of discrimination. Rather, special measures of assistance or protection may be needed to ensure the equal enjoyment of human rights to groups of people who are particularly vulnerable or disadvantaged.<sup>5</sup>

## **Instruments Incorporated in Federal Legislation**

A number of international human rights instruments have been incorporated in Federal legislation in the *Human Rights and Equal Opportunity Commission Act* — although, as clearly emerges in Part III of this report, this is only a small contribution to making these rights a reality in law and in practice.

### **The International Covenant on Civil and Political Rights**

The International Covenant on Civil and Political Rights (ICCPR) was adopted by the United Nations General Assembly in 1966. Australia ratified (that is, became a Party to) the ICCPR on 13 August 1980. This treaty requires that all

Parties 'respect and ensure **to all individuals** within their territory and subject to their jurisdiction' the rights which the Covenant recognises. These rights include:

- the right to life (Article 6);
- the right to freedom from cruel, inhuman or degrading treatment or punishment (Article 7);
- the right to liberty and security of the person (Article 9);
- the right to be treated with respect for dignity and with humanity, if deprived of liberty (Article 10);
- the right to freedom of movement and choice of residence (Article 12);
- the right to equality before the courts and tribunals, and to a fair hearing in any criminal case or law suit; to be presumed innocent until proved guilty if charged with a criminal offence; and in determination of any criminal charge to guarantees including the right of every person:
  - to be informed promptly, in detail and in a language the person understands of the nature and cause of the charge;
  - to be tried without undue delay;
  - to be tried in his or her presence, and defend him or herself in person or through counsel of his or her own choosing;
  - to have legal assistance assigned where required by the interests of justice, free of charge where the person has insufficient means to pay;
  - to examine witnesses;
  - to have the free assistance of an interpreter if he or she cannot speak the language used in court (Article 14);
- the right to recognition as a person before the law (Article 16);
- the right to freedom from arbitrary interference with privacy or family life (Article 17);
- the right to freedom of conscience and religion (Article 18);

- the right to freedom of opinion, expression and information (Article 19);
- the right to freedom of association including the right to form and join trade unions (Article 22);
- the right to marry and found a family (Article 23);
- the right of children to special protection (Article 24);
- the right to take part in public affairs, to vote and to be elected, and to have access on equal terms to public service (Article 25);
- the right to equality before the law and the right to equal protection of the law; and
- the right of people belonging to ethnic, religious or linguistic minorities to enjoy their own culture, practice their religion or use their own language, in community with other members of their group (Article 27).

The meaning and application of these rights, and the extent to which they are protected and respected in practice for people with a mental illness in Australia, are discussed in later chapters of this report.

Article 2.2 of the ICCPR requires Governments to ‘adopt such legislative or other measures as may be necessary to give effect to the rights recognised’. Article 2.3 requires them ‘to ensure that any person whose rights or freedoms as herein recognised are violated shall have an effective remedy’.

The ICCPR specifically requires each country which has ratified it:

to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognised in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status (Article 2.1).

The terms of this Article indicate that discrimination ‘of any kind’ (including, by definition, discrimination relating to mental illness or psychiatric disability) which affects the exercise or enjoyment of rights recognised elsewhere in the ICCPR is included.<sup>6</sup> Discriminatory or unequal treatment affecting people with mental illnesses but which is based on other factors (such as race or sex) is also subject to the non-discrimination provisions of international human rights law.<sup>7</sup>

The obligation to ‘respect’ these rights requires that Governments refrain from any action which infringes them. The obligation to ‘ensure’ these rights is,



however, more far reaching — requiring Governments to take active measures where necessary to guarantee these rights.

The non-discrimination provision embodied in Article 2 of the ICCPR applies *only to rights recognised in the ICCPR itself*. These rights, clearly, do not cover all significant aspects of social life — for example, neither employment nor health care is expressly mentioned. However, there is also a more general equality and non-discrimination provision in the ICCPR. Article 26 stipulates:

All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, language, religion, political or other opinion, national or social origin, property, birth or other status.

Unlike Article 2, Article 26 deals with discrimination not only with respect to those rights recognised in the ICCPR itself but with discrimination in any area of law or government action. In Australia this clearly includes actions of State and Territory governments in addition to those of the Federal Government.<sup>8</sup>

It is less certain whether there is any obligation imposed by the non-discrimination provisions of the ICCPR to prohibit discrimination by individuals or in the private sector (beyond the area of the rights specifically recognised in other provisions of the ICCPR). There are, however, other international human rights instruments which deal with these issues.

### **Discrimination (Employment and Occupation) Convention 1958**

The Discrimination (Employment and Occupation) Convention 1958 (also known as International Labour Organisation Convention No111),<sup>9</sup> is also incorporated in Federal law in the *Human Rights and Equal Opportunity Commission Act*.

This Convention defines discrimination to mean:

any distinction, exclusion or preference [made on any of the grounds specified in the Convention itself or specified by the State concerned] which has the effect of nullifying or impairing equality of opportunity or treatment in employment or occupation

but does not include distinctions based on the inherent requirements of the job. The Convention specifically includes vocational training within the definition of employment and occupation.<sup>10</sup>

The Convention itself does not specify mental illness, disability, impairment or medical record as prohibited grounds of discrimination. However, it does provide<sup>11</sup> for Parties to the Convention (such as Australia) to specify additional grounds of discrimination.

Following recommendations from the Human Rights Commissioner, regulations under the *Human Rights and Equal Opportunity Commission Act* were made to add a number of grounds (including physical, mental, intellectual and psychiatric disability; impairment and medical record) to the Commission's jurisdiction in relation to this Convention as from January 1990.<sup>12</sup>

By ratifying this Convention, Australia has undertaken to pursue a national policy designed to 'promote equality of opportunity or treatment in respect of employment and occupation with a view to eliminating any discrimination in respect thereof' (Article 2). More specifically, Australia is obliged:

- (a) to seek the co-operation of employers' and workers' organisations and other appropriate bodies in promoting the acceptance and observance of this policy;
- (b) to enact such legislation and to promote such educational programs as may be calculated to secure the acceptance and observance of the policy;
- (c) to repeal any statutory provisions and modify any administrative instructions or practices which are inconsistent with the policy;
- (d) to pursue the policy in respect of employment under the direct control of a national authority;
- (e) to ensure observance of the policy in the activities of vocational guidance, vocational training and placement services under the direction of a national authority...<sup>13</sup>

The Convention also specifies that special measures for people with disabilities, including affirmative action, may be introduced without being prohibited as discrimination against other workers.<sup>14</sup>

### **The Declaration on the Rights of Disabled Persons**

The Declaration on the Rights of Disabled Persons was adopted by the United Nations in 1975. It defines 'disabled person'<sup>15</sup> to mean '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, whether congenital or not, in his or her physical or mental capacities'. This definition would include many people with a mental illness, whether or not they also have other disabilities. The United Nations Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (discussed later

in this chapter) specifically recognise<sup>6</sup> the applicability of this Declaration to people with a mental illness.

The Declaration recognises that people with disabilities are entitled to:

- the inherent right to respect for their human dignity;
- the same fundamental human rights, *whatever the origin, nature and seriousness of their handicaps and disabilities*, as their fellow citizens, including the right to a decent life, as normal and full as possible (Principle 2);
- the right to legal safeguards against abuse of any limitation of rights made necessary by the severity of a person's handicap, including regular review and the right of appeal (Principle 4);
- the right to any necessary treatment, rehabilitation, education, training and other services to develop their skills and capabilities to the maximum (Principle 6);
- the right to economic and social security and the right, according to their capabilities, to secure and retain productive employment and to join trade unions (Principle 7);
- the right to have their needs considered in economic and social planning (Principle 8);
- the right to family life, the right to participate in all social, recreational and creative activities, and the right not to be subjected to more restrictive conditions of residence than necessary (Principle 9);
- the right to protection against exploitation or discriminatory, abusive or degrading treatment (Principle 10);
- the right to qualified legal assistance to protect their rights, and to have their condition taken fully into account in any legal proceedings (Principle 11).

### **The Declaration of the Rights of the Child**

The Declaration of the Rights of the Child, which was adopted by the United Nations General Assembly in 1959, is also incorporated in the *Human Rights and Equal Opportunity Commission Act*. This Declaration specifically provides that 'the child who is physically, mentally or socially handicapped shall be given the special treatment, education and care required by his [or her]

particular condition' (Principle 5). The Declaration of the Rights of the Child also provides that every child should have the right, without discrimination, to:

- opportunities and facilities, by law and by other means, to enable him or her to develop physically, mentally, morally, spiritually and socially in a healthy and normal manner and in conditions of freedom and dignity (Principle 2);
- enjoy the benefits of social security;
- grow and develop in health, and for this purpose is entitled to special care and protection;
- adequate nutrition, housing, recreation and medical services (Principle 4);
- where possible, grow up in the care and protection of his or her family (Principle 6);
- receive education which will enable the child, on the basis of equal opportunity, to develop his or her abilities, judgment and sense of responsibilities and to become a useful member of society;
- opportunities for play and recreation (Principle 7);
- protection from neglect, cruelty and exploitation, from child trafficking, and from any occupation or employment which would prejudice his or her health or education or interfere with his or her physical, mental or moral development.

Although these Declarations do not create international legal obligations in the same way as a treaty, such as the ICCPR, they represent accepted international standards. Further, their incorporation by the Federal Parliament into the *Human Rights and Equal Opportunity Commission Act* represents a formal commitment to the rights and standards which these Declarations set out.

## **Other International Conventions**

In addition to the international instruments incorporated in the *Human Rights and Equal Opportunity Commission Act*, there are a number of other instruments which are particularly relevant to the effective protection of human rights of people with disabilities.

## **Convention on the Rights of the Child**

Australia has now ratified the Convention on the Rights of the Child (CROC), adopted by the United Nations General Assembly in 1989.<sup>17</sup> The Convention (which has recently been added to the list of international instruments by which 'human rights' are defined for the purpose of jurisdiction of the Human Rights and Equal Opportunity Commission) is a binding international treaty which Australia has committed itself, as a matter of international law, to comply with and implement.<sup>18</sup>

The Convention applies to everyone under the age of 18<sup>19</sup> and requires Parties to the Convention to:

respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parents' or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, **disability**, birth or other status.<sup>20</sup>

The Convention deals with a much wider range of rights than the Declaration on the Rights of the Child. These include:

- rights to life, survival and development (Article 6);
- rights against interference with family life (Articles 9 and 16);
- rights to support services for families (Article 18);
- rights to protection from abuse, neglect or exploitation (Article 19 and Articles 32-36);
- the right of the child to the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. Parties are also obliged to ensure adequate pre- and post-natal care for mothers<sup>21</sup> (Article 24);
- rights concerning education, including that primary and secondary education be available and accessible to all (Article 29);
- rights to social security and adequate living standards (Articles 26 and 27);
- rights of children in substitute care or alternative family care, including in relation to standards of facilities (Article 3);

- the right of children placed for treatment of mental health problems to periodic review of treatment and other relevant circumstances (Article 25);
- rights of children of minority communities or indigenous peoples to enjoy their own culture (Article 30);
- the right to measures to promote physical and psychological recovery and social reintegration of child victims of any form of neglect, exploitation or abuse, torture or other cruel, inhuman or degrading treatment or punishment, or of armed conflicts; and for such recovery and reintegration to take place in an environment which fosters the health, self respect and dignity of the child and;
- rights in the administration of justice and for children deprived of liberty (Articles 37 and 40) including:
  - freedom from arbitrary detention;
  - that detention should be a measure of last resort and for the shortest appropriate period;
  - that every child deprived of liberty should be treated with humanity and consistently with the needs of persons of his or her age;
  - the right to maintain contact with family;
  - the right to prompt access to legal and other appropriate assistance.

The rights in each of these areas are required<sup>22</sup> to be guaranteed without discrimination.

The Convention also makes specific provision for children with disabilities in Article 23, which includes requirements that Parties take steps to:

ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.

The Convention does not specifically define 'disabled child'. It is clear, however, in the Inquiry's view, that this term includes children who have a psychiatric disability and that the obligations set out in this provision apply to children who have a mental illness or comparable condition.

## **The International Covenant on Economic, Social and Cultural Rights**

The International Covenant on Economic, Social and Cultural Rights (ICESCR)<sup>23</sup> was adopted by the United Nations General Assembly together with the ICCPR in 1966, and ratified by Australia in 1975.

In addition to recognising rights concerning employment,<sup>24</sup> the ICESCR recognises rights in a range of other areas, including housing,<sup>25</sup> health,<sup>26</sup> and education.<sup>27</sup> The ICESCR is not incorporated in the *Human Rights and Equal Opportunity Commission Act* or other Federal legislation.

Article 2.1 of the ICESCR requires States Parties to 'take steps...by all appropriate means, including particularly the adoption of legislation' with a view to the progressive realisation of the rights which the Covenant recognises. This provision allows for progressive rather than immediate implementation in recognition that many of the rights set out require significant resource allocation. To whatever extent enjoyment of these rights is achieved in a particular nation, however, the ICESCR requires that they be guaranteed on a non-discriminatory basis.

Article 2.2 provides that States Parties must:

guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, or other status.

This Covenant is one of the sources of power on which the new national *Disability Discrimination Act* is based. Clearly, however, guaranteeing the rights recognised in the Covenant to people with a mental illness requires a wider range of measures than legislation alone, including anti-discrimination legislation.

## **Convention on the Elimination of All Forms of Racial Discrimination**

The Convention on the Elimination of All Forms of Racial Discrimination (CERD), ratified by Australia in 1975, is incorporated in Federal law in the *Racial Discrimination Act 1975*. This Convention is relevant to issues of equal treatment by and access to mental health services for people of whatever race or national or ethnic origin, including appropriate responses to special needs.

As with other international conventions in this area, CERD requires a broader range of measures of implementation than simply the enactment of anti-

discrimination legislation. This Convention stipulates a comprehensive obligation:

to prohibit and to eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law, notably in the enjoyment of the following rights...<sup>28</sup>

The Convention then lists a wide range of the rights recognised in the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights, specifically including rights such as the right to public health and medical care and the right to equal treatment before tribunals and other organs administering justice.

### **Convention on the Elimination of All Forms of Discrimination Against Women**

The Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), ratified by Australia in 1983, is incorporated in Federal law in the *Sex Discrimination Act* 1984. As with CERD, CEDAW sets out wide ranging obligations for the elimination of discrimination and promotion of equality, which are not limited to enactment of anti-discrimination legislation. Specifically, the Convention requires Parties to take measures to ensure women equal access to health care services and information.<sup>29</sup>

## **Mental Illness Principles**

Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care were adopted by the United Nations General Assembly in 1991. These Principles have not been formally incorporated in Australian legislation. However, they have been endorsed in the National Mental Health Policy released by the Minister for Health, Housing and Community Services in April 1992, which sets 1998 as a target date for ensuring full compliance by Australian mental health legislation with the standards set out in the Principles.

The Principles are particularly valuable in specifying the way in which human rights recognised in other instruments apply to people with mental illness and to situations affecting them. This report, therefore, treats them as a basic benchmark.

The Principles specify that they are to 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.

While they focus primarily on human rights in relation to the mental health system, the Principles also stipulate:

- that every person with a mental illness has the same basic rights as every other person, specifically including the rights set out in the International Covenant on Civil and Political Rights and the rights recognised in the Declaration on the Rights of Disabled Persons (Principle 1.5);
- that discrimination on the basis of mental illness is not permitted (Principle 1.4);
- that every person with a mental illness has the right to live and work, as far as possible, in the community (Principle 3); and
- that people being treated for a mental illness must be accorded the right to recognition as a person before the law (Principle 13).<sup>30</sup>

The Principles re-affirm that individuals who have a mental illness or who have experienced mental illness have the right to protection from:

- exploitation — whether economic, sexual or in other forms;
- abuse — whether physical or in other forms; and
- degrading treatment (Principle 1.3).

In relation to mental health care, the Principles are not restricted to a remedial approach (dealing only with abuses and the means to prevent them). Rather, they recognise the positive contribution which mental health care should make to the enjoyment of human rights, and the right of everyone in the community to such care when necessary.

The Principles provide that:

All persons have the right to the best available health care, which shall be part of the health and social care system (Principle 1.1);

and that:

every patient shall have the right to receive such health and social care as is appropriate according to his or her health needs, and is entitled to care and treatment in accordance with the same standards as other ill persons (Principle 8).

This emphasises that people with mental illness or people who have experienced mental illness should not be stigmatised, or disadvantaged in the care available, simply because of the nature of their illness.

The Principles also clearly provide that it is not permissible to have lower standards for mental health care, in terms of either programs or resources, than for the rest of the health system. They specifically require that every mental health facility be inspected by competent authorities with sufficient frequency to ensure that the conditions, treatment and care of patients comply with the Principles.

The Principles also give important emphasis to the concept of the 'least restrictive alternative' in relation to treatment and require an individualised plan for treatment, to be discussed with the patient and reviewed regularly.

They recognise the right to be treated and cared for as far as possible in the community, and the right to treatment suitable to each person's cultural background. At the same time, treatment in the community is clearly required to provide adequate care and adequate resources.

Treatment is required to be directed towards enhancing personal autonomy. Accordingly, patients in mental health facilities are to have their rights respected, including their privacy and freedom of communication. Such facilities are to include opportunities for education and vocational training, in addition to appropriate professional care and treatment.

The Principles embody detailed requirements for informed consent to treatment. Importantly, they provide a rigorous definition of what constitutes informed consent — which Australian law generally lacks at present — and require safeguards, including review by an independent authority, for the limited number of cases where informed consent cannot be obtained.

Special protection is required for children in these circumstances and in relation to mental health care generally.

The Principles make provision in relation to medication, including that it is never to be administered for the convenience of others.

They also require that patients in mental health facilities be fully informed of their rights, and have access to their own health records, except in exceptional circumstances. They require that confidentiality of information must be respected.

Statements of rights without effective monitoring of their implementation, or remedies for their violation, are of little effect — as experience in this area has demonstrated. The Principles therefore require that:

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 22).

They also require appropriate legislative, judicial, administrative, educational and other measures of implementation (Principle 23).

## **Developing Further International Standards**

Clearly, therefore, there are now well-defined international standards applicable to a wide range of human rights problems confronting people with disabilities, and particularly those affected by mental illness.

Equally clearly, however, implementation of these standards and application to particular situations remains incomplete.

In 1990, the United Nations Commission for Social Development was authorised to prepare a set of 'standard rules' on the equalisation of opportunities for people with disabilities, to be submitted to the General Assembly in 1993. It is not yet established what status the proposed Standard Rules will have. It appears, however, that they may take the form of 'Standard Minimum Rules'<sup>31</sup> which will assist in the promotion, application and interpretation of relevant instruments which have more formal status as treaties (such as the ICCPR).

There is clearly no need or justification for action in Australia to wait for further international standards to emerge. There is already in existence, and binding on Australia, a substantial body of international human rights law, recognising rights which must be respected and ensured on an equal basis to all Australians affected by mental illness.

1. United Nations Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care, Principle 1.4.
2. Covenant and Convention are both terms used to describe a binding international treaty.
3. International obligations and commitments entered into by Australia do not automatically become part of Australian law. While courts can refer to these standards as part of the common law process of interpreting existing laws, legislation by Parliament is generally required in order to give binding legal effect to international commitments on human rights. The High Court has confirmed (most notably in the 'Dams Case', *Commonwealth v Tasmania* (1983) 158 CLR 1) that the Federal Parliament has power under the Federal Constitution to legislate to implement international treaty obligations. Under s.51(xxix) of the Australian Constitution, the Federal Parliament may legislate with respect to 'external affairs'. In addition to power to legislate to implement international treaties, the High Court has indicated that there is power to legislate to some extent on matters of 'international concern' even where there is no treaty obligation. The extent of this power, however, remains uncertain.

The Federal Government is also, importantly, the level of government internationally accountable for the way in which Australia (including State and Territory Governments) complies with its human rights obligations. There is, however, no legal reason why State and Territory legislation and administration should not also refer to international standards.

4. For example, the International Covenant on Civil and Political Rights, Article 2(1). This Article, and equivalent provisions in several other instruments, go on to specify particular grounds of discrimination: '...such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.'
5. United Nations Principles for the Protection of Persons with Mental Illness, discussed later in this chapter, sum up international law in this area as follows (Principle 1.4): '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.' A similar approach to the meaning of 'discrimination' has been taken by the international Human Rights Committee in interpreting the International Covenant on Civil and Political Rights: see for example General Comment 18(37) Adopted by the Human Rights Committee, printed in the Report of the Human Rights Committee, 1990 (UN Doc A/45/40), vI p173.
6. This is, in fact, implicit in the requirement to ensure these rights to 'all individuals'. Essentially the same point was made by Australia's representative participating in the drafting of the Universal Declaration of Human Rights: '...logically, discrimination was prohibited by the use in each Article of the phrase 'every person' or 'everyone' (UN Doc E/CN.4/AC.1/SR.24 at 4; cited in J Morsink, 'Women's Rights in the Universal Declaration', *Human Rights Quarterly* v13, 1991, p230). In addition 'disability' should be regarded as covered by the concluding phrase 'or other status' in Article 2.1. While there is no clear consensus among legal writers as to the breadth of the obligation imposed by the term 'or other status' or whether disability or illness constitutes a 'status', when the phrase 'or other status' was subsequently discussed in the drafting of the ICCPR, it was regarded as an all inclusive term (see M Bossuyt, *Guide to the Travaux Preparatoires of the International Covenant on Civil and Political Rights*, 1987, p486). On accepted rules of interpretation in international law, the view held by the drafters of the Covenants should be applied.

7. This report (Part III) examines the situation of a number of groups with special needs — including women, Aboriginal and Torres Strait Islander peoples, people of non-English speaking background and people who have a disability in addition to mental illness. In the case of several of these groups, the non-discrimination provisions of the general human rights instruments (such as the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights) are reinforced by specific instruments on discrimination (the Convention on the Elimination of All Forms of Racial Discrimination and the Convention on the Elimination of All Forms of Discrimination Against Women).
8. Decisions of the Human Rights Committee (the United Nations body responsible for monitoring compliance with the ICCPR) indicate that the obligation embodied in the first sentence of Article 26 to respect and ensure the 'equal protection of the law' constitutes an obligation to prevent discrimination in the law, in the application of the law or in any action under the authority of law. See, for example, *Broeks v Netherlands* (Communication No172/1984) UN Doc A/42/40 (1987), a case concerning social security legislation.
9. Ratified by Australia in 1973.
10. Article 1.3.
11. In Article 1(b).
12. This Convention, in conjunction with the external affairs power, is one of the sources of constitutional power for the new national *Disability Discrimination Act* 1992. In the Commission's view, the decision of the High Court in *Richardson v Forestry Commission* (1988) 164 CLR 261, confirms that the same constitutional power attaches to these additional grounds as attaches to the grounds specified in the Convention itself. In the *Richardson* case the High Court decided that the external affairs power covered legislative measures which were not positively required by the international instrument in question (the World Heritage Convention) but which were preconditions for its application and were left to the judgment of States Parties (in that case the protection of potential heritage areas pending identification and an inquiry to facilitate identification). Clearly, there is no explicit obligation under the Discrimination (Employment and Occupation) Convention to specify additional grounds of discrimination. But equally clearly, to do so would be to implement Article 1(b) of the Convention and further its objects in the same way that the law at issue in *Richardson* was found to further the objects of the World Heritage Convention.
13. Article 3.
14. Article 5: '1. Special measures of protection or assistance provided for in other Conventions or Recommendations adopted by the International Labour Conference shall not be deemed to be discrimination. 2. Any Member may, after consultation with representative employers' and workers' organisations, where such exist, determine that other special measures designed to meet the particular requirements of persons who, for reasons such as sex, age, disablement, family responsibilities or social or cultural status, are generally recognised to require special protection or assistance, shall not be deemed to be discrimination.'
15. The term 'disabled person' is used here (rather than the preferable term 'person with a disability') because it is the phrase used in the Declaration.
16. Principle 1.4.
17. Australia signed the Convention on 22 August 1990 and ratified it on 17 December 1990.
18. Parties to the Convention (including Australia) are obliged, under Article 4, to 'undertake all appropriate legislative, administrative and other measures for the implementation of the rights recognised in the present Convention'.
19. Article 1.

20. Article 2. 'Disability' was included in the Convention at the suggestion of the Australian Human Rights Commissioner.
21. This is relevant to evidence regarding women experiencing post-natal depression. See Chapter 19.
22. Article 2.1.
23. Ratified by Australia on 10 December 1975.
24. Articles 5 and 6.
25. Article 11.
26. Article 12.
27. Article 13.
28. Article 5.
29. Article 12.
30. This Principle was inserted at the request of the Australian Human Rights Commissioner
31. Comparable, for example, to the Standard Minimum Rules on the Treatment of Prisoners.

## Chapter 3

# DEFINITIONS AND CONCEPTIONS OF MENTAL ILLNESS

### Introduction

What mainstream Australian society tends to refer to as 'mental illness' in the last decade of the 20th century has not always been, and is not universally, regarded as a medical matter. Similarly, our tendency to distinguish between mental, physical and spiritual concerns is not, and has not always been, shared by other societies. This chapter briefly traces some of the major historical trends in western society which have influenced our modern perceptions and practices and considers several cross-cultural differences of approach to the symptoms, behaviour or states of being that we now call 'mental illness'. Legal definitions of mental illness from various Australian jurisdictions are also considered — together with differing medical definitions and conceptions.

### Changing Views of Mental Illness

In Ancient Greek medical science there was a level of understanding that abnormalities of the mind arose from natural causes in exactly the same way as other forms of disease. Supernatural explanations for mental abnormalities were, however, also common in the early Greek and Roman societies from which western culture developed.

Literature available from the Middle Ages in Europe indicates that with the spread of Christianity natural causes were lost sight of and madness was seen as a manifestation of possession by the devil or other evil spirits, heresy, or some other form of immorality. This theological model involving exorcism rather than treatment was used to justify punitive measures against those displaying mental disturbance and systematic persecution of those labelled as witches. The distinctions between witchcraft, heresy and insanity were deliberately blurred by a number of 'scholars' and other influential figures. The *Malleus Maleficarum*, published in 1487 under the authority of a Papal Bull, defined those who saw visions as witches.<sup>1</sup> A century later, emerging trends to regard such people as ill and to treat them with sympathy and medical care, were condemned by King James VI of Scotland (later James I of England) in a treatise entitled *Daemonologie*.<sup>2</sup>

The 'medical model' did not re-emerge quickly. The period generally known as the 'Enlightenment' in Europe produced some scholarly exploration of the nature and origins of mental disturbance.<sup>3</sup> On the other hand, this period in Europe is referred to by Foucault as 'The Great Confinement,'<sup>4</sup> in which there was large scale institutionalisation of those considered lunatic or insane together with 'rogues, vagabonds and other idle and disorderly persons.'<sup>5</sup> The prevailing concept of madness moved from that of supernatural disorder to one of a natural condition akin to bestiality. Public concern and official action focussed on the need to restrain and confine 'dangerous lunatics' as one would wild animals. There is considerable literature and some legislation from the 18th century indicating that there was systematic neglect and abuse of insane persons subject to such confinement, and that this situation was beginning to be perceived as requiring redress.<sup>6</sup>

The acceptance of mental disorder as a 'natural' phenomenon led to the study of psychology and various approaches to clinical treatment of mental conditions. By the 19th century the science of psychiatry was well established, embracing many divergent views as to cause and treatment, but consensus on the basic conception of mental illness as a medical phenomenon. The first half of the 20th century saw the elaboration of psychoanalytic and other psychotherapeutic approaches to mental illness. Despite great differences in approach, psychiatrists established themselves as the recognised experts to deal with mental disorders, and a degree of standardisation in the classification and diagnosis of mental conditions began to develop.

In the second half of the 20th century, the medical model was reinforced by advances in research on the physiology of mental illness. Refinements in genetics, biochemistry and neurophysiology, particularly in relation to the understanding of abnormalities in the transmission of electrical impulses in the brain, led to developments in the aetiology, therapy and management of mental illness. Modern anti-psychotic drugs have enabled maintenance on medication to largely replace long term institutionalisation of those with some of the most difficult mental disorders and have brought these conditions more clearly into line with physical illnesses.

However, the increasing dominance of the medical model of mental illness has been challenged in recent decades by some sociologists and others critical of the role of psychiatrists. To these critics, what psychiatrists regard as symptoms of mental illness should be seen as behaviour deviating from social norms. This approach does not necessarily deny certain organic causes of mental disorder, but focusses attention on the social effects of disordered perception and behaviour. A small number of theorists and practitioners entirely reject the concept of an individual condition in favour of the notion of madness or



disorder in social relationships, interactions or reactions. Those most critical of the medical model see the concept of mental illness as a 'conspiracy' between psychiatrists and family members or others hostile to the person subjected to the label.

The sociological approach has also given rise to the educational model of mental illness or disorder. According to this view, the behaviour of a person who might be diagnosed as mentally ill is the result of defective or ineffective learning. Questions of causation are explained by looking at the developmental stages of social interaction. The most practical application of the educational model is in the area of rehabilitation, where learning or relearning patterns of normal behaviour is more important than a 'cure' per se. This approach has the advantage of involving less stigma than psychiatric treatment. It also clearly involves a continuing process, rather than engendering expectations of a transformation from illness to recovery. This difference is critical in relation to continuity and follow-up in psychiatric services.

In this report no single model of mental illness or mental disorder is adopted. Indeed, the evidence placed before the Inquiry suggests a need to integrate and appropriately balance elements of much of the current thinking about mental illness as a disease process and as a social process.

## **Legal Definitions of Mental Illness**

The problem of defining mental illness for legal purposes has been approached differently in the various States and Territories of Australia. In some cases, those responsible for drafting mental health legislation have not attempted a definition, leaving the matter in the first instance in the hands of medical practitioners who have the effective decision-making power under the legislation. Ultimately, in these jurisdictions, the courts can settle questions of definition, applying a combination of expert evidence and common law principles. Upon close examination, however, many legislative formulations are little more than token gestures — marked by circularity of reasoning and apparently designed to intrude to a minimal degree upon the territory of psychiatrists.

The NSW *Mental Health Act* of 1990, however, contains a relatively comprehensive operational definition of mental illness, as well as definitions of 'mentally ill person' and 'mentally disordered person'. The NSW definition of mental illness is as follows:

mental illness means a condition which seriously impairs, either temporarily or permanently, the mental functioning of a person and is characterised by the presence in the person of any one or more of the following symptoms:

- (a) delusions;
- (b) hallucinations;
- (c) serious disorder of thought form;
- (d) a severe disturbance of mood;
- (e) sustained or repeated irrational behaviour indicating the presence of any one or more of the symptoms referred to in paragraphs (a) to (d).<sup>7</sup>

The definition in the Act of a 'mentally ill person' is even more detailed, requiring not only that a person suffers from mental illness but also that there are, as a result, 'reasonable grounds for believing care, treatment, or control of the person is necessary' for the person's own protection from serious physical harm; or for the protection of others from serious physical harm. Alternatively, the person qualifies as a mentally ill person under the Act if he or she is suffering from a mental illness:

characterised by the presence in the person of the symptom of severe disturbance of mood or the symptom of sustained or repeated irrational behaviour indicating the presence of that symptom and, owing to that illness, there are reasonable grounds for believing that care, treatment, or control of the person is necessary for the person's own protection from serious financial harm or serious damage to the person's reputation.<sup>8</sup>

Moreover, the Act provides an inclusive definition of 'damage to the person's reputation', specifying that damage to important personal relationships is sufficient.

Under the Act a 'mentally disordered person' is one whose 'behaviour for the time being is so irrational to justify conclusion on reasonable grounds that temporary care, treatment or control of the person is necessary' for his or her own protection from serious physical harm or for the protection of others.

The NSW Act, like legislation in several other States, contains a list of those criteria considered to be insufficient in themselves to identify a person as mentally ill or mentally disordered. These criteria are:

- (a) expression, refusal or failure to express a particular political opinion or belief;
- (b) expression, refusal or failure to express a particular religious opinion or belief;
- (c) expression, refusal or failure to express particular philosophy;
- (d) expression, refusal or failure to express particular sexual preference or sexual orientation;
- (e) engaging in or refusing to or failing to engage in a particular political activity;
- (f) engaging in or refusing to or failing to engage in a particular religious activity;
- (g) engaging in sexual promiscuity;
- (h) engaging in immoral conduct;
- (i) engaging in illegal conduct;

- (j) having a developmental disability of mind;
- (k) taking alcohol or any other drug;
- (l) engaging in antisocial behaviour.<sup>9</sup>

The Western Australian *Mental Health Act* of 1962 contains definitions of mental illness and mental disorder. Mental disorder is defined as 'any illness or intellectual defect that substantially impairs mental health.'<sup>10</sup> Mental illness is defined as 'a psychiatric or other illness that substantially impairs mental health.'<sup>11</sup> The legislation covers both people with mental illness and people with intellectual disability. Under the provisions for voluntary and involuntary admission, a person must be considered to be suffering from a 'mental disorder requiring treatment under the Act.'<sup>12</sup> (The details of admission criteria are discussed in Chapter 8 of this report.) There is no provision in the WA legislation excluding political, religious or other beliefs or activities as the basis for determinations as to mental illness or mental disorder.

The Tasmanian *Mental Health Act* of 1963 also covers those with intellectual disability as well as those with mental illness. The Act does not contain a definition of mental illness but does define 'mental disorder' as 'mental illness, arrested or incomplete development of mind, psychopathic disorder, and any other disorder or disability of mind.'<sup>13</sup> The Act does not contain definitions of psychopathic disorder or any of the other terms used in the definition. Under the Tasmanian legislation, the only considerations which the Act excludes as sole criteria for determinations relating to mental disorder are 'promiscuity or other immoral conduct.'<sup>14</sup>

The Australian Capital Territory *Mental Health Act* of 1983 has no definition of mental illness, but defines 'mental dysfunction' as 'a disturbance or defect, to a severely disabling degree, of perceptual interpretation, comprehension, reasoning, learning, judgement, memory, motivation or emotion.'<sup>15</sup> Mental dysfunction is the basis for involuntary detention and for the making of treatment orders under the Act. The ACT legislation states that a person shall not be treated as suffering from mental dysfunction by reason only of expressing or engaging in particular political, religious, lawful (or unlawful), moral (or immoral) opinions or activities.

The South Australian *Mental Health Act* of 1977, which covers people with intellectual disability as well as those with mental illness, defines mental illness simply as 'any illness or disorder of the mind.'<sup>16</sup> There is no legislative provision prohibiting any particular form of opinion, belief or conduct from being treated as sufficient to determine the presence of mental illness or disorder of the mind.

Neither the Victorian *Mental Health Act* of 1986, the Queensland *Mental Health Services Act* 1974 to 1991, nor the Northern Territory *Mental Health Act* of 1990 contain definitions of mental illness or of any equivalent term. However, all three statutes contain provisions preventing particular forms of political, religious or moral opinions or engaging in particular political, religious or moral (or immoral) activities, from sufficing to identify a person as mentally ill.

The following rationale for omitting a statutory definition of mental illness was provided by the Queensland Minister for Health in his second reading speech:

The question of mental illness is not decided on whether a person can be given certain diagnostic labels. Mental illness can refer to any degree of mental or emotional defect or aberration, whether from physical or psychological causes. Whether provisions of the Act should apply depends on a medical assessment of the nature and the degree of the disorder, and its effect on the person and on other people.<sup>17</sup>

The Victorian rationale appears to have been the same — the legislators again deferring to the medical practitioners. It should also be noted that the doctors' discretion has not been significantly limited by decisions of the courts. In those rare cases in which the definition of mental illness reaches court, judges frequently display reluctance, resorting to generalised tests in lay terms such as 'what would the ordinary sensible person have said about the patient's condition?'<sup>18</sup> — or, alternatively, relying upon expert medical opinion.

A notable exception to the general judicial reluctance to subject the definition of mental illness to legal analysis may be found in the many decisions of Mr Justice Powell of the NSW Supreme Court's Protective Division, prior to the passage of the 1990 mental health legislation. The NSW *Mental Health Act* of 1958 contained no definition of mental illness and the definition contained in the NSW *Mental Health Act* of 1983 was never proclaimed. Mr Justice Powell was repeatedly called upon to determine the limits of the term mental illness as used in the 1958 *Mental Health Act*. In 1982 His Honour expressed the view that the term 'mental illness' had 'not been the subject of definitive judicial exposition' but that its use in the 1958 legislation was a reference 'to a mental illness in the classic sense of being disease of the mind.'<sup>19</sup> His Honour went on to decide that senile dementia was not a mental illness for the purposes of the NSW *Mental Health Act* 1958. After examining common law definitions involving concepts such as 'unsound mind' and 'depravity of reason or want of it', His Honour pointed to the distinction to be drawn between a mental infirmity arising from disease of age which could be 'attended by confusion and disorientation reflecting loss of memory' and a condition 'attended by hallucinations or delusions such as are not uncommon in schizophrenia, or by

strong and irrational antipathies or fears such as are not uncommon in the case of psychosis.<sup>20</sup> This approach anticipates that taken in the 1990 legislation in NSW, using characteristic symptomatology to define mental illness. In subsequent unreported decisions, the judge also excluded alcoholism<sup>21</sup> and anorexia nervosa<sup>22</sup> from the scope of mental illness for the purposes of the Act.

The absence of legislative definition of mental illness in Victoria has produced a significant amount of analysis by the Victorian Mental Health Review Board in its determinations, excerpts from which are published in the Board's Annual Report. The Victorian *Mental Health Act* 1986 requires the Board to consider whether a person 'appears to be mentally ill'<sup>23</sup> and the approach taken by the Board, as set out in the 1991 Annual Report, also focusses on symptomatology:

a person appears to be suffering from a mental illness if he/she has recently exhibited symptoms which indicate a disturbance of mental functioning which constitutes an identifiable syndrome or, if it would not be possible to ascribe the symptoms of such a disturbance of mental functioning to a classifiable syndrome, they are symptoms of a disturbance of thought, mood, volition, perception, orientation or memory which are present to such a degree as to be considered pathological.<sup>24</sup>

The increasing use of operational definitions in the legal context may indicate that a constructive convergence of legal and medical definitions of mental illness will develop, or may already be developing, from the increasing collaboration of lawyers and psychiatrists in the context of specialist review bodies.

## Medical Conceptions of Mental Illness

To the psychiatrist, the distinguishing feature of mental illness is the presence of symptoms indicating disturbance in mental functioning such as thought, perception, memory or judgement. Psychiatric diagnosis involves identifying clusters of signs and symptoms, usually according to one or another of the standard psychiatric diagnostic protocols. One of the earliest of these which is still, in revised form, in widespread official use is the *ICD* or *International Classification of Disorders*, first developed at the beginning of the century and now in its ninth revision.

The *ICD*, which is primarily a statistical classification system, classifies mental disorders as psychoses, neurotic disorders; personality disorders or other non-psychotic disorders; and mental retardation as follows:

## **Psychoses**

### *Organic Psychotic Conditions:*

Senile and presenile organic psychotic conditions;  
Alcoholic psychoses;  
Drug psychoses;  
Transient organic psychotic conditions;  
Other organic psychotic conditions (chronic).

### *Other Psychoses*

Schizophrenic psychoses;  
Affective psychoses;  
Paranoid states;  
Other non-organic psychoses;  
Psychoses with origins specific to childhood.

## **Neurotic, Personality and Other Non-Psychotic Mental Disorders**

Neurotic disorders, including anxiety state, hysteria, phobic state, obsessive-compulsive disorder, neurotic depression, and other conditions;  
Personality disorders;  
Sexual deviations and disorders;  
Alcohol dependence syndrome;  
Drug dependence;  
Non-dependent use of drugs;  
Physiological malfunction arising from mental factors;  
Special symptoms or syndromes including stammering, anorexia nervosa, tics, sleep disorders, etc;  
Acute reaction to stress;  
Adjustment reaction;  
Specific non-psychotic mental disorders due to organic brain damage.

## **Mental Retardation**

Mild mental retardation;  
Other specific mental retardation;  
Unspecified mental retardation.

A more comprehensive and widely accepted psychiatric classification system is that developed by the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*. The most recent version of this manual, *DSM-III-R*,<sup>25</sup> was last revised in 1987. This system involves rigorous application of operational criteria and is designed to produce a high level of consistency in psychiatric diagnosis. The current manual arranges over 300 mental disorders in diagnostic hierarchies (from the general to the more specific categorisation) with descriptions of the essential and the associated features for each one. The manual also includes discussion of 'differential diagnosis' (those other conditions to be considered and distinguished in arriving at a particular

diagnosis); as well as a discussion of the likely course of a condition, the degree of impairment it may produce and complications that may arise.

The Introduction to *DSM-III-R* contains a definition of mental disorder:

In *DSM-III-R* each of the mental disorders is conceptualised as a clinically significant behavioural or psychological syndrome or pattern that occurs in a person and that is associated with present distress (a painful symptom) or disability (impairment in one or more important areas of functioning) or with a significantly increased risk of suffering, death, pain, disability, or an important loss of freedom. In addition, this syndrome or pattern must not be merely an expectable response to a particular event, eg the death of a loved one. Whatever its original cause, it must currently be considered a manifestation of a behavioural, psychological, or biological dysfunction in the person. Neither deviant behaviour, eg political, religious, or sexual, nor conflicts that are primarily between the individual and society are mental disorders unless the deviance or conflict is a symptom of a dysfunction in the person...

There is no assumption that each mental disorder is a discrete entity with sharp boundaries (discontinuity) between it and other mental disorders, or between it and no mental disorder.<sup>26</sup>

Both the *ICD* and the *DSM* systems are constantly under review. The aim is to ensure, as far as possible, coverage of the full range of psychiatric disorders, and to simultaneously refine the delineation of syndromes into clear, clinical entities. Clinical rigour is the psychiatrist's response to criticism by those who challenge the validity of psychiatric diagnosis or the concept of mental illness itself.

## Cross Cultural Conceptions

Recognition of the multicultural nature of Australian society requires an appreciation that people from different cultures do not simply speak different languages. They may also have very different ways of viewing the world; different systems of belief; and different values relating to certain forms of behaviour, social relationships and spiritual or religious obligations and relations. Distinctions drawn in contemporary western culture between such things as sickness and health or social and spiritual relations may be inappropriate in another cultural context. The concept of 'mental illness', in particular, may have no real equivalent, for example, in traditional Aboriginal culture.

Traditional Aboriginal culture, like many others, does not conceive of illness, mental or otherwise, as a distinct medical entity. Rather, there is a more holistic conception of life in which individual wellbeing is intimately associated with collective wellbeing. Both individual and collective wellbeing involve harmony in social relationships, in spiritual relationships, and in the fundamental relationship with the land and other aspects of the physical environment. In

these terms, diagnosis of an individual illness is meaningless, or even counter-productive if it isolates the individual from these relationships.<sup>27</sup> Recognition of this conception of wellbeing is fundamentally important in assessing the impact of policies and practices of family separation on members of Aboriginal communities, and on those separated from them.<sup>28</sup> (See also Chapter 23 — Aboriginal and Torres Strait Islander People.)

Other cultures have a variety of ways of conceptualising the phenomena that we label 'mental illness', similar in range and content to the differing approaches adopted by western society over time, as outlined above.<sup>29</sup> For example, in the Yoruba culture in Nigeria, there are clinical categories of psychotic illness that closely parallel those of current western psychiatry.<sup>30</sup> Among the Baganda of Uganda, there are a number of diseases associated with the heart, which is seen as both the seat of emotions and the control centre for thought and other cognitive processes.<sup>31</sup> The Baganda also have concepts of disease associated with other organs, such as the brain and stomach, which can be roughly equated to entities labelled as mental illnesses by western psychiatry.<sup>32</sup> There are some conditions that the Baganda consider to be caused by physical means such as poisoning; some that are the result of spirit possession or witchcraft; and others that are the work of gods, either punishing the person for transgression or acting capriciously.<sup>33</sup>

Although no systematic studies of these issues are available for the diverse range of cultures now represented in Australian society, evidence presented to the Inquiry suggested a significant spectrum of conceptions clearly exists.<sup>34</sup> In addition to differing traditional cultural concepts and values, there may be important differences in the meanings attaching to 'mental disorder' and 'mental illness' arising from the cultural or political environment from which a person may have emigrated or in which he or she may continue to live outside middle class, Anglo-Australian society. Conceptions and connotations of 'mental illness' and 'mental disorder' are significantly affected by individuals' experience and expectations of the relative roles of the citizen and the State; the psychiatrist and the State; and doctor and patient.

Many people who have recently migrated to Australia — particularly those from countries with repressive governments — are unclear about the ways in which Australian culture and society differ from those of their homelands.<sup>35</sup> These differences do exist and are sometimes significant in a mental health context (a point explored in greater detail in Chapter 24 — People from Non-English Speaking Backgrounds).



1. See H P Greenberg, 'Historical Perspectives', in P Beumont and R Hampshire (eds), *Textbook of Psychiatry*, Blackwell Scientific Publications, Sydney 1989, p19.
2. id.
3. For example, by Hobbes; Locke; Robert James (*The Medical Dictionary*, 1743); Richard Blackmore (*Treatise of the Spleen and its Vapours, or Hypochondriacal and Hysterical Affections*, 1725); William Cullen and many others, discussed in Greenberg, op cit, and in M Foucault, *Madness and Civilisation*, Tavistock, London 1967, passim.
4. Foucault, op cit.
5. From the title of the first English statute ((1744) 17 Geo II c5) to provide for detention on the ground of lunacy. See Powell J, 'Mental Health Law: The Development of the Law and Changes in its Context' in *Madness in the Law*, seminar papers published by UNSW Law Faculty, 1990.
6. See discussions in Powell, op cit; in Greenberg, op cit; and in Foucault, op cit.
7. See Schedule 1 (Dictionary of Terms) to the NSW *Mental Health Act* 1990.
8. s.9 NSW *Mental Health Act*.
9. s.11 NSW *Mental Health Act*.
10. s.5 WA *Mental Health Act*.
11. id.
12. ss.27, 28 and 29 WA *Mental Health Act*.
13. s.4 Tasmanian *Mental Health Act*.
14. id.
15. s.4 ACT *Mental Health Act*.
16. s.5 SA *Mental Health Act*. (See, however, Chapter 29, relating to legislative proposals currently under consideration in South Australia and Western Australia.)
17. Queensland Parliamentary Debates 1974, v263, p2205.
18. See judgement of Lawton LJ in *W v L* (1974) 1 QB.
19. *RAP v AEP and anor* [1982] 2 NSWLR 508, p510.
20. id.
21. 1986 NSW Supreme Court, unreported.
22. id.
23. s.8 Victorian *Mental Health Act*.
24. Victorian Mental Health Review Board, *Annual Report 1991-92*, p23.
25. American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders: DSM-III-R*, Third Edition-Revised, Washington 1987.
26. ibid, pxxii.
27. Prof Joseph Reser, Department of Psychology, James Cook University. Oral evidence, Townsville 13.8.91, p1277.
28. Carol Kendall, Coordinator and Stan Bowden, member, LINK-UP (NSW) Aboriginal Corporation. Oral evidence, Sydney 21.6.91, pp593-602. Also see Dr Ernest Hunter, Sydney 21.6.91, pp540-541. These issues are considered in detail in Chapter 23 – Aboriginal and Torres Strait Islander People with Mental Illness.

29. For example, a variety of ways of approaching the phenomena identified by Western psychiatrists as schizophrenia has been identified by R Warner, *Recovery from Schizophrenia: Psychiatry and Political Economy*, Routledge and Kegan Paul, London 1985.
30. See discussion in R Littlewood and M Lipsedge, *Aliens and Alienists: Ethnic Minorities and Psychiatry*, 2nd edition, Unwin and Hyman, London 1989.
31. J Orley, *Culture and Mental Illness*, East African Publishing House, Nairobi 1970.
32. id.
33. id.
34. Dr Elsa Bernardi, oral evidence, Sydney 17.6.91, p109; and Reser, op cit, p1274.
35. Margaret Cunningham and Rise Becker, oral evidence, Sydney 20.6.91, p438; and Prof Derek Silove, oral evidence, Sydney 21.6.91, pp573-574. See Chapter 24, People from Non-English Speaking Backgrounds, for further discussion of these issues.

## Chapter 4

# THE LEGAL FRAMEWORK

Most of our legislation is directed to people who are in hospitals. We have mental health acts, official visitors, mental health review tribunals. These are for people in hospital but for the people outside there isn't such protection.<sup>1</sup>

This chapter provides an overview of current Commonwealth, State and Territory legislation governing or bearing upon the provision of mental health services in Australia. The Commonwealth laws which provide for funding in various forms and which set certain parameters for mental health services are dealt with first. This is followed by an examination of the legislative provisions in each State and Territory that regulate the infrastructure of mental health services and related functions such as guardianship. The status of anti-discrimination legislation in each jurisdiction in relation to mental illness is also addressed.

The Inquiry was informed by several State and Territory Governments that mental health legislation is 'under review'. Current proposals for legislative change are examined in Chapter 29.

## Commonwealth Legislation

The fact that psychiatric disability is an episodic thing means that someone is disabled one minute, ill the next.<sup>2</sup>

### Disability Services Act

[The addition of psychiatric disability to the definition of the target group for the disability services legislation] is not going to add a whole lot to the cost of this legislation because, quite simply, and I make no bones about it, I will continue to administer the legislation the way we have administered it in the past.<sup>3</sup>

The *Disability Services Act* 1986 covers persons with a disability that is attributable to a psychiatric impairment, provided the disability is 'permanent or likely to be permanent'<sup>4</sup> and results in 'a substantially reduced capacity of the person for communication, learning or mobility; and the need for ongoing services.'<sup>5</sup>

The Act replaces previous legislation (the *Handicapped Persons Assistance Act* 1974 and Part III of the *Social Security Act* 1947) 'with provisions that are

more flexible and more responsive to the needs and aspirations of persons with disabilities'. It is the stated intention of the Act that people with disabilities receive 'the services necessary to enable them to achieve their maximum potential as members in the community'. The other statutory objectives include: furthering the integration of persons with disabilities; complementing the services generally available to persons in the community; promoting a positive image of persons with disabilities and enhancing their self esteem; and ensuring that consumer outcomes are taken into account when granting financial assistance for the provision of services.

The Act empowers the Minister to formulate principles and objectives to be advanced and guidelines to be complied with in the Act's administration. The Minister is also given the power to approve a class of services as eligible for funding if satisfied that it would comply with Ministerial guidelines. The types of services that may be approved include: accommodation support; advocacy; employment training and placement; supported employment; independent living training; respite care; and services to facilitate access to information by people with disabilities and their families.

Financial assistance to a State or to an organisation is granted under the Act for the provision of 'eligible [ie approved] services' and also for services that were funded under the previous legislation — even if these services do not comply with the statutory objects and Ministerial objectives and principles of the *Disability Services Act*. The Minister is able to impose conditions on funding, including requirements as to funding by the State; and requirements for consumer outcomes in relation to the service to be provided. Compliance with the terms and conditions of grants must be reviewed at intervals of no more than five years.

Under the *Disability Services Act*, provision is also made for financial assistance for research or development activities that would further the principles and objectives and comply with the Ministerial guidelines.

The Commonwealth is also able to provide rehabilitation services which meet these criteria under the *Disability Services Act*. The 'target group' for such services includes people with a disability attributable to a psychiatric impairment that results in 'a substantially reduced capacity...to obtain or retain unsupported paid employment or to live independently.'

## **Aged or Disabled Persons Care Act 1954**

For the purposes of the *Aged or Disabled Persons Care Act 1954*, (as amended), a 'disabled person' is an individual who is either permanently blind or permanently incapacitated and unable to work.

The Act enables the Commonwealth to make capital and recurrent grants to approved hostels as well as capital grants to nursing homes approved under the *National Health Act 1953*. The stated purposes of this Act are to encourage and assist the provision of:

- (i) suitable homes for those eligible to 'reside in conditions approaching as near as practicable normal domestic life'; and
- (ii) accommodation where 'care services and respite care services may be provided for eligible persons'.

The term 'eligible person' is defined in the Act as an aged or disabled person who is assessed as requiring hostel care services or both hostel care and personal care services. A person wanting only hostel care services is eligible without assessment but a person wanting both hostel care and personal care services must be assessed for eligibility.

Assessment for eligibility is made by the Hostel Care Assessment Authority, in accordance with criteria contained in regulations made under the Act. According to these criteria, an applicant is not suitable for hostel care if the person's cognitive or affective functioning means that he or she has major problems coping in the community and suffers from a mental condition requiring a level of care beyond that defined as personal care. Personal care is taken to include the provision of long term emotional support and direct supervision for any eligible person diagnosed as suffering from dementia or from a functional psychotic condition that requires long term medication.

A person assessed as eligible to receive hostel care may still be refused admission by the operator of a hostel.

The *Aged or Disabled Persons Care Act* provides for agreements to be made between the Minister and an organisation which receives funding to operate a hostel. Under such agreements, the conditions of the grant may include giving priority access to specific classes of persons. Certain hostels specialise in caring for people suffering from dementia. However, the definition of hostel under the Act specifically excludes 'an institution carried on exclusively or primarily for the treatment of mentally ill or mentally defective persons, being an institution

conducted by, or in receipt of a grant for maintenance from, a State.’ This definition should not prevent the funding of hostels specialising in services for the mentally ill, provided the hostel was neither conducted by nor receiving a maintenance grant from a State Government. The fact that the Commonwealth Government does not appear to have funded hostels specialising in care for people with mental illness appears to reflect the traditional view that mental illness services are the responsibility of State Governments — rather than any legislative limitation.

The *Aged or Disabled Persons Care Act* provides for formulation by the Minister and approval by Parliament of a common form of agreement between proprietors of hostels and residents. The agreement covers such matters as fees and charges; services to be provided to residents; residents’ participation in decision-making in relation to standards of care and quality of life; and resolution of disputes between residents and hostel operators.

The agreement must also be consistent with the *Charter of Residents’ Rights and Responsibilities* which is set out in a Schedule to the Act. This Charter, in its preamble, states the general rights and freedoms applicable to every person in the community, pointing out that these are not diminished when a person moves into a hostel ‘regardless of his or her mental frailty or ability to exercise or fully appreciate his or her rights.’

The Charter enumerates a range of rights of particular relevance to residents of hostels, including quality care which is appropriate to individual needs; full information about one’s own state of health and about available treatments; treatment with dignity and respect and without exploitation, abuse or neglect; personal privacy; continuation of one’s cultural or religious practices and retention of the language of choice; freedom of speech; access to services and activities which are generally available in the community and access to advocates and other avenues of redress without reprisal. The responsibilities of residents are also listed in the Charter, including respect for the rights and needs of others in the hostel; responsibility for one’s own wellbeing to the fullest extent possible; and the responsibility to inform one’s medical practitioner as far as possible about relevant medical history and current health.

### **National Health Act 1953**

The *National Health Act* 1953 (as amended) provides for the payment of various pharmaceutical, sickness and hospital benefits, including the domiciliary nursing care benefit. It also provides for the recurrent funding of nursing homes, subsuming this function of the *Nursing Homes Assistance Act* of 1974 which related to private nursing homes. The *National Health Act* covers

government and non-government nursing homes and those for aged persons as well as those for persons with disabilities. In practice, however, the funding of nursing homes for persons with disabilities is not given the same emphasis as funding for the care of aged persons.

Under the *National Health Act* the Minister is empowered to approve both the premises and the operators of nursing homes. The Minister may formulate principles to be complied with in the exercise of these powers of approval. There are also conditions set by the Act on the Minister's approval of a nursing home. These may include special admission requirements or the designation of special purposes for particular nursing homes. Other conditions require agreements between residents and nursing home proprietors similar to those applying to hostels under the *Aged or Disabled Persons Care Act*. The *National Health Act* also contains a *Charter of Residents' Rights and Responsibilities in Approved Nursing Homes* which is phrased in similar terms to the charter for hostels.

The conditions imposed on the Ministerial approval of nursing home premises include a requirement that the proprietor must permit a designated community visitor to enter the nursing home to meet with residents and observe the care provided. The Act also provides for authorised inspection of premises and of records kept by the proprietors of nursing homes.

The *National Health Act* authorises the Minister to determine standards to be observed in the provision of care in approved nursing homes. The Minister may periodically publish statements concerning levels of compliance with these standards. Failure to comply may result in suspension of recurrent funding to nursing homes.

Funding for nursing homes under this Act is calculated by reference to the number of days for which care is provided to patients and the level of care provided. The Act provides for classification of patients according to the extent of their personal care needs, measured in terms of criteria known as the Resident Classification Instrument (RCI). Since the Inquiry began, changes have been made to this index to give greater consideration to non-physical factors. However, the RCI is still weighted in terms of the care required by physically disabled patients rather than those whose symptoms relate to cognitive or affective functioning.<sup>6</sup>

The *National Health Act* also makes provision for payment of the Domiciliary Nursing Care Benefit (DNCB) to those providing care to a patient at home. The patient must have an infirmity, illness, disease, incapacity or disability of a kind that would meet the criteria for admission to an approved nursing home

under the Act. The carer must be a spouse, parent, child, sibling or other close relative of the patient or a person approved as a carer. The rate at which DNCB is paid is \$52 per fortnight. An important restriction on payment of the DNCB is that both the carer and the patient must live in the same home.

## **Home and Community Care Act 1985**

The *Home and Community Care Act 1985* is brief enabling legislation which makes financial assistance available from the Commonwealth to the States through an agreement on the provision of home and community care services. The form of this agreement is contained in a Schedule to the Act.

The agreement establishes a Commonwealth-State Home and Community Care (HACC) program designed to promote provision of a comprehensive and integrated range of home and community care, maintenance and support services, either directly to people within the target population or through their carers. Other objectives are 'to ensure access to home and community care among all groups within the target population, including migrants, Aborigines, persons suffering from brain failure and financially disadvantaged persons; [and] to ensure that, within available resources, priority is directed to persons within the target population most in need of home and community care.'

The 'target population' is defined in the Schedule as follows:

- (a) persons living in the community who, in the absence of basic maintenance and support services provided or to be provided within the scope of the program, are at the risk of premature or inappropriate long term residential care, including
  - i. frail or at risk aged persons, being elderly persons with moderate or severe disabilities;
  - ii. younger disabled persons, being persons with moderate or severe disabilities;
  - iii. such other classes of persons as are agreed upon by the Commonwealth Minister and State Minister; and
- (b) the carers of those persons.'

HACC services include home help, personal care, home maintenance, community respite care, community nursing and paramedical services, education and training for service providers and users, and the provision of information and transport.

Services and facilities that are eligible for funding may be provided by State or local government; by a community organisation; or by two or more of these acting jointly. Projects formerly funded by the Commonwealth may also be eligible where no alternative funding arrangements are available.



The agreement allows the Commonwealth Government and the State Minister to approve jointly, and from time to time vary, certain aspects of the management and administration of the program including priorities and sub-program guidelines.

### **Health Insurance Act 1973**

The Medicare system does, however, [militate] against quality service by a general practitioner because of the low amount of benefit paid in respect of long consultations which are so often essential.<sup>8</sup>

The *Health Insurance Act 1973* provides for payment of Medicare benefits for certain medical and hospital services and for provision of grants from the Commonwealth to organisations approved by the Minister for health services or health service development projects.

The 'professional' medical services which attract Medicare benefits are itemised in Schedules to the Act.<sup>9</sup> The Schedules only include services provided by medical practitioners and certain optometrists. Another significant feature of this Act enables the Commonwealth to enter into agreements with States for the provision of hospital and other health services.

### **Social Security Act 1991**

The cyclical nature of psychotic episodes means that people move into and out of programs. Many services are based on a model of linear progression and don't cope with missed appointments or repeated dropping out.<sup>10</sup>

The new *Social Security Act*, which became operative in July 1991, was substantially amended from the date of its commencement by the *Social Security (Job Search and Newstart) Amendments Act 1991*. It was further amended by the *Social Security (Disability Support) Amendments Act 1991* which came into force in November 1991. The latter replaced the old Invalid Pension and Sickness Benefit with the Disability Support Pension and Sickness Allowance. The *Job Search and Newstart Amendment Act* replaces unemployment benefits with a Job Search Allowance for people unemployed for less than 12 months and a Newstart Allowance for people registered as unemployed for more than 12 months.

Eligibility for either the Job Search or Newstart Allowances depends on the claimant satisfying an 'activity test'. This requires a person to be either actively seeking to undertake work or taking 'reasonable steps' to undertake a particular form of work considered suitable.<sup>11</sup> Alternatively the individual may be

required to undertake a course of vocational training; participate in a labour market program; or participate in another course. In the case of a person living in an area with no locally accessible labour market or vocational training course or labour market programs, participation in an activity suggested by the person and approved by the CES may be required.

Job Search Allowance is not payable to an individual who has not provided a tax file number, or who fails to attend or contact an office of the Department of Social Security or the CES when required, or to provide any information required by the Department. There are a number of other circumstances in which the Job Search Allowance is not payable. Many of these are of potential relevance to people with mental illness, including unemployment due to a voluntary act; unemployment due to misconduct; and failure to continue registration with the CES.

For a person unemployed for more than 12 months, eligibility for Newstart Allowance requires entry into a Newstart Activity Agreement with the CES and also requires the person to take reasonable steps to comply with the terms of this agreement. Under the terms of a Newstart Activity Agreement, the individual must undertake one or more of the following activities approved by the Secretary:

- (a) A Job Search;
- (b) A vocational training course;
- (c) Training that would help in searching for work;
- (d) Paid work experience;
- (e) Measures designed to eliminate or reduce any disadvantage the person has in the labour market, not being a measure compelling the person to work in return for payment of Newstart Allowance;
- (f) Participation in a labour market program conducted by the CES;
- (g) An activity proposed by the person such as unpaid voluntary work.

The Newstart Allowance may be refused or suspended in a variety of circumstances — including those referred to above in relation to the Job Search Allowance. In addition, a person may be denied the allowance for failure to enter into a Newstart Activity Agreement or failure to comply with the terms of such an agreement.

The 'Disability Reform Package', as the new Disability Support Pension and Sickness Allowance provisions are known, also has an emphasis on rehabilitation and makes substantial changes to the criteria for eligibility. In order to qualify for a Disability Support Pension a person must have 'a physical, intellectual or psychiatric impairment' which is assessed at 20 percent or more — together with a continuing inability to work. Impairment for the purposes of

the Disability Support Pension is measured in terms of Tables contained in Schedule 2 to the *Social Security (Disability and Sickness Support) Amendment Act 1991*. The Table relating to psychiatric impairment contains the following criteria for impairment at the 20 percent level:

any serious symptomatology or impairment in functioning that most clinicians would think obviously requires treatment or attention, eg suicidal occupation, severe obsessional rituals, frequent severe anxiety attacks, serious antisocial behaviour.

The only guidance available from the Table concerning the required frequency of symptoms is by reference to criteria for other levels of impairment, particularly those less than 20 percent. The criteria for impairment at the 15 percent level are as follows:

Moderate and regular symptoms or generally functioning with some difficulty (eg as manifest by short periods of absence from work, noticeable reduction in social contacts or recreational activities, or the beginnings of family conflict. Likely to have received psychiatric treatment which has stabilised their condition).

By extrapolation, therefore, 20 percent psychiatric impairment requires more than moderate to regular symptoms and more than short periods of absence from work.

Guidelines issued to officers of the Department responsible for applying these criteria indicate that a report from a treating psychiatrist is required. The Guidelines also provide brief notes on the 'key features' of schizophrenia — but not on other mental illnesses.

The test of 'continuing inability to work' requires that the person's impairment is, of itself, sufficient to prevent the person from doing his or her 'usual work', or work for which the person is currently skilled, for at least two years. In addition, the impairment must be sufficient either to prevent the person from undertaking retraining for two years or to prevent such retraining equipping the person within two years with new skills to undertake work.

Work is defined in the legislation as employment for more than 30 hours per week for award wages or above, available anywhere in Australia — not necessarily in the labour market locally accessible to the person concerned. This definition is intended to encourage those receiving Disability Support Pension to engage in part-time work. The combined effect of the definition of impairment by reference to criteria contained in the impairment tables and the express exclusion in the Act of the relevance of availability of work, is to confine the concept of inability to work to medical considerations. The Minister's Second Reading Speech indicates the Government intended to replace

the various socioeconomic and labour market factors relevant to eligibility for invalid pensions, and to focus attention on impairment defined exclusively in medical terms.

Disability Panels, consisting of specialised staff from the Department of Social Security, the Department of Employment, Education and Training (DEET) and the Commonwealth Rehabilitation Service, assess those receiving Disability Support Pensions and Sickness Allowances who are identified as likely to gain assistance from education, training or rehabilitation.<sup>12</sup>

A person otherwise qualified for a Disability Support Pension may have the payment deferred in a number of circumstances specified under the Act. Some of these arise from procedural requirements, such as providing the Department with a tax file number or nominating a bank, credit union or building society account into which the pension is to be paid. Deferment may also result if the person fails to comply with a requirement to contact the Department, attend an interview, complete a questionnaire or attend a medical, psychiatric or psychological examination. A person receiving a Disability Support Pension may also be requested to undertake a program of assistance or rehabilitation. In the Bill as drafted and passed by the House of Representatives, this power was mandatory and it was intended that failure to take reasonable steps to undertake a program of assistance or Jobsearch activity would result in deferment of pension. Amendments made in response to representations from community groups removed the power to compel such participation by a threat of deferment. The element of compulsion remains in relation to compliance with the requirements to attend an interview or an examination, complete a questionnaire or provide a medical report.

Eligibility for Sickness Allowance requires that a person be incapacitated for work because of sickness or accident; that this incapacity be 'caused wholly or virtually wholly by a medical condition arising from the sickness or accident'; and that the incapacity be temporary. In addition, individuals (other than those already in receipt of sickness benefit under the old provisions) must satisfy the Government either that they have suffered or are likely to suffer loss of income because of their incapacity, or that they would be likely to qualify for a Job Search or Newstart Allowance if able to work.

Work is defined, for those still under a contract of employment, as that which they are contracted to perform and, in any other case, work of a kind that a person could reasonably be expected to do. The latter includes part-time or casual work of eight or more hours a week at award wages or above.

Sickness Allowance is intended to be a short term measure and, in the first instance, is payable for a maximum of 13 weeks. This period may only be extended if the recipient provides a medical certificate containing specific information as to diagnosis, prognosis and whether the person is likely to benefit from treatment or a rehabilitation program. The Act provides that a person ceases to be eligible for Sickness Allowance after 52 weeks — unless a determination is made to extend the Allowance on the basis of considerations set out in the Act. These include the case of a person whose incapacity is caused 'by a chronically relapsing medical condition.' (This basis for extension did not appear in the original Bill but was added by amendments introduced in the Senate after expressions of community concern.) Similarly, the Act contains a prohibition on eligibility for Sickness Allowance for two years from the time when the person ceased to be eligible. Here too there is an exception (also added by amendment to the original Bill) for medical conditions that are 'chronically relapsing.'

Deferment of Sickness Allowance is provided for in similar circumstances to those applicable to Disability Support Pensions.

### **Disability Discrimination Act**

In October 1992 legislation was passed by Federal Parliament prohibiting direct and indirect discrimination on the ground of disability, including physical, sensory, intellectual and psychiatric impairment. Harassment on the ground of disability is made unlawful.

The *Disability Discrimination Act* complements legislation already existing in some States, in that it prohibits discrimination throughout Australia in employment, provision of goods and services (including transport and education services), accommodation, membership of clubs and the administration of Commonwealth programs. The legislation includes a requirement to make 'reasonable accommodation' for an individual with disabilities — balanced by the proviso that such accommodation is not required if it would cause 'unjustifiable hardship.' The recently appointed Disability Discrimination Commissioner, operating as a member of the Human Rights and Equal Opportunity Commission, administers this legislation.

## **New South Wales**

The *NSW Mental Health Act* of 1990 is the most recent State legislation in Australia and the most comprehensive. It forms a package with the *Mental Health (Criminal Procedure) Act* 1990 and the *Guardianship Act* 1987. The *Mental Health Act* contains a detailed definition of mental illness, as well as definitions of 'mentally ill person' and 'mentally disordered person' (in Schedule 1 of the Act), as discussed in Chapter 3 of this report.

The Act also contains detailed statements of statutory and administrative objects, Departmental objectives and statutory functions of the Director General of Health. The objects include facilitating the care, treatment and control of persons who are mentally ill or mentally disordered through hospitals and community care facilities on an informal and voluntary basis where appropriate and, in a limited number of situations, on an involuntary basis. The statutory objects include the statement that it is intended that every function, discretion and jurisdiction conferred or imposed by the Act is, as far as is practicable, to be performed or exercised to enable care and treatment of those who are mentally ill or disordered to be 'the best possible in the least restrictive environment', with 'any restriction on the liberty of patients or other persons who are mentally ill or disordered and any interference with their rights, dignity and self respect [to be] kept to the minimum necessary in the circumstances.'

### **Voluntary Admission**

The *NSW Mental Health Act* provides for a person to be admitted to a hospital as an informal (voluntary) patient on an oral or written application to the medical superintendent made by the person concerned or, in the case of a person under guardianship within the meaning of the *Guardianship Act*, by the person's guardian with approval of the Guardianship Board. The Act allows the medical superintendent to refuse to admit a person as an informal patient where the superintendent is not satisfied that the person is likely to benefit from care or treatment as an informal patient.<sup>13</sup> Provisions are also made for the parent of a person under 14 to veto their admission as an informal patient and for the parent or guardian of a person between 14 and 15 years old to object to that person receiving care or treatment at a hospital, in which case the medical superintendent must discharge the person unless he or she elects to remain. The Act requires the medical superintendent to 'do all such things as are reasonably practicable to notify the person's parent or guardian of the person's admission' as soon as practicable after admission.

Informal patients may discharge themselves at any time and the medical superintendent may discharge them if of the opinion that they are not likely to benefit from further voluntary treatment.

An individual who is refused admission as an informal patient or is discharged from hospital, having been admitted as a voluntary patient, may apply to the medical superintendent for review of the refusal or discharge. This review must be conducted as soon as practicable.

If, having regard to the condition of an informal patient, the medical superintendent considers it appropriate, he or she may take steps to have the patient admitted and detained as an involuntary patient.

### **Involuntary Admission**

But a mentally ill person taken to a hospital by a relative has to follow stringent admission procedures before help is given or treatment proceeds... Quite often, both the sufferer and the carer are denied their human right to treatment and turned away until the necessary procedures of admission and scheduling have taken place.<sup>14</sup>

The NSW *Mental Health Act* states that a person must not be admitted or detained in hospital as an involuntary patient unless the medical superintendent is of the opinion that no other care of a less restrictive kind is appropriate and reasonably available. The Act provides for detention on the certificate of a medical practitioner who has, immediately before completing that certificate, personally examined or observed the person and formed the opinion that he or she is 'a mentally ill person or mentally disordered person'.<sup>15</sup> The doctor must also be satisfied that no other appropriate means of dealing with the person are reasonably available and that involuntary admission and detention are necessary. The Act specifies time limits of five days between certification of a person as mentally ill and their admission and one day between certification and admission of a person who is mentally disordered.

Where the certifying doctor considers the condition of the person is such that assistance of the police is required to take the person to hospital and that no other means is reasonably available, the doctor may endorse a certificate accordingly. Police must then 'apprehend and take or assist in taking the person to a hospital'. For these purposes the police are authorised, without obtaining a warrant, to enter premises (by force if necessary) to apprehend the person to be certified.

Involuntary detention may also be initiated under the Act by the police, a welfare officer, a magistrate or, in special circumstances, on the request of a relative or friend. Detention at the request of a relative or friend may occur if the medical superintendent is satisfied that the urgency of the circumstances and the 'distance required to be travelled in order to have the person examined by a medical practitioner' render it 'not reasonably practicable' to follow the normal procedure for examination and certification by a doctor.

An individual may be taken to a hospital by a welfare officer who may make a written statement to the medical superintendent expressing the belief that the person is a mentally ill or mentally disordered person. The magistrate may authorise a doctor and any other person to visit (this can, where necessary, involve forcible entry to premises) and personally examine or observe a person thought to be mentally ill or mentally disordered, if no other means of examination or observation are practicable. The person examined or observed in this way may then be detained on the certificate of the doctor.

In all these cases, and in the case of an order for detention made under the *Mental Health (Criminal Procedures) Act*, the medical superintendent of the hospital must refuse to detain a person if he or she is of the opinion that the person is not a mentally ill or mentally disordered person. A person taken to and detained in a hospital must be examined by the medical superintendent as soon as practicable — and not more than four hours after arrival.

The NSW *Mental Health Act* further requires that as soon as practicable after the medical superintendent has certified a person as mentally ill or disordered, the detainee must be examined by another doctor. If the medical superintendent is not a psychiatrist then the further examination must be conducted by a psychiatrist. If the doctor conducting the further examination is of the opinion that the person is not mentally ill or mentally disordered, the Act requires examination by another psychiatrist. If that psychiatrist is also of the opinion that the person is not mentally ill or mentally disordered, he or she must be discharged from the hospital.

Where the medical superintendent and the doctor who conducts the further examination agree that the person is mentally ill or mentally disordered, the detainee must be brought before a magistrate as soon as practicable. The medical superintendent has the responsibility to inform the person concerned and to do all such things as are reasonably practicable to give notice of the hearing to the person's nearest relative or a relative nominated by the person; to the person's guardian, if any; and to one or two personal friends. While the NSW *Mental Health Act* allows a person who has been involuntarily detained to be given 'such treatment (including any medication) as the medical



superintendent sees fit', there is an express requirement to have 'due regard for the possible effects of the medication' and to 'prescribe the minimum medication, consistent with proper care, to ensure that the person is not prevented from communicating adequately with any person who may be engaged to represent the person at an inquiry' before a magistrate. The Act also expressly requires the medical superintendent to ensure, so far as is reasonably practicable, that the person is dressed in street clothes when brought before a magistrate.

A person certified as mentally disordered must not be detained in hospital on that ground for more than three days. The medical superintendent is required to examine that patient at least every 24 hours. If the medical superintendent forms the opinion that appropriate care of a less restrictive kind is reasonably available, that person must be discharged. A person may not be admitted and detained as a mentally disordered person more than three times in any one month.

### **Review, Discharge, Leave and Transfer**

The fact that they can now go before magistrates fully dressed and not in pyjamas...was a major thing which should have been obvious but wasn't.<sup>16</sup>

The NSW *Mental Health Act* contains detailed provisions for the conduct by magistrates of inquiries to review involuntary detention.<sup>17</sup> Such inquiries must be open to the public unless the person detained objects and the magistrate upholds that objection. However, there are penalties for publishing the name of the detained person or any report of the inquiry which would lead to their identification.

The medical superintendent is responsible for making all necessary arrangements for medical witnesses and medical evidence to be placed before the magistrate. The Act provides that a person brought before a magistrate who is 'unable to communicate adequately in English but who is able to communicate adequately in another language' be entitled to a competent interpreter. The person detained (and, with the leave of the magistrate, any other person appearing at the hearing) may be legally represented. The Act gives the person whose detention is at issue a right, unless the magistrate otherwise determines, to inspect any relevant medical records. The magistrate can also require the production of evidence or the attendance of a witness at the inquiry.

If the magistrate is satisfied, on the balance of probabilities, that a person is mentally ill, he or she may order that person discharged to the care of a relative or friend or order another course of appropriate action, including

making a community treatment order or community counselling order. If the magistrate considers that no other care of a less restrictive kind is appropriate and reasonably available, the magistrate must direct that the person be detained for further observation or treatment or as a temporary patient for a period not exceeding three months. If the magistrate is not satisfied on the balance of probabilities that the individual is mentally ill, he or she must order the person to be discharged. Where the magistrate considers it is in the person's interest, he or she may defer the operation of an order for discharge for a period not exceeding 14 days.

If an order is made by a magistrate for detention of a person as a temporary patient, the medical superintendent must, as soon as practicable, ensure that the patient is given a statement of his or her rights of appeal. There is, however, no right of appeal conferred by the Act against a magistrate's finding that an individual is mentally ill, or against a community treatment order, a community counselling order or a detention order.

Where the medical superintendent considers that a temporary patient should be detained beyond the period ordered by the magistrate, the superintendent is required to arrange for that patient to be reviewed by the Mental Health Review Tribunal. The Tribunal, which is required to take account of the effect of any medication on the patient's ability to communicate, must determine whether the patient is mentally ill and whether appropriate care of a less restrictive kind is reasonably available. The Tribunal may then determine that the patient be detained for a further period of observation or treatment as a temporary patient; or whether the person should be classified as a continued treatment patient. The Tribunal must review the detention of temporary patients at intervals of not more than three months. Continued treatment patients must be reviewed by the Tribunal every six months.

The Act also requires the Mental Health Review Tribunal to review, at least every 12 months, the case of each informal patient who has received care or treatment in hospital for a continuous period of 12 months or more. The Tribunal is empowered to order the discharge of such a patient and also to defer such discharge for a period not exceeding 14 days.

The Act specifies the circumstances in which a medical superintendent must discharge involuntary patients, and their rights to apply for discharge. It also sets out the rights of informal patients to discharge. Relatives or friends of involuntary patients may apply for the discharge. There is a right of appeal to the Tribunal where a medical superintendent refuses an application for discharge or fails to determine such an application within three working days.

Provision is made in the Act for the medical superintendent to grant an involuntary patient leave of absence from hospital, for such periods and subject to such conditions as the superintendent thinks fit. The superintendent is also empowered to transfer an involuntary patient from one hospital to another. In such cases, the Act requires notification of the transfer to the patient's nearest relative, a relative nominated by the patient or, where there is no such relative, a personal friend of the patient.

## **Treatment**

The medical superintendent of a hospital is authorised to give such treatment, including any medication, as he or she thinks fit where a person is detained involuntarily.

The superintendent, and others administering or authorising the administration of medication, must have due regard to the possible effects of the medication and must specifically strike a balance between the level of medication 'consistent with proper care' and that which would prevent individuals from communicating with their representative for the purposes of a magisterial inquiry. The superintendent is required to establish and maintain an internal review system to monitor and review the prescription and use of medication in terms of frequency of administration, dosage, intended and unintended effects and appropriateness of use.

The NSW *Mental Health Act* contains a general prohibition on administration to a person who is or is suspected to be suffering any mental illness or any mental condition, of 'a dosage (or dosages) of a drug or drugs, which having regard to proper professional standards, is excessive or inappropriate.' There is also a prohibition on the administration or performance of deep sleep therapy, insulin coma therapy, or any operation or treatment proscribed by regulation made under the Act.

The Act requires that consent be obtained for surgical operations on temporary patients, continued treatment patients, forensic patients suffering from mental illness or any other person detained under the Act. The absence of corresponding requirements for the administration of psychiatric treatment, together with the provision allowing the medical superintendent to authorise treatment for those detained under the Act, indicates that informed consent to general psychiatric treatment appears not to be required for involuntary patients. The position in relation to voluntary patients is unclear.

The Act also contains elaborate provisions concerning electro convulsive therapy (ECT). The Act limits the use of ECT to gazetted psychiatric hospitals, authorised private hospitals or other places authorised by the Director General of Health. It may only be administered in the presence of two doctors and also requires administration of anaesthesia by a doctor. For persons other than involuntary patients, ECT may only be administered if the person is capable of giving informed consent to the treatment and has done so in writing. Two doctors, including at least one psychiatrist, must also certify in writing that they consider the treatment reasonable, proper and necessary or desirable for the safety or welfare of the person, considering that person's clinical condition, history of treatment and any appropriate alternative treatment. The Act sets out at length procedures to be followed for obtaining consent, including a fair explanation of the techniques or procedures; full description of attendant discomfort and risks; full disclosure of alternative treatments, if any; and notice of the right to obtain legal and medical advice before giving consent. Provision is made for ECT to be administered without consent to involuntary patients in emergencies, subject to certain conditions, and after an inquiry and determination by the Mental Health Review Tribunal.

Psychosurgery under the *NSW Mental Health Act* is subject to even more stringent controls. It requires not only consent by the person but also consent by the Psychosurgery Review Board, a body consisting of seven part-time members including a legally qualified President, a neurosurgeon, neurologist or neuroscientist, a clinical psychologist, a person nominated by the Council for Civil Liberties and two psychiatrists. Before giving consent to psychosurgery, the Board must conduct a public hearing at which the patient may be legally represented. The Board may only consent if satisfied the patient is capable of giving informed consent; that the psychosurgery proposed has clinical merit; that the doctors are properly qualified and the hospital is a proper place to perform psychosurgery. If the Board is not satisfied that a patient is capable of giving consent but is satisfied as to the other matters, the Board must state a case for the Supreme Court to determine whether the patient is capable of giving informed consent and, if not, whether consent should be given on the person's behalf.

Treatment for mental illness outside hospitals is encouraged by the Act's provisions for community treatment orders and community counselling orders. These allow for treatment and care to be given entirely on an outpatient basis or following hospital treatment. The Act also provides for non-compliance with community counselling or treatment orders, authorising the police to enter premises and use reasonable force to apprehend the person subject to the order without a warrant. The person may then be taken to the appropriate health care

agency. If treatment is refused at a community health service, a person subject to a community treatment order may be taken to a hospital.

## **Forensic Patients**

I think that at the moment 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 because they then become forensic patients and they frequently serve longer in prison than they would have done had they been found guilty in the ordinary way.<sup>18</sup>

The *Mental Health (Criminal Procedures) Act* 1990 contains provisions by which persons involved in criminal proceedings may be found unfit for trial and ordered to be detained in a hospital or other place. It also contains provisions for those found not guilty of an offence by reason of mental illness to be ordered to be detained in strict custody in a hospital or other place. The *Mental Health Act* contains detailed provisions for reviewing the cases of persons found unfit for trial and those found not guilty by reason of mental illness. It also provides for transfer to a psychiatric hospital of persons serving sentences of imprisonment who appear to the Chief Health Officer to be mentally ill. The Chief Health Officer must make this determination on the basis of a certificate signed by two doctors including a psychiatrist who has examined the prisoner, but is not limited by the definition of mental illness contained in the *Mental Health Act*.

The Mental Health Review Tribunal is required, at intervals of not more than six months, to review the case of each forensic patient and make recommendations to the Minister for Health concerning the patient's continued detention, care or treatment; the patient's release, either conditionally or unconditionally; and, in the case of a patient found unfit for trial, the fitness of that patient to be tried. In contrast to the Tribunal's powers in relation to other patients, the Tribunal has no power to make final determinations in relation to forensic patients.

Apart from the limitations on the powers of the Tribunal in relation to forensic patients, the general rights conferred on mentally ill persons under the *Mental Health Act* also apply to forensic patients. These include the following:

- the right to be informed of legal rights and other entitlements under the Act;
- the right to legal representation and an interpreter in review hearings;
- other procedural rights in relation to review hearings including confidentiality ;
- the right to information as to medication;

- the right to freedom from wilful assault, ill treatment or neglect by hospital staff;
- rights in relation to psychosurgery, ECT, and proscribed treatments.

Like other involuntary patients, forensic patients have statutory rights to informed consent in relation to ECT, psychosurgery or surgical operations for physical conditions. Otherwise, forensic patients (like other involuntary patients under the *Mental Health Act*) may be given such treatment, subject to the Act, as the medical superintendent thinks fit.

### **Administration, Monitoring and Complaint Handling**

A young man...was attacking other patients and, as an official visitor, I and the other official visitors raised this matter with the staff a number of times and no action was taken until this young man started attacking staff.<sup>19</sup>

The NSW *Mental Health Act* provides for public hospitals or other premises to be gazetted as psychiatric hospitals for the purposes of the Act.<sup>20</sup> Provision is also made for the Director General of Health to grant licences for privately owned premises to be 'authorised hospitals' for the purposes of the Act. Patients may only be admitted under the Act to a gazetted or authorised hospital. Unlike gazetted hospitals, authorised hospitals require an annual statement relating to the conduct of the hospital, the admission of patients and the care and treatment provided on the premises.<sup>21</sup> The Director General may cancel a licence or vary the terms and conditions to which it is subject. There are also statutory requirements regarding the ratio of patients to services provided by qualified doctors at authorised hospitals.

The Act continues the use of official visitors to inspect hospitals and other health care agencies as a means of monitoring standards of service delivery. Two or more official visitors, including a medical practitioner and one a suitably qualified or interested person, are appointed by the Minister for each hospital or health care agency and must visit the facility at least once a month. They are required, as far as practicable, to inspect every part of the hospital or health care agency and make such inquiries as they think necessary concerning the care, treatment and control of informal patients and those detained in the hospital who are subject to community counselling or community treatment orders. Official visitors must be permitted to see and interview patients and to examine all relevant records and documents.<sup>22</sup> They may report to the Minister.

The Act also provides for the appointment by the Director General of authorised officers who are required to inspect hospitals and make such investigations and inquiries as they consider necessary and as the Director General may direct. Authorised officers have powers to gain access to medical records, other documents and information.

The Health Department has a Complaints Unit which is active in investigating and referring for determination complaints against doctors and others employed by health care agencies. Legislation is due to be introduced to provide a statutory basis for the handling of such complaints.

### **Mental Health Review Tribunal**

The NSW Mental Health Review Tribunal, established under the *Mental Health Act*, consists of a President, Deputy President and other members (both full-time and part-time). They are appointed by the Governor and able to be removed by the Minister at any time. The Tribunal's functions are to review the detention of temporary patients, continued treatment patients, informal patients and forensic patients at regular intervals; and to hear and determine appeals from temporary or continued patients whose applications for discharge have been refused or not dealt with by the medical superintendent. It also determines whether consent should be given to administration of ECT to an involuntary patient who has refused or not consented to the therapy, and it may determine the validity of a patient's consent to such treatment where the medical superintendent makes application for this. If ECT is administered without consent in an emergency, the Tribunal must receive a written report of the treatment including copies of relevant medical records.

The Tribunal members are to include barristers and solicitors, psychiatrists and people with other suitable qualifications or experience. In cases relating to forensic patients, the President or Deputy President must chair the proceedings. The Tribunal is not bound by the rules of evidence and may inform itself of any matter it thinks appropriate. The Act specifically states that in determining whether a person is a mentally ill person the Tribunal is to have due regard to any cultural factors which may be relevant and to any evidence by an expert witness concerning the person's cultural background.

The Tribunal's proceedings are open to the public unless a party to the proceedings objects and the Tribunal upholds the objection. Names and other material which may identify an individual are not to be published. There are

statutory rights to appearance before the Tribunal, to representation and to assistance by a competent interpreter. A patient or another applicant is entitled to inspect any medical records unless the Tribunal otherwise determines. Representatives also have rights of access to medical records. The Tribunal may, of its own motion or on the application of any person before it, issue a summons for a witness to attend or for the production of documents. All determinations or recommendations of the Tribunal must be recorded in writing and, if requested by any party to proceedings, must include reasons for the determination or recommendation.

## **Guardianship**

The *Guardianship Act 1987* covers those who are 'intellectually, physically, psychologically or sensorily disabled' and specifically extends to a person 'who is a mentally ill person within the meaning of the *Mental Health Act*'. Application may be made to the Guardianship Board for a guardianship order. If the Board is satisfied that the person has a disability, is 'restricted in one or more major life activities to such an extent that he or she requires supervision or social habilitation', and is 'in need of a guardian' it may make a limited or, if necessary, a plenary order on a temporary or continuing basis, subject to such conditions as it considers appropriate. The guardian may be an individual or the Public Guardian.

Where the Board makes a continuing guardianship order appointing a person other than the Public Guardian, it is required to refer a copy of the order to the Public Guardian. The Board may review any guardianship order of its own motion or at the request of any person entitled to do so under the Act; and at the expiration of any period for which the order had effect. A review may be requested by the guardian, the person under guardianship, the Public Guardian or any other person who, in the Board's opinion, has a genuine concern for the welfare for the person under guardianship.

The Guardianship Board also has power, under the *Protected Estates Act 1983*, to make orders appointing financial managers for those incapable of administering their own property.

For the purpose of exercising its functions, the Board is constituted by three to five members. These must include one person who is legally qualified (who presides in a hearing); a person such as a medical practitioner, psychologist or social worker, who in the Minister's opinion, has experience in assessing or treating people with disabilities; and a person who, in the Minister's opinion,



has experience with people with disabilities. The Board is not bound by the rules of evidence and may inform itself of any matter in such a manner as it thinks fit. Proceedings are to be open to the public unless the Board determines otherwise. The Act prohibits the publication of the names of those subject to proceedings before the Board, witnesses or those mentioned in evidence. Parties to proceedings have a statutory right to appear in person and may, by leave of the Board, be represented by a lawyer or agent. The Board may compel the attendance of witnesses or the production of any relevant document. The Board is also required to attempt to achieve a conciliated settlement in any case before determining an application. Determinations are required to be in writing and to include the reasons for decision.

The guardianship legislation complements the *Mental Health Act* in several respects. It allows a person with a disability that is not a mental illness within the meaning of the *Mental Health Act* to be admitted to a psychiatric hospital as an informal patient where such care and/or treatment is in that person's interest. It also allows a person who is not mentally ill within the meaning of that Act, but who nevertheless has some form of mental illness, to be given care or treatment in that person's interest either as an informal patient in a psychiatric hospital or elsewhere. The *Guardianship Act* provides that in the event of an inconsistency between the provisions of that Act concerning medical consent and the provisions of the *Mental Health Act*, the latter shall prevail. There is also provision in the *Guardianship Act* for a guardianship order to be suspended while a person is involuntarily detained under the *Mental Health Act*.

### **Anti-Discrimination Legislation**

Under the NSW *Anti-Discrimination Act 1977*, discrimination is prohibited on the grounds of physical or intellectual disability. The statutory definitions of these do not specifically include or exclude mental illness. It may be argued that conditions that have a physiological aetiology (as schizophrenia and manic-depression are now thought to) come within those definitions of intellectual or physical disability under the Act which refer to 'defect or disturbance of the structure and functioning' of the brain or body respectively.

# Victoria

I think there's always going to be confusion between where one draws the line between the responsibility to intervene and give someone help and the responsibility to let that person declare that they do not want to be treated.<sup>23</sup>

The Victorian *Mental Health Act* 1986 and related legislation includes some of the best provisions in Australia relating to the treatment of mental illness. The Victorian Public Advocate and Health Services Commissioner have been used for models for recent reforms in the ACT and Queensland. The *Mental Health Act* contains detailed statements of statutory objects and departmental objects. However, there are also deficiencies in the Victorian legislation — such as the absence of a statutory definition of mental illness.

## Voluntary Admission

Every day of the week in this State people remain in private psychiatric hospitals as de facto involuntary patients in that they are told, 'If you are not prepared to stay here you will be certified'.<sup>24</sup>

The Victorian Act provides for voluntary admission as a psychiatric patient, subject to the discretion of the psychiatrist authorised as the senior officer of the hospital or facility. Admission may be refused if the authorised psychiatrist is not satisfied that the person is likely to benefit from care and treatment as a voluntary patient. There is a right of appeal against refusal to the chief psychiatrist.

A voluntary patient may leave the inpatient facility at any time or may be discharged by the authorised psychiatrist. There is provision under the Act for the senior psychiatric nurse on duty to 'reasonably restrain the voluntary patient and prevent the voluntary patient from discharging himself or herself for a period not exceeding six hours so that the voluntary patient can be examined by a medical practitioner', where the nurse considers that the patient meets the criteria for involuntary admission under the Act.<sup>25</sup>

## Involuntary Admission

The criteria for admission and detention as an involuntary patient under the Victorian Act are as follows:

- (a) that the person appears to be mentally ill; and
- (b) that the person's mental illness requires immediate treatment or care and treatment or care can be obtained by admission to and detention in a psychiatric inpatient service; and

- (c) that the person should be admitted and detained as an involuntary patient for that person's health and safety or for the protection of members of the public; and
- (d) that the person has refused or is unable to consent to the necessary treatment or care for the mental illness; and
- (e) that the person cannot receive adequate treatment or care for the mental illness in a manner less restrictive of that person's freedom of decision and action.<sup>26</sup>

The procedure for involuntary admission under the Victorian Act requires the production of a request for detention, together with a recommendation for admission by a medical practitioner who considers that the relevant criteria for admission and detention are met. This recommendation need not be based on personal examination by the doctor who signs the recommendation provided that doctor relies upon a medical examination made within the previous 28 days. The person must be admitted to a psychiatric inpatient service by a doctor employed in or by that service and must be examined within 24 hours of admission by the authorised psychiatrist for that service. The authorised psychiatrist must, upon examination, confirm the admission if satisfied that continued detention is warranted; or if not so satisfied must discharge the person.

### **Discharge, Leave, Transfer and Review**

An involuntary patient may be discharged at any time by the authorised psychiatrist if he or she is satisfied that continued detention is not necessary in terms of the criteria for involuntary detention under the Act. An order for discharge of an involuntary patient may also be made by the Mental Health Review Board where the Board is not satisfied that continued detention is necessary, having regard to the statutory criteria.

Provision is made under the Victorian Act for involuntary patients to be granted leave of absence for such periods and subject to such conditions as the authorised psychiatrist considers appropriate.

The authorised psychiatrist also has power under the Act to order the transfer of an involuntary patient to another psychiatric inpatient service if the authorised psychiatrist is satisfied that the transfer would be of benefit to the patient or that it is necessary for the patient's care and treatment. The authorised psychiatrist of the service to which it is proposed to transfer the patient must approve the transfer and the chief psychiatrist must be notified. Provision is made for a patient to appeal to the Mental Health Review Board against a transfer. The Board must consider whether the transfer will be of benefit to the patient and whether it is necessary for the patient's care and treatment. The Board may either confirm the transfer or direct that the patient continue to be detained at, or be returned to, the original facility.

The Mental Health Review Board established by the Victorian Act consists of a President and other members appointed by the Governor.<sup>27</sup> The Board sits in divisions consisting of three members, one of whom must be a senior barrister and solicitor; one a psychiatrist other than the authorised psychiatrist of the facility at which the division is to sit; and one a person appointed to represent the views and opinions of members of the community.

The Mental Health Review Board must hear appeals against involuntary detention four to six weeks after detention and review continued detention thereafter at intervals of not more than 12 months.<sup>28</sup> The Board also has the power to:

- appeal against transfers;
- receive reports on the use of restraint, seclusion or electro convulsive therapy given without consent;
- receive reports on consent by guardians or authorised psychiatrists to non psychiatric treatment to patients deemed incapable of giving informed consent themselves; and
- hear appeals from security patients against involuntary detention or refusal of leave.

The Board is empowered to discharge involuntary patients unless satisfied, in terms of the statutory criteria, that continued detention is necessary. The Board also receives reports on specified matters such as administration of ECT without the patient's consent and the use of seclusion and restraint.

Proceedings of the Mental Health Review Board must be conducted according to equity and good conscience without regard to technicalities or legal forms. The Board is not bound by the rules of evidence and may inform itself in such manner as it sees fit although the Act expressly requires that the rules of natural justice be observed.<sup>29</sup> Hearings of the Board are to be closed to the public unless it is satisfied that it would be in the interest of the patient or in the public interest to open any particular proceedings or any parts of proceedings. The Board is required to provide written statements of its decisions and, where requested by a party to the proceedings to do so, to provide written reasons for decisions. These are only to be published if the Board determines this to be appropriate in a particular case in the public interest. Where a report is made public the Board must ensure that it does not contain any particulars that could lead to the identification of any person involved in the proceedings.

A person aggrieved by a determination of the Mental Health Review Board may apply to the Victorian Administrative Appeals Tribunal for review. The Victorian *Mental Health Act* also provides for the Board, of its own motion or on the application of any person who is a party to proceedings, to reserve a

question of law arising in proceedings before the Board, and to state a case for the opinion of the Supreme Court. The Court's opinion must be obtained and applied by the Board in determining the matter before it.

## **Treatment**

One of the conundrums that arises in the care of people with psychiatric illness is the feeling that consent, as is enshrined in the law, is perhaps out of place in dealing with mental illness.<sup>30</sup>

In accordance with the principle of treatment in the least restrictive environment, the Victorian *Mental Health Act* provides for the making of community treatment orders as an alternative to inpatient treatment for a person who meets the criteria for involuntary detention.<sup>31</sup> Such community treatment orders must specify the doctor to supervise the treatment and care of the patient; the place at which the patient is to receive the treatment; and the manner in which the doctor is to report on the patient's progress. The duration of the order must not exceed 12 months. During this time the person subject to the order is deemed to be an involuntary patient. The order may be revoked or varied by the Mental Health Review Board or by an authorised psychiatrist.

The need for immediate treatment for mental illness and refusal and inability to consent to necessary treatment or care are among the criteria for involuntary detention under the Act. The provisions for admission and detention of involuntary patients include a provision for the authorised psychiatrist or guardian to consent to treatment for a patient's mental illness where such patient has refused to consent to the necessary treatment or is not capable of giving written consent for treatment of his or her mental illness.<sup>32</sup> This is a relatively clear abrogation of common law rights in relation to informed consent and refusal of treatment. The only remaining scope for these common law rights is in relation to voluntary patients and to involuntary patients who are capable of giving written consent or who are being offered treatment other than necessary treatment.

Non-psychiatric treatment is defined as:

- any surgical operation or procedure or series of related surgical operations and procedures; or
- administration of an anaesthetic for the purpose of medical investigation; or
- administration of any course of treatment or medication requiring a prescription or medical supervision, the primary purpose of which is not the treatment of any mental illness or the effects of mental illness.

The Act also contains detailed provision for consent in relation to psychosurgery and electro convulsive therapy. Administration of psychosurgery requires written consent from the person on whom it is to be performed after a clear explanation of the benefits, discomforts, risks, any beneficial alternative treatment and any other information concerning the techniques or procedures to be used about which the patient may ask.

A doctor who is to perform psychosurgery must also apply to the Psychosurgery Review Board. There is provision for the person on whom the surgery is to be performed to be legally represented at this hearing. The Psychosurgery Review Board must consider whether the person on whom the surgery is to be performed has the capacity to give informed consent; whether he or she has given informed consent; whether the proposed psychosurgery has clinical merit and is appropriate; whether the person proposing to perform the psychosurgery is properly qualified; whether the place in which it is to be performed is appropriate and whether all other reasonable treatments have already been adequately and skilfully administered without sufficient and lasting benefit. Any approval by the Board must specify the name of the doctor to perform the psychosurgery; the nature of the psychosurgery to be performed; the place in which it is to be performed and the period within which it is to take place. Reports of all psychosurgery performed must be submitted to the Psychosurgery Review Board and the Board must review at regular intervals the case of any person on whom psychosurgery has been performed.

In relation to electro convulsive therapy (ECT), the Victorian Act also requires informed consent except in the case of an involuntary or security patient who is incapable of giving informed consent. In these cases, it is necessary for a psychiatrist to authorise ECT and, wherever possible, for the consent of the primary caregiver or guardian to be obtained. The Act also provides an exception to the general requirement for informed consent in relation to electro convulsive therapy for cases where 'the nature of the mental illness from which the patient is suffering is such that the performance of ECT is urgently needed'. The administration of ECT is permitted under the Act only in premises licensed for the purpose. There are detailed provisions for such licensing.

The use of mechanical means of bodily restraint is limited under the Victorian Act to cases where it is necessary for the purposes of medical treatment of the patient; to prevent the patient from causing injury to himself or herself or any other person; or to prevent the patient from persistently destroying property.

The use of mechanical restraint must be approved by the authorised psychiatrist or, in an emergency, by the senior psychiatric nurse on duty. In the latter case the authorised psychiatrist must be notified without delay. A report on the use

of mechanical restraint must be sent to the Mental Health Review Board on a monthly basis.

The use of seclusion is limited under the Act to situations where it is necessary 'for the protection, safety or well being of the patient or other persons with whom he or she would be in contact.' Its use must be approved in the same way as mechanical restraint and a report must be made to the Mental Health Review Board each month. The Act specifies that supervision must be given to a patient in seclusion and lists other conditions such as supply of appropriate bedding, clothing, food and drinks.

### **Forensic Patients**

We still have in this State the iniquitous system of people who are found not guilty on the grounds of insanity or unfit to plead detained in custody, sometimes in prison, sometimes in psychiatric hospitals, for an indefinite period. Release decisions are made by State Cabinet, and inevitably it appears political considerations are taken into account...<sup>33</sup>

The Victorian *Mental Health Act* contains provision for hospital orders and restricted community treatment orders to be made for persons charged with or convicted of criminal offences. The hospital order may be made for admission and detention of a person in a psychiatric inpatient service subject to the normal provisions applicable to involuntary patients under the Act, with the exception that if the patient is discharged by the Mental Health Review Board or by an authorised psychiatrist before the expiration of the hospital order, application must be made to the court for sentence to be passed. In doing this, the court may take into account the period spent in detention under the hospital order.

A hospital order may also be made for admission or detention of a person as an involuntary patient for a specified period not exceeding three months for the purpose of diagnosis, assessment and treatment. Hospital orders may be made as an alternative to sentencing after a person is found guilty of a criminal offence if a court is satisfied on the production of a psychiatric certificate and such other evidence as it may require, that the person appears to be suffering from a mental illness that requires treatment; that the treatment can be obtained by admission to and in a service; and that the person should be admitted as an involuntary patient for their own health and safety or for the protection of members of the public.

The Victorian Act also empowers the Director General of Corrections to make a hospital order to transfer a person already imprisoned or legally detained who appears to be mentally ill. The criteria for the exercise of this discretion are identical to those applicable to the making of a hospital order by the court. The

Director General must be satisfied as to these criteria after receiving a certificate from a psychiatrist. The Director General must also receive a report from the authorised psychiatrist at the facility to which it is proposed to admit the person with a recommendation that the transfer be made.

Hospital orders made by the Director General of Corrections may either be for admission in the normal course as an involuntary patient or may be in the form of a 'restricted hospital order' under which a person is admitted and detained in a psychiatric inpatient service as a security patient. In deciding whether to make a restricted hospital order, the Director General of Corrections must consider the public interest in all the circumstances of the case including the person's criminal record and psychiatric history. As with involuntary patients, the Act provides that security patients are to be detained and treated for mental illness and if incapable of consenting to treatment or refusing to consent to necessary treatment, consent to psychiatric treatment may be given by an authorised psychiatrist or a guardian.

The *Mental Health Act* provides that security patients are in the custody of the authorised psychiatrist of the inpatient service to which they are admitted and subject to such security conditions as the authorised psychiatrist considers necessary. Security patients may be transferred to another psychiatric inpatient service and may be given leave of absence by the chief psychiatrist or by the Mental Health Review Board, provided that the safety of members of the public will not be seriously endangered. The Act provides for discharge of security patients by the Mental Health Review Board or by the chief psychiatrist where their continued detention is not necessary in terms of the statutory criteria for detention of security patients. The Director General of Corrections must be notified by the Mental Health Review Board or the chief psychiatrist of the discharge of a security patient and the person must be returned to prison custody. The *Mental Health Act* provides that where a security patient is granted bail, released from custody by a court or completes his or her sentence of imprisonment, the detention as a security patient ceases. The Director General of Corrections is required to notify the chief psychiatrist when a patient's sentence of imprisonment is to expire.

Restricted community treatment orders may be made under the *Mental Health Act* in respect of persons detained as involuntary patients under hospital orders made by a court. The authorised psychiatrist at the hospital at which the person is detained may apply to the chief psychiatrist for a restricted community treatment order to be made where the patient who appears to be suffering from a mental illness requires treatment and where either the person's own health or the safety or protection of members of the public requires such an order.



The restricted community treatment order must specify not only the psychiatrist to supervise the treatment and the place where the treatment is to be received, but also the intervals at which the patient must attend for treatment and the intervals at which they must attend the psychiatric inpatient service for monitoring. The Act requires that, having made a restricted community treatment order, the chief psychiatrist must send a copy to the Mental Health Review Board for review as soon as practicable. Only when the Mental Health Review Board has conducted this review does the restricted order take effect. The chief psychiatrist or the Mental Health Review Board may vary or revoke restricted community treatment orders. The Act provides for restricted community treatment service orders to be extended for up to 12 months at a time.

Under the Victorian *Sentencing Act* of 1991, the courts have available a further option of a 'hospital security order' which allows a person found guilty of a criminal offence to be admitted to a psychiatric hospital for a specified period as a security patient. The authorised psychiatrist of the hospital concerned must recommend to the court an admission as a security patient. The person subject to a hospital security order has a right of appeal to the Mental Health Review Board and must be reviewed at regular intervals by the Board. If the Board determines that a person no longer satisfies the criteria for detention as a security patient, they must be discharged from the hospital and detained in prison for the remainder of the specified term.

Victoria also has a law which was designed to enable one individual (the late Mr Garry David) to be detained on the basis of a finding by the Supreme Court that he was a serious risk to the safety of any member of the public and likely to commit an act of personal violence to another person: the *Community Protection Act* 1990. This legislation followed the finding by the relevant authorities that Garry David had a personality disorder rather than a mental illness and therefore could not be detained under the *Mental Health Act* at the expiration of his prison sentence.

### **Monitoring and Complaint Handling Mechanisms**

Alone amongst public hospitals in Victoria our psychiatric hospitals do not have anyone who is designated as a complaints liaison officer.<sup>34</sup>

The Victorian *Mental Health Act* gives the Governor the power to proclaim any premises provided by the State for the care and treatment of persons who are mentally ill as an approved psychiatric hospital. The Governor may also proclaim the psychiatric unit of a general hospital to be an approved psychiatric

unit if that unit satisfies 'an appropriate standard as determined by the department'.

Other than the statements of statutory objects and departmental objectives there are no standards specified in the Act. Provision is made in the Act for community support services, including crisis services, residential services, community assistance or rehabilitation services, family support services, advocacy services and any other training, education, recreation or therapeutic services to be funded by the Department subject to any conditions considered appropriate by the Chief General Manager. Registration of these community support services depends upon the Chief General Manager being satisfied that the service operates in accordance with the principles specified in the Act.

The Chief General Manager enters into funding and service agreements with registered community services on the understanding that services use their funding for specified purposes and keep appropriate records in relation to financial matters and the kinds of services provided. An administrator may be appointed where the Minister forms the opinion that a community support service is inefficiently or incompetently managed; has failed to provide an effective service in accordance with the statutory principles; or has breached any of the provisions of the funding and services agreement.

The Act also provides for the appointment by the Chief General Manager of a Chief Psychiatrist who is to be responsible for the medical care and welfare of persons receiving treatment for mental illness. The Chief Psychiatrist has the power to visit any psychiatric service, including community health centres, psychiatric outpatients' clinics, community support services and general or private hospitals which care for persons who are mentally ill. The Chief Psychiatrist may inspect the premises or any part of the premises; may see any person who is receiving treatment for mental illness; make inquiries relating to admission, detention, care, treatment and control of patients; and inspect any documents relating to any patient.

The *Guardianship and Administration Board Act 1986* established an Office of the Public Advocate with functions encompassing all persons with disability. These functions include promoting the provision, development and coordination of facilities provided by Government, community and voluntary organisations for persons with disability. The objective is to enable people with disabilities to act independently, to minimise restrictions on their rights and to maximise utilisation of services and facilities, encouraging the involvement of voluntary organisations, relatives, guardians and friends in the management and provision of such services and facilities.

The Public Advocate is appointed by the Governor for a period of seven years and can only be removed from office on a motion by both houses of Parliament. The powers conferred on the Public Advocate are relatively broad and include intervention in any proceedings before the Guardianship and Administration Board; representation or advocacy on the part of any person with disability; provision of advice concerning the provisions of the *Guardianship and Administration Act*; investigation of any complaint or allegation that a person is under inappropriate guardianship or is being exploited or refused or in need of guardianship; and reporting or making recommendations to the Equal Opportunity Board on behalf of people with disabilities.

The Victorian *Mental Health Act* provides for the appointment by the Governor of community visitors with the power to inspect premises or documents and to make inquiries into the admission, detention, care, treatment and control of patients. The community visitors are required to report to the Public Advocate and to the Minister. Their functions include:

- (a) inquiry into the adequacy of services for the assessment and treatment of inpatients, outpatients and other persons referred for assessment and treatment under the *Mental Health Act*;
- (b) inquiry into the appropriateness and standard of facilities for the accommodation, physical well being and welfare of persons receiving treatment and care for mental illness;
- (c) inquiry into the adequacy of opportunities and facilities for recreation, occupation, education, training and rehabilitation; and
- (d) inquiry into the extent to which treatment or care is provided in the least restrictive environment.

The *Health Services (Conciliation and Review) Act 1987* establishes the position of Health Services Commissioner with powers to investigate and conciliate complaints in relation to health services; to identify and review the causes of such complaints; and to propose ways of improving those situations. The Commissioner is appointed by the Governor and can only be removed on a motion by both Houses of Parliament. The legislation gives the Commissioner significant powers to obtain information including compulsory powers to require attendance at inquiries and to call for documents or other evidence. The Commissioner provides the Minister with an annual report on his or her activities.

The Victorian *Health Services Act 1988* empowers the Minister to declare a specified committee, council or other body established by one or more health

service agencies to be an approved quality assurance body. The functions of such a body include the assessment and evaluation of the quality of health services provided by the agency or establishment, including the review of the clinical practices and clinical competence of a person providing those services.

## **Guardianship and Administration**

The *Guardianship and Administration Board Act* of 1986 establishes the Guardianship Board as an independent body constituted by a legally qualified member and such other members as are necessary from time to time. The Board may make a guardianship order if satisfied that a person has a disability, is by reason of that disability unable to make reasonable judgements in respect of all or any of the matters relating to his or her person or circumstances, and that the person is in need of a guardian. A guardian may be appointed on either a plenary or limited basis.

The Board's proceedings are public unless the Board decides otherwise. However, the Board's determinations are not to be published unless the Board considers that it would be in the public interest to do so, in which case the identifying particulars of the case are to be deleted. The Board's proceedings are to be conducted informally in accordance with equity and good conscience but without regard to technicalities or legal forms. The Board is bound by the rules of natural justice. The representation of the applicant and of the person in respect of whom the application is made is permitted but not required. The Board may appoint either the Public Advocate or a private individual as guardian. A plenary guardianship order confers 'all the powers and duties which the plenary guardian would have if he or she were a parent and the represented person was his or her child'. An order appointing a limited guardian may specify one or more of the powers and duties that may be conferred on a plenary guardian.

The Guardianship and Administration Board also has the power to appoint an administrator for the estate of a person if it is satisfied that the person has a disability, is by reason of that disability unable to make reasonable judgements in respect of matters relating to all or any part of their estate, and is in need of an administrator of their estate. The Board may appoint the State Trust, Public Advocate or any other person who satisfies the statutory requirements as a suitable administrator. The administrator has the powers and duties conferred on the State Trust under the *State Trust Corporation of Victoria Act 1987*.

## **Anti-Discrimination Legislation**

The Victorian *Equal Opportunity Act* of 1984 covers discrimination on the ground of 'impairment.' This includes an impairment which has ceased to exist and an impairment which is imputed to a person. The definition of an impairment in the Act includes 'a mental or psychological disease or disorder'.

## **Queensland**

The Queensland *Mental Health Services Act*, originally passed in 1974, has since been significantly amended and displays a mixture of old and more progressive provisions. It contains no definition of mental illness or mentally ill person and states that its provisions apply 'to drug dependence and intellectual handicap as if each of these conditions were a mental illness.' The legislative criteria for involuntary or 'regulated' admission are broad and the Act allows for 'removal to a place of safety' with or without a warrant.

### **Voluntary Admission**

The Queensland Act allows the patient 'who is in need of treatment for mental illness' to be admitted to any hospital other than a security patients' hospital. A patient who has been detained involuntarily under the Act may also be admitted as a voluntary patient once he or she ceases to be liable for regulated patients' admission. The Act provides that a hospital administrator may refuse to make arrangements to admit a patient to or to keep a patient in hospital after medical examination and assessment of the patient's condition. Where the hospital administrator thinks the patient would benefit from treatment at any other place, he or she must refer the patient to that place.

### **Involuntary Admission**

The criteria for involuntary admission under the Queensland Act are broadly defined:

- (a) That [the person] is suffering from mental illness of a nature or to a degree that warrants detention in a hospital;
- (b) that [the person] ought to be so detained in the interests of [the person's] own welfare or with a view to the protection of other persons.<sup>35</sup>

Application may be made by a relative or 'authorised person' (defined in the regulations as a person appointed as such by the Minister) and must be supported by a written recommendation from a medical practitioner.<sup>36</sup> An application for admission together with a medical recommendation in the

prescribed form are sufficient authority for the person whose admission is sought to be conveyed to hospital. The Act requires members of the police force to assist in this process, 'accompanied by an authorised person'.<sup>37</sup>

Provided the hospital administrator consents to admission, a patient may be admitted for a period of up to three days on the basis of the application and medical recommendation.<sup>38</sup> For detention beyond that period, another recommendation, also in the prescribed form, must be provided by a different doctor who has examined the patient after admission. On the basis of the second medical recommendation, the patient may be detained for a period of up to 21 days from the day of admission. Up to this point there is no statutory requirement for examination by a psychiatrist. However, for involuntary detention beyond 21 days the hospital administrator must have the patient examined by a psychiatrist. If it appears to the psychiatrist that it is 'necessary in the interests of the patient's welfare or for the protection of other persons that the patient should continue to be liable to be detained' a report to this effect must be supplied to the hospital administrator. This report may then form the basis for renewal of detention for up to three months and subsequently for a period not exceeding 12 months from admission. Renewals of detention for periods beyond 21 days must be reviewed by the Patient Review Tribunal.

A person may also be involuntarily detained under the *Mental Health Services Act* in accordance with provisions allowing 'removal to a place of safety' with or without a warrant. The Act allows for any person to lay information on oath before a justice. If, on the basis of such information, it appears to the justice that 'there is reasonable cause to suspect that a person is mentally ill and that in the interests of that person or for the protection of other persons it is necessary' to issue a warrant for removal to a place of safety, the justice may issue such a warrant. This authorises and requires the police for a period of 14 days from the date of the warrant, in the company of a doctor and 'designated authorised person', to:

- (a) apprehend the person in respect of whom the warrant is issued;
- (b) enter and search, if need be by force, the premises specified in the warrant and any other premises in which the police reasonably believe the person will be found; and
- (c) remove the person to a place of safety.

The doctor accompanying the police officer may provide the officer with a written opinion that the person who is the subject of the warrant is not mentally ill or that it is not necessary for the person to be removed to a place of safety in his or her own interests or for the protection of others. If provided with such a written opinion, the police officer must not execute the warrant and must

report accordingly, with reasons, to the Director of Psychiatric Services. The term 'place of safety' is defined in the Act as 'any hospital (other than a security patients' hospital) or police station, or any other suitable place the occupier of which is willing to receive temporarily a patient.'

The procedure under the *Mental Health Services Act* for removal without a warrant to a place of safety authorises a member of the police force to remove any person the police officer 'believes to be mentally ill and a danger to himself or other persons and in need of immediate treatment or control'. The Act prescribes certain limitations on this power in relation to removal of a person 'from any place that is not a public place': the police officer must reasonably believe that obtaining a warrant would involve unreasonable delay and must obtain the consent of the occupier or person apparently in control of the place in question unless that person is not readily identifiable or available.

A person removed to a place of safety under the Queensland *Mental Health Services Act* may be detained 'for the purpose of being examined...as soon as practicable by a doctor and being interviewed by an authorised person with a view to the making of an application for involuntary detention or the making of other arrangements for treatment.' Detention in a 'place of safety' must not exceed three days. If, upon medical examination, the doctor does not consider the person to be mentally ill, or in need of detention on the ground of mental illness, the doctor must certify accordingly and the person must be discharged.

### **Review, Leave and Transfer**

The Queensland *Mental Health Services Act* establishes Patient Review Tribunals, each constituted by three to five members appointed, and capable of being removed from office, by the Governor in Council. Each Tribunal must be chaired by a retired Judge or a person qualified to be a District Court Judge. Tribunals must include at least one member who is a medical practitioner and at least one other member qualified to practice a profession 'that requires a special knowledge and interest with respect to mental illness'. The Act does not specify procedures other than for making applications to the Tribunals. Nor does the Act require the Patient Review Tribunals to adhere to the rules of natural justice, allowing them to 'admit, and proceed and recommend upon such information or evidence as [they think] fit, whether the same as the law would allow or admit in other cases or not.'

In any case of involuntary detention under the *Mental Health Services Act* in excess of 21 days, the hospital administrator must apply to the Tribunal for review of the detention. The administrator is also required to ensure that the patient is informed of their right to apply, or to have application made on their

behalf, to the Patient Review Tribunal for discharge. Application may be made on behalf of the patient by any authorised person or relative or any other person by leave of the Tribunal. The Tribunal also has discretion to allow an applicant to be assisted during a hearing by a lawyer who provides 'legal representation determined by the Tribunal to be warranted' or by any other person.

Where the Patient Review Tribunal is satisfied that the patient is not suffering from mental illness of a nature or to a degree that warrants detention in hospital and does not need to be detained for their own welfare or for the protection of others, the Tribunal may order the Director to discharge the patient. The Tribunal also has power to order the Director to make appropriate arrangements for transfer or leave of absence, and to make recommendations in respect of any other matter. The Director may, within seven days of receiving a Tribunal order for the discharge of a patient, apply to the Mental Health Tribunal to have the order set aside. In this case the discharge order made by the Patient Review Tribunal does not operate, pending determination of the application by the Mental Health Tribunal. An application may also be made to the Mental Health Tribunal to set aside the refusal of a patient's application for discharge. However, in the case of a determination confirming renewal of detention upon an application made by the hospital administrator, the patient has no right to seek review by the Mental Health Tribunal.

The Mental Health Tribunal established under the *Mental Health Services Act* consists of a Judge of the Supreme Court, assisted by two psychiatrists who are not members of the Tribunal. The Judge and psychiatrists are appointed by Order in Council.

The rules for procedure before the Mental Health Tribunal (the Mental Health Tribunal Practice Rules 1985) repeat the formula used in the Act for the Patient Review Tribunal, allowing the Tribunal to 'admit and proceed and make determination upon such information or evidence as it thinks fit whether or not such information or evidence is such that the law would require or admit in other proceedings.' There is, however, also a provision in the *Mental Health Services Act* itself which deems proceedings before the Mental Health Tribunal to be judicial proceedings, thereby importing common law rules of natural justice. The Act also requires that evidence before the Mental Health Tribunal be taken on oath or affirmation.

Power is conferred on the Mental Health Tribunal to direct any person to visit and examine a person detained as mentally ill and to inquire into and report upon such matters in relation to that person as the Tribunal thinks fit. The Tribunal may exercise these powers on the application of any person or of its own motion. Similarly, the Tribunal may, on application or of its own motion,



direct the hospital administrator or the occupier or resident of any house in which a person may be detained as mentally ill, to bring such a person before the Tribunal. Where the Tribunal is satisfied that such a person is not suffering from mental illness of a nature or to a degree that warrants detention in the hospital and does not need to be detained in the interests of their own welfare or the protection of others, or that the person is unlawfully detained, the Tribunal must order the person to be immediately discharged. The Tribunal is given powers to require the production of evidence and for attendance of witnesses relating to these matters as well as powers to direct a doctor to examine and assess a person whose mental condition is in question.

Provision is made in the Queensland *Mental Health Services Act* for transfer of involuntary patients from any hospital to any other hospital other than a security patients' hospital, under arrangements made by the hospital administrators and in accordance with an order for the transfer of the patient, signed by a doctor. Where a hospital administrator believes the assistance of a member of the police force is necessary in the transfer, a certificate stating this provides the necessary authority for the police to provide such assistance. Provision is also made under the Act for the removal of patients interstate by order of the Mental Health Tribunal on application made by any person. The Tribunal must determine that it would be in the interests of the patient's welfare that they be removed from Queensland and that they have 'a relative or other person in that place...who is willing to undertake the care and charge' of the patient.

There is also provision under the *Mental Health Services Act* for involuntary patients, other than security patients, to be granted leave from hospital, subject to such conditions as the designated medical practitioner may consider necessary 'in the interests of the patient or for the protection of other persons.' Such conditions may, specifically, include a direction that the patient is to remain in the custody of another person during the period of leave. Leave of absence may be revoked and the patient recalled to hospital whenever the designated medical practitioner or the hospital administrator or the Director of Psychiatric Services considers that it is 'necessary so to do in the interests or the patient's welfare or the protection of other persons'.

These provisions and the provisions for the discharge of patients are subject to exceptions in relation to 'restricted patients'. The Act gives the Director of Psychiatric Services the discretion to classify an involuntary patient as a restricted patient where the Director is of the opinion that such a patient, 'if granted leave of absence or discharge from a hospital, would be likely to act in a manner dangerous to himself or to other persons, and that it is necessary in the interests of the patient's health or safety or for the protection of other persons that the patient should be restricted.' A restricted patient may only be

granted leave of absence or discharge from a hospital with the written consent of the Director of Psychiatric Services.

Patients other than restricted patients may be discharged from hospital by the medical authorities, by an authorised person or by the patient's nearest relative. However, in the case of discharge by a relative or authorised person, at least 72 hours notice must be given in writing to the hospital administrator. During that period the designated medical practitioner may furnish to the hospital administrator a report certifying that, in his or her opinion, the patient 'if discharged would be likely to act in a manner which is dangerous to himself or to other persons.' In this case the discharge cannot proceed and the relative or authorised person may not seek discharge again for a period of three months. Where discharge is refused in this fashion, there is a right of review by the Patient Review Tribunal.

## **Treatment**

The Queensland *Mental Health Services Act* describes voluntary admissions as being for those who 'are in need of treatment for mental illness' and regulated admissions as being 'for treatment of mental illness'. The Act does not provide for treatment outside the context of the hospital, with the exception of the leave provisions outlined above. There is no express provision authorising treatment in any form or limiting the form or the circumstances of such treatment. An enabling provision, allowing the Governor to declare 'any surgical, procedural medical or therapeutic intervention' to be a 'proscribed treatment', does not appear to have been used. Neither the Act nor the Regulations contain prohibition or restriction on the use of electro convulsive therapy or psychosurgery.

Under the *Mental Health Services Regulations 1985* there are detailed provisions for the use of seclusion of patients. These include the requirement of an order by the medical superintendent or doctor in charge of the patient's treatment, except in a case involving extreme violence. The order for seclusion must specify the extent of observation, medical and nursing treatment and supervision to be provided to the patient and the period for which the patient is to be secluded. A register must be kept containing particulars of the use of seclusion.

There is no reference in the Act or Regulations to informed consent nor is there any provision which authorises treatment in terms which clearly indicate an intention that a patient, on admission, loses his or her common law right to refuse treatment. Voluntary patients, who are capable of discharging themselves, would almost certainly retain the right to refuse treatment. The position of involuntary patients is less clear.<sup>39</sup> There is a general provision exempting

from any liability actions done 'in good faith and without negligence' in the exercise of powers under the Act, including the use of 'force that is reasonably necessary in the circumstances and does not cause...death or grievous bodily harm'. This, however, does not constitute an express authorisation or justification of the use of force to administer medication or any other form of treatment to a patient, as was pointed out by Mr Carter, QC in the report of the inquiry into Ward 10B of Townsville General Hospital.<sup>40</sup>

## **Forensic Patients**

A person charged with or convicted of a criminal offence may be admitted under the Queensland *Mental Health Services Act* to an ordinary psychiatric hospital or to a security patients' hospital if he or she is suffering from a mental illness 'of a nature or to a degree that warrants detention in a hospital' and where he or she 'ought to be so detained in the interests of his own welfare and with a view to the protection of other persons'.<sup>41</sup> The Act provides that such patients are to be treated as restricted patients.

Security patients' hospitals are established under both the *Prisons Act 1958 — 1974* and the *Mental Health Services Act*. The Regulations under the *Mental Health Services Act* give the medical superintendent of a security patients' hospital the responsibility in relation to treatment of patients and the supervision of medical and other staff engaged in treatment; and give to the Comptroller of Prisons the responsibility in matters relating to the safe custody of patients and the security of the hospital. The Regulations allow for the superintendent to refuse to grant permission to visit. Patients' mail at a security patients' hospital may be examined and withheld.

Restricted patients are subject to significantly greater limitations on leave and discharge. In particular, written consent of the Director General of Health is required for leave or discharge. There is a conspicuous absence of provision for positive rights for restricted patients other than rights of review.

The Queensland *Mental Health Services Act* allows justices, acting on the evidence of two doctors, to admit a person before them charged with a summary offence to a hospital other than a security patients' hospital as a restricted patient. Following the admission of such a patient, a psychiatrist must conduct an examination and report to the Director of Psychiatric Services who must, in turn, report to the Minister for Justice. The Minister for Justice, in relation to a patient charged with a summary offence, may direct that the hearing of the complaint may not proceed; may direct that the hearing should proceed if the patient is no longer detained; or may defer the determination for up to three months in which case the Minister is required to refer to the Patient

Review Tribunal the question of the patient's mental condition. The Tribunal, after consideration of all material that it considers relevant, shall report to the Minister on the mental condition of the patient and state whether, in its opinion, the patient needs to be further detained on account of mental illness and whether he or she is fit for trial. If the Tribunal reports that in its opinion the patient requires further detention on account of mental illness or is not fit for trial, the complaint against the patient is deemed to have been dismissed and the patient continues to be detained as an involuntary patient but not as a restricted patient.

In the case of patients charged with indictable offences, the procedure is similar except that they are to be admitted to security patients' hospitals and the body to which the question of the patient's mental condition may be referred is the Mental Health Tribunal. If this Tribunal finds that the person was not suffering from unsoundness of mind at the time of the offence, it shall inquire and determine whether he or she was suffering from diminished responsibility. If the person is found by the Tribunal to be fit for trial and not to have been suffering from unsoundness of mind at the material time, the proceedings are to continue according to law. Where, however, the Mental Health Tribunal does not find the person fit for trial, it shall order that the person be detained as a restricted patient in a security patients' hospital or in some other hospital.

The Patient Review Tribunal is required to review the fitness of the patient for trial once every three months for the first 12 months from the time of the Mental Health Tribunal's order for detention, and thereafter at 'reasonable' periods. If the Patient Review Tribunal finds that it is unlikely that the person will be fit for trial within a reasonable time, it shall report to the Minister for Justice who shall report to the Governor with a recommendation as to the continuance or discontinuance of proceedings against the person. The Governor in Council may order discontinuance of proceedings or defer the question of continuance for a period not exceeding six months at any one time.

There are similarly detailed provisions under the *Queensland Mental Health Services Act* relating to persons who are mentally ill while imprisoned on remand, either awaiting trial or awaiting sentence. There are also provisions dealing with the admission of persons found not guilty on the basis of unsoundness of mind and the admission of prisoners serving a sentence of imprisonment or detention following conviction for an offence. Such persons are to be detained in a security patients' hospital or other hospital pursuant to an order of the court or of the Governor in Council, and are to be treated as restricted patients. Their mental condition is to be reviewed at least every 12 months by the Patient Review Tribunal. The Tribunal may make a recommen-

dition to the Parole Board for the release of a patient found not guilty on the basis of unsoundness of mind.

### **Monitoring and Complaint Handling Mechanisms**

The Queensland *Mental Health Services Act* provides for the Governor in Council to appoint two or more official visitors in relation to any hospital. One of these is to be a medical practitioner or a person qualified to practice a profession that requires a special knowledge and interest with respect to mental health; and the other is to be a barrister, solicitor, magistrate or person qualified for appointment as stipendiary magistrate. Official visitors are required to visit the hospital to which they are appointed at least once a month and make special visits as the Minister or Director General or Director of Psychiatric Services may direct. Reports made by official visitors after each visit are to be furnished, in the case of a visit made at the direction of the Minister or Director General, to the Minister or Director General as the case may be, and otherwise to the Director of Psychiatric Services. The functions, powers and duties of Official Visitors are set out in the Mental Health Services Regulations 1985, together with the requirements that the hospital administrator facilitate performance of those functions and duties. The official visitors are required to inspect the registers, books and records kept in accordance with the Act (including the medical recommendations and applications for involuntary admission) as well as inspecting every part of the hospital and every patient.

The ACT provides for the Governor in Council to establish psychiatric hospitals and security patients' hospitals and other such places as he or she thinks fit for the purposes of the Act. The Governor in Council is given power under the Act to declare that any such hospital or other place shall cease to be a psychiatric hospital, security patients' hospital or other place. The Act does not provide criteria upon which such declarations are to be based. The Mental Health Services Regulations 1985 set out certain requirements for the administration of psychiatric hospitals, security patients' hospitals and other places established under the Act. These consist of the general duties and responsibilities of the medical superintendent of a hospital or establishment; duties and responsibilities of a manager; and duties and responsibilities of a principal nurse. There is a penalty of \$200 for breach of these Regulations.

The Act gives the Director General of Health discretionary powers to visit and inspect without notice every hospital as he or she thinks necessary or as directed by the Minister. The Director General also has the Powers of a Commissioner under the Queensland *Commissions of Inquiry Act 1950* for the purposes of inspection.

In 1991 the *Health Rights Commission Act* was passed by the Queensland Parliament, establishing an independent body with broad functions including the handling of health service complaints; identifying and reviewing issues arising out of such complaints and suggesting ways of improving health services and preserving and increasing 'health rights.' The Commissioner is appointed by the Governor in Council to head the Commission.<sup>42</sup> There is an express requirement that in the performance of the functions of office the Commissioner is required to Act 'independently, impartially and in the public interest.'

### **Guardianship and Management of Property**

The Queensland *Mental Health Services Act* gives to the designated medical practitioner the power to form an opinion when a person is admitted to a hospital as to whether that person is capable of managing his or her estate. No criteria are set out in the Act for this opinion. The Act requires the designated medical practitioner to notify the Public Trustee in writing 'forthwith' when the practitioner is of the opinion that a patient is incapable of managing his or her property and affairs. The Public Trustee shall 'without further or other authority, manage the estate' of every person of whose incapacity the Public Trustee has been notified or who is declared by the Supreme Court to be incapable. The Supreme Court has the power, on the application of the Public Trustee or of any other person, to appoint another person as well as or instead of the Public Trustee to manage the estate of a patient. The Court shall not appoint any person other than the Public Trustee for this purpose 'unless the court finds that there is sufficient reason why such person should be so appointed in preference to the Public Trustee.'

Management of the 'property and affairs' of a patient does not, however, involve guardianship. Queensland legislation contains no provision for guardianship for people with mental illness. The *Intellectually Disabled Citizens Act* 1985 does not extend to persons whose incapacity is purely a result of mental illness.<sup>43</sup>

### **Anti-Discrimination Legislation**

The Queensland *Anti-Discrimination Act* of 1991 covers discrimination on the ground of impairment, which is defined to include 'a condition, illness or disease that impairs a person's thought processes, perception of reality, emotions or judgement or that results in disturbed behaviour'. It covers discrimination in the following areas: work, education, goods and services, superannuation and insurance, disposition of land, club membership, administration of State laws and programs and local government.

## South Australia

The SA *Mental Health Act 1977* (the Act) is unusual in the prominent role it accords to the Guardianship Board established under the Act. This role has been reviewed and legislation has been tabled in Parliament which would establish a new Guardianship Board under separate legislation, subsuming powers currently exercised by the Mental Health Review Tribunal.

### Voluntary Admission

The Act provides for a person to be admitted at their own request as a patient in an approved hospital. The Act also provides for such a patient to leave the hospital at any time.<sup>44</sup>

### Involuntary Admission

The Act enables a doctor to make an order for immediate admission and detention of a person in an approved hospital where he or she is satisfied that the following criteria are applicable:

- (a) that the person is suffering from mental illness that requires immediate treatment;
- (b) that such treatment can be obtained by admission to and detention in an approved hospital; and
- (c) that the person should be admitted as a patient in an approved hospital in the interests of his or her own health and safety or for the protection of other persons.

The Act defines mental illness as 'any illness or disorder of the mind'.<sup>45</sup> An order made by a doctor on these criteria is sufficient to detain a person for up to three days. The Act further provides that where possible within 24 hours of admission and otherwise as soon as practicable after admission a person detained under such an order must be examined by a psychiatrist. After this examination, the psychiatrist may, if satisfied that the continued detention of the patient is justified, confirm the order or, if not so satisfied, discharge the order. Confirmation of the order authorises detention for a period of up to 21 days from the expiry of the initial order. The Act requires that if two psychiatrists, after independent examination of the patient, agree that 'further detention is necessary for the protection of others' they may make an order for further detention of the patient. This provision does not set any limit on the duration of such continued detention. Although it requires that the patient be detained under a previous order the only criterion specified for further detention is that it is necessary for the protection of others.

Another means by which a person may be involuntarily detained under the Act is by order of the Guardianship Board. After receiving a person into guardianship the Board may require that the protected person 'be received into a specified hospital...or other institution for treatment or care' and that the protected person be placed in the custody of the person for the time being in charge of that hospital or other institution. In order to receive a person into its guardianship, the Board must be satisfied that the individual is suffering from mental illness and is therefore incapable of looking after their own health or safety or managing their own affairs. There are general principles the Board must consider before making any order in relation to a protected person. These involve balancing 'the object of minimising interference with the rights and independence of the person with proper protection and control' and treating 'the welfare of the person as the paramount consideration.' There are, however, no specific criteria for making an order to involuntarily admit a protected person to a psychiatric hospital.

### **Discharge, Leave, Transfer and Review**

A person involuntarily detained under the Act must be discharged if the examining psychiatrist does not confirm the detention within three days. Thereafter, an involuntary patient may be discharged at any time by the superintendent or, in the case of a further detention order made by two psychiatrists, the Mental Health Review Tribunal.

Where a person has been detained in an approved hospital pursuant to a further detention order under the Act, the superintendent may permit that person to take leave from the hospital for up to six months. The superintendent may impose such conditions on the leave as he or she thinks fit and may revoke the leave at any time.

Under the Act, the superintendent of an approved hospital may decline to admit a patient on the basis that the hospital lacks proper facilities for their care and treatment, but must immediately make arrangements for their admission to another approved hospital. A patient detained in an approved hospital may also be transferred to another hospital if the superintendent is satisfied that that hospital is better equipped for the care and treatment of that patient.

The Act establishes a Mental Health Review Tribunal, consisting of three members appointed by the Governor. The Chairman of the Tribunal must be a Judge, magistrate or senior legal practitioner. Members may be removed from office by the Governor on specified grounds. The Tribunal is given powers to compel witnesses to attend and to produce evidence.



The Act requires that the Tribunal review the circumstances of detention or custody of a person detained in an approved hospital or a protected person placed in the custody of another person within two months of admission,<sup>46</sup> and thereafter at least every six months. The Tribunal has the power to extend the review period to a maximum of 12 months. The Tribunal must discharge an order for detention or custody unless satisfied that there is good cause for continuing detention of the patient or custody of the protected person. Provision is made for an appeal by the patient, a relative, the Director of Mental Health Services or any other person the Tribunal considers to have a proper interest in the care and protection of the patient, against the detention of a patient in an approved hospital. There is also provision for an appeal to the Tribunal against an order of the Guardianship Board receiving a person into the guardianship of the Board or placing a protected person in the custody of another person. The Tribunal has the power to affirm, vary or revoke an order made by the Guardianship Board.

The Act provides for appeals to the Supreme Court by any person aggrieved by a decision or order of the Mental Health Review Tribunal.

There is a statutory right of representation by counsel before the Mental Health Review Tribunal or the Supreme Court. The Act also provides that where a person is not represented at his or her own expense, counsel may be chosen by that person or by the Law Society of SA from a panel of practitioners willing to undertake such matters. There is statutory provision for payment of the fees of legal practitioners chosen from the Law Society panel.

The provisions of the Act stipulating the powers of the Guardianship Board require the Board to review the circumstances of a protected person at reasonable intervals.<sup>47</sup>

## **Treatment**

The only statutory requirements for informed consent in the South Australian legislation are those for ECT and psychosurgery and those which provide for consent to medical and dental procedures to be carried out on persons suffering from mental illness who are incapable of giving effective consent on their own behalf.

Provision is made for an emergency medical procedure to be undertaken without consent where the doctor carrying it out (and, where practicable, a second doctor) considers the procedure necessary 'to meet imminent risk to the person's life or health'. In all cases other than emergencies, and sterilisation and termination of pregnancy (for which special provisions are made), the

Guardianship Board may either give consent on behalf of those incapable of effectively consenting themselves or appoint a delegate to do so. Delegates may be family members or institutional caregivers. They are appointed on a continuing basis and the delegation is reviewed by the Board after five years, or earlier if the Board considers the delegate is not acting in the best interests of the individual.

Although the definition of medical procedure does not explicitly exclude psychiatric treatment, this is not considered to be covered by these provisions since the only 'procedures' in the strict sense of this word are ECT and psychosurgery which are subject to specific requirements.

The criteria for involuntary admission under the Act include the need for treatment for mental illness and the opportunity to obtain it at an approved hospital. Alternatively, the Guardianship Board, after receiving someone into guardianship on grounds including incapacity, may order them placed in a hospital or other institution. The Guardianship Board also has power to order that the 'protected person' receive 'medical or psychiatric treatment'. This combination of powers in the Board is probably sufficient to displace a common law right of informed consent. It is not clear, however, that involuntary admission by a doctor who expresses an opinion as to the need for and availability of treatment is sufficient basis for abrogation of the right to informed consent in relation to any and every form of treatment administered in the course of the detention.

The Act, as amended in 1985, states that the provisions relating to consent by the Guardianship Board to medical or dental procedures apply 'whether or not the person [who is incapable of consenting] is a protected person'. This appears to indicate an intention that the Guardianship Board exercise power to consent without having necessarily received the person concerned into its Guardianship. However, there is no express provision in the Act that confers separate power on the Board to give consent to medical or dental procedures for such persons, merely a provision deeming consent by the Board to be consent given by the person and to have the same effect as if the person were incapable of giving effective consent. In practice, the Guardianship Board makes determinations consenting to medical and dental treatment, and about delegation of consent, without having received the persons concerned into guardianship.

## **Forensic Patients**

It has been South Australia's view that forensic psychiatric treatment facilities should be within the health care system rather than the custodial system...<sup>48</sup>

Under the *SA Criminal Law Consolidation Act 1935*, a person acquitted 'on the ground of insanity' or found insane 'so that he cannot be tried', must be held in strict custody 'until the Governor's Pleasure is known'. The same Act provides for the Governor to release such persons on licence on the recommendation of the Parole Board.

A separate piece of legislation, the *Mental Health (Supplementary) Provisions Act 1935*, makes provision for 'criminal mental defectives'. The Act provides for the proclamation of hospitals to receive people believed or determined to have mental illness and accused or convicted of criminal offences under Ministerial order for indeterminate periods. However, there are no longer any hospitals proclaimed under the Act. The only facility in SA for forensic patients is James Nash House, which is approved as a psychiatric hospital under the *Mental Health Act* but administered by the Department of Corrective Services.

Admission to James Nash House is either by court order or, as for other approved hospitals, as a voluntary or involuntary patient under the *Mental Health Act*. Forensic patients have the same rights as those afforded to other patients under the *Mental Health Act* apart from limitations arising from the prison sentences in relation to matters such as transfer, leave or discharge. Persons ordered by the courts to be held in strict custody at the Governor's pleasure may be admitted to James Nash House.

The powers of the Guardianship Board under the *Mental Health Act* extend to prisoners with mental illness. These powers may be used where treatment or care is required that would not otherwise be available.

## **Monitoring and Complaint Handling Mechanisms**

Under the *SA Mental Health Act*, the Minister may declare, by notice in the Gazette, any hospital, clinic or other premises to be an approved hospital for the care and treatment of persons with mental illness. The Minister may also vary or revoke such a notice. The Act does not contain any mechanisms for monitoring standards in approved hospitals, other than to require the superintendent of every approved hospital to keep records in prescribed form for every patient admitted. These records must contain the patient's name and address; the nature of any mental or physical condition suffered by the patient; full particulars of treatment given and the authorisation for that treatment; the

date and cause of death of any patient; and such other information as may be prescribed.

The Act contains an express statement of statutory objectives. However, these are couched in general terms and would provide little assistance in terms of accountability for hospitals or other mental health services.

Provisions are made under the Act for licensing premises, other than hospitals, which provide accommodation for persons subject to detention under the Act. Such licences are granted for use of the premises as psychiatric rehabilitation centres. Licences must be renewed annually and may contain conditions concerning the staff employed by the centre and their qualifications; class or classes of persons permitted to reside at the centres; the numbers of people to receive care; standards of accommodation and facilities provided; the standard of diet provided; compliance with directions as to care and treatment; and such other conditions as the Minister may think fit. The Health Standards Committee, consisting of representatives of the Health Commission, the Community Accommodation Support Scheme and health professionals has been established by the SA Health Commission to assist in the licensing of psychiatric rehabilitation centres.

The *Mental Health Act* does not contain provisions for official visitors or any similar mechanism for handling complaints or monitoring standards. The Health Advice and Complaints Service established by the SA Health Commission has no statutory basis and its role is presently under review.

### **Guardianship and Administration**

Guardianship orders as they are in our legislation are very broad band sort of orders and so to some extent that's a restriction on people's rights. What they're wanting is treatment and what they're getting is a general sort of guardianship order.<sup>49</sup>

The Guardianship Board, which is constituted under the *SA Mental Health Act*, consists of five members, appointed by the Governor for a term of up to three years. The term may be renewed or a member may be removed by the Governor on specified grounds. The Chairman of the Board must be a Judge, magistrate or senior legal practitioner. The Act provides for the Board to conduct its proceedings as it thinks fit. It has the power to require the production of evidence or the attendance of any person and must afford anyone whose protection is the subject of proceedings an opportunity to appear and make representations to a court.

As noted above, the Guardianship Board is empowered to receive into its guardianship a person who it is satisfied:

- (a) is suffering from a mental illness;
- (b) is, as a result, incapable of looking after his or her own health or safety; and
- (c) is incapable of managing his or her own affairs.

As guardian, the Board may:

- (a) by order, place the protected person in the care and custody of a relative...or some other person, who, in the opinion of the Board, will take the proper care of the protected person;
- (b) by order, require that the protected person be received into specified hospital, hostel, home or other institution for treatment or care and place the protected person in the custody of the person for the time being in charge of that hospital, hostel, home or other institution;
- (c) give directions as to the upbringing, education, and training of the protected person;
- (d) require that the protected person receive medical psychiatric treatment'.

The Guardianship Board may also exercise any other power which the courts would confer on a guardian. The Board is required to review the circumstances of the protected person under its guardianship at reasonable intervals and may vary or revoke any of its orders.

The *SA Mental Health Act* also empowers the Guardianship Board to appoint an administrator where, in the Board's opinion, a person is suffering from a mental illness and is incapable of administering their own affairs. The Act requires the Public Trustee to be appointed as an administrator unless the Board considers there is some other reason to appoint another person.

### **Anti-Discrimination Legislation**

At present the *SA Equal Opportunity Commission Act* expressly excludes mental illness as a ground of discrimination covered by the Act. The Inquiry was advised that a report by a departmental working party has recently recommended coverage of mental illness by the *Equal Opportunity Commission Act* and this is under consideration.

## Western Australia

The WA *Mental Health Act* 1962 shows its age in its broad and circular definition of mental illness and relative paucity of provisions providing safeguards for patients' rights. It does not establish a specialist tribunal. It is, however, clear and concise (increasing the likelihood of compliance with its requirements) and does provide basic safeguards. Legislative provision for guardianship is now available under the *Guardianship and Administration Act* 1990.

### Voluntary Admission

The WA *Mental Health Act* (the Act) allows the voluntary admission of a person who 'is, or who appears to be, suffering from mental disorder', in the opinion of the superintendent or another psychiatrist. Such admission requires a request by the prospective patient or, in the case of a person under 18, a request from a parent or guardian. An individual over 18 who requests admission must, in the opinion of the superintendent or psychiatrist, be able to understand the nature and effect of the request.

A voluntary patient may not simply leave the hospital at will. An application for discharge may be made by the patient or by the parent or guardian at whose request the patient was admitted, and the patient must then be discharged within 72 hours. Alternatively, a voluntary patient may be discharged by order of the superintendent or Director of Mental Health Services (the Director).

### Involuntary Admission

There are frequently long delays between the onset of the psychotic episode and the patient getting the treatment. Usually what was required for steps to be taken to get that person to hospital was some form of abnormal behaviour which was seen to be unacceptable, dangerous or disruptive to society which would then mobilise the authorities... These delays usually lead to immense and largely unnecessary suffering on the part of the individual patient and his or her family including breakdown in family relationships and financial disaster...<sup>50</sup>

The Act provides for involuntary admission either by referral of a doctor or by order of a justice. The doctor must have personally examined the person to be detained within 14 days of admission and must be of the opinion that the person 'appears to be suffering from mental disorder...and should be admitted for treatment to an approved hospital.' Such a referral is authority for the individual to be received and detained at a psychiatric hospital for up to 72 hours 'for observation'. During this time the person must be examined by the superintendent or another psychiatrist. If, after this examination, the superin-

tendent or other psychiatrist is of the opinion that the referred person needs to be treated in an approved hospital, the person must be admitted as a patient. Otherwise the person must leave the hospital.

The other method provided under the Act for involuntary admission is by application made by any person to a justice for a reception order. If the justice is satisfied that the person 'is suffering from mental disorder and in the interests of that person or of the public he should be admitted to an approved hospital for treatment under this Act', the justice may order that the person be taken to and received into an approved hospital. The justice may only make such an order on the basis of a referral from a doctor who has, in the 14 days immediately prior to the application, personally examined the person whose admission is sought, and expressed the opinion that this person is suffering from mental disorder. The Act also enables a justice to order the apprehension of a person by a police officer or other duly authorised person for the purpose of having that person examined by a doctor, where a complaint has been made on oath before the justice that the person concerned appears to be suffering from mental disorder and:

- (a) is without sufficient means of support;
- (b) is wandering at large; or
- (c) has been discovered under circumstances that denote a purpose of committing an offence against the law, or of attempting to take his own life'.

If the doctor who conducts an examination in these circumstances considers the person to be suffering from a mental disorder, the doctor must refer the person to an approved hospital. Provisions are also made for the Director, any other departmental officer or a police officer to make a complaint on notice before a justice if he or she has reason to suspect that a person who appears to be suffering from a mental disorder:

- (a) is not under proper care or control; or
- (b) is cruelly treated or neglected by any person having or assuming the charge of him; or
- (c) is detained in contravention of any of the provisions of [the] Act'.

An order made under these circumstances authorises entry (by force if necessary) by a police officer accompanied by a doctor and referral of the person to an approved hospital if the doctor considers the person appears to be suffering from a mental disorder.

A person taken to an approved hospital may be admitted for observation for a period of not more than 72 hours during which time they must be examined by the superintendent or another psychiatrist. If the superintendent or other psychiatrist considers the person needs to be treated as an inpatient under the

Act, the person must be admitted as a patient. Otherwise the person must leave the hospital. A person admitted on the referral of a doctor or on the order of a justice is considered to be 'detained' under the Act.

A patient may initially be detained for a period of up to six months from admission. Detention is renewable for periods of 12 months at a time 'if the superintendent, on the advice in writing of another psychiatrist, is of the opinion that it is in the interest of the patient' to do so.

### **Discharge, Transfer, Leave and Review**

The Act provides for a patient detained under the Act to be discharged by order of the superintendent to 'aftercare'. This is a form of continued supervision or treatment outside the hospital and may be ordered under the following conditions:

- (a) under the supervision of the superintendent or any other medical officer of the department; or
- (b) under the supervision of a medical practitioner, or other suitable person, willing to undertake it; or
- (c) at the superintendent's discretion, without supervision'.

The period for which aftercare may be ordered is the balance of the period, or the extended period, during which the patient is liable to be detained under the Act.

Provision is made for the superintendent to grant an involuntary patient leave of absence 'upon such conditions as to treatment, custody, conduct or behaviour' as the superintendent thinks fit.

The Act provides for a patient to be transferred from one approved hospital to another by order of the Director.

Provisions under the Act for discharge of involuntary patients, as for voluntary patients, require an order of the superintendent or Director of Psychiatric Services or an application for discharge by the patient or other person. An involuntary patient may be discharged 72 hours after such an application is made unless the superintendent refuses the application on any of the following grounds:



- (a) the discharge of the patient would be to the serious detriment of the patient or of the public;
- (b) adequate and satisfactory arrangements have not been made for the care, after discharge, of the patient;
- (c) the applicant is not a suitable person to exercise the care of the patient;
- (d) in the case of a person under the age of 18 years, the applicant is not the parent, guardian or other person who has the legal custody of the patient’.

The superintendent must state the reasons for refusing an application for discharge and the applicant may appeal to the Director against the refusal. The Director must give the applicant an opportunity to be heard before deciding whether or not to discharge the patient.

Provision is also made under the Act for discharge of an involuntary patient by the Board of Visitors,<sup>51</sup> an independent body consisting of five members appointed to each hospital under the Act. The Board members are appointed by the Governor and include a legal practitioner, two medical practitioners and two other persons, one of whom must be a woman. The Act provides that three members constitute a quorum and the Board has discretion to conduct proceedings ‘in such manner as may be prescribed and, until prescribed, as the Board determines’. No regulations or other prescriptions have been made limiting this discretion. In addition, there are no statutory rights to representation in such proceedings; or rights of access to records or other evidence.

The Act requires the Board to report to the Minister but makes no mention of providing the patient or other applicant with a written statement of decision or reasons. The Board has the power, of its own motion or on application, to consider the case of any involuntary patient and order their discharge, notwithstanding refusal by the superintendent of an application for discharge.<sup>52</sup> The Act requires the Board to inform the Minister and the Director of any decision it makes which countermands an order made by the superintendent.

The Act also allows any person to apply to the Supreme Court for discharge of a patient detained in any approved hospital or discharged to aftercare. The Court is empowered by the Act to hear such applications. Such hearings must be in camera. There is no statutory right to representation or access to records or other evidence. However, these may be imported by the application of the common law rules of natural justice in the context of judicial proceedings.

## **Treatment**

Other than a provision enabling the making of regulations, which has not been utilised, the only references in the Act to treatment are in those provisions which stipulate the criteria for admission. Admission by referral of a doctor requires the practitioner to believe that a person suffering from mental disorder should be 'admitted for treatment'. Admission by reception order requires the justice to be satisfied that a person suffering from mental disorder should be admitted to an approved hospital 'for treatment'.

The provisions of the Act allowing for voluntary admission, by contrast, make no reference to treatment. However, as noted above, a voluntary patient cannot leave without an order for discharge or a delay of 72 hours. Voluntary patients may, nevertheless, retain their right at common law to refuse treatment.

The position is less clear in relation to involuntary patients. As noted above, the Act specifically provides that patients admitted involuntarily by medical referral or judicial reception order are 'detained'. That provision, combined with the express reference to treatment as the purpose of involuntary admission, may be taken to indicate an intention to abrogate the common law right to refuse treatment. There is, however, no definitive statement relating to consent other than the Regulation giving the Director the right to consent to any surgical operation considered necessary for a patient under the Act. Neither the Act nor its Regulations contain any prohibitions on ECT, psychosurgery or any other form of treatment.

There are Regulations requiring the superintendent of a hospital to make 'such arrangements as he considers necessary for the safety and security of patients showing suicidal or homicidal tendency or making attempts to escape'. There is also a prohibition in the Regulations on restraint or seclusion of a patient without an order from a medical officer. An exception allows a matron, head male nurse or deputy to use restraint or seclusion in circumstances that require immediate action, provided a medical officer is immediately informed.

## **Forensic Patients**

There is a move to de-politicise a whole lot of things to do with the criminal justice system but for some reason or other this system of governor's pleasure detention...has resisted that particular move.<sup>53</sup>

The *WA Mental Health Act* confers on courts of summary jurisdiction the power to remand someone charged with a summary offence for up to 28 days.

The person may be remanded on bail, to be examined by a doctor, or in custody for reception into an approved hospital for observation. Following examination under these provisions, a person may be referred to an approved hospital by the doctor; received at that hospital for observation for a period not exceeding 72 hours; and admitted as an inpatient under the Act if, in the opinion of the superintendent or another psychiatrist, the person is in need of treatment under the Act. The person remanded in custody for observation in an approved hospital may also be admitted as a patient if the superintendent considers he or she is suffering from a mental disorder. The superintendent is required by the Act to inform the court prior to discharge of such a patient and, if required to do so by the court, 'discharge the person into his former custody'.

The Act also provides for a person found not fit to stand trial by means of mental disorder after having been committed for an indictable offence to be admitted by the Chief Secretary to a psychiatric hospital as a security patient. The duration of such detention is to be determined by the Chief Secretary, acting on the advice of the superintendent or another psychiatrist. A security patient may, if found fit, stand trial. On discharge, a security patient is to be returned 'whence he came prior to admission'. The Chief Secretary's decision to discharge a security patient must be based on the advice of the superintendent or another psychiatrist.

Where a person has been found not guilty on the grounds of mental illness, the Act permits the court to order the person held in custody at the Governor's pleasure. The Act confers a discretion on the Governor to order the admission of such a person to an approved hospital as a security patient and to discharge that person 'as he thinks fit'.

The provisions of the Act relating to leave and discharge for other involuntary patients do not apply to security patients.

The *WA Prisons Act 1903-1971* provides that a prisoner may be transferred, by order of the Director of the Prison Service or of a medical officer, to any hospital including a psychiatric hospital. The *Prisons Act* does not, however, provide any criteria to be applied when transferring prisoners to psychiatric hospitals.

The *Mental Health Act* states that provision for voluntary admission and for admission by medical referral or judicial reception order under the Act are not applicable to sentenced or remand prisoners. Overall, there would appear to be no criteria for admission of prisoners to psychiatric hospitals.

## **Monitoring and Complaint Handling Mechanisms**

The WA *Mental Health Act* provides for the establishment of hospitals for treatment of mental illness and the development of specialist facilities for children, old people and for alcoholics and drug addicts. The Act also provides for the establishment of day hospitals, day centres and outpatient facilities for welfare, rehabilitation and other specified purposes.

Such hospitals, funded from State Consolidated Revenue, are referred to in the Act as 'approved hospitals' and it is expressly prohibited to detain a person under the Act other than in an approved hospital. However, the only provisions made in the Act for inspection or monitoring of these approved hospitals are those relating to the Boards of Visitors.

The Director of Psychiatric Services is responsible to the Minister 'for the medical care and welfare of every person treated by the Department and for the proper operation of every approved hospital and every service established 'under the Act.' Apart from standard annual reporting requirements covering medical care and welfare of those treated under the Act, there are no statutory procedures governing accountability.

The Act does contain detailed provisions for the approval of private hospitals. These include a report by the Director to the Minister setting out details of certain matters and the issue and annual review of permits and the annual payment of subsidies subject to regulations, conditions or directions by the Minister. There are no private psychiatric hospitals approved to admit involuntary patients in WA.

The Boards of Visitors established under the Act monitor the standards of care and treatment in hospitals and provide a basic complaint handling service. The Boards are required to visit their hospital at least once a month and at other times as directed by the Minister. They interview any patients who wish to see them and receive complaints or recommendations concerning their welfare. The Boards have a discretion to make 'such inquiries, examinations and inspections as [they] may from time to time think necessary in the interests of patients'. They are also required to inspect every part of the hospital where patients are accommodated or which 'appertains to the welfare of patients', at least once every three months.

Board members may order a patient to be examined by a psychiatrist and make comments and recommendations to the Minister concerning the welfare (but not the medical treatment) of patients or the management of a hospital. They may

also furnish the Minister with a copy of a report of the psychiatric examination of any patient.

## **Guardianship and Management**

The *Guardianship and Administration Act* was passed by the WA Parliament in 1990 and assented to in the same year. But it has not yet been fully implemented. It provides for the establishment of a Guardianship Board, consisting of a Chairman and two other members, appointed by the Governor. The Chairman is to be a Judge of the Supreme Court and there is also provision for appointment of a Judge as Deputy Chairman. The Act provides that in the performance of its functions, the Board must act according to the substantial merits of the case without regard to technicalities or legal forms and is not bound by the rules of evidence, with a discretion to inform itself on any matter in such manner as it thinks fit.

The Board is not given the power to consent to medical treatment other than sterilisation for which special considerations apply.

The Board is empowered to appoint a guardian where it is satisfied that a person is incapable of looking after their own health and safety; is unable to make reasonable judgements in respect of matters relating to his or her person; or is in need of oversight, care or control in the interest of their own safety or for the protection of others.

The Board may only appoint a plenary guardian (ie with full powers) if appointment of a limited guardian would not be sufficient to meet the needs of the person in respect of whom the application is made. Plenary powers include the power to consent to any treatment or health care other than hospitalisation under the *Mental Health Act*. The guardian must be an individual over the age of 18 who has consented to act; who, in the opinion of the Board, will act in the best interests of the person in question; and who is not in a position of conflict of interest with that person. The Public Guardian may be appointed only if there is no other person suitable and willing to act.

The *Guardianship and Administration Act* also empowers the Guardianship Board to appoint an administrator or joint administrators of someone's estate, if it is satisfied that that person is unable by reason of mental disorder, intellectual handicap or other mental disability to make reasonable judgements in respect of matters relating to all or any part of their estate and is in need of

an administrator. The administrator may be an individual over the age of 18 or a corporate trustee.

There is also provision under this Act for review of guardianship or administration orders by the Board. An appeal may be made to the Full Court of the Supreme Court against a determination made by the Guardianship Board with the leave of the court, on the grounds of error of law or fact, combined law and fact, or error of jurisdiction.

### **Anti-Discrimination Legislation**

The WA *Equal Opportunity Commission Act* covers discrimination on the ground of impairment which is expressly defined to include 'any illness or condition which impairs a person's thought processes, perception of reality, emotion or judgement or which results in disturbed behaviour.'

## **Tasmania**

In our view, mental health legislation should start with the principle that it is an extremely serious matter to deprive an individual of his liberty. Allowing for that, it should allow for prompt, effective action in an emergency to provide 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 individuals' 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>54</sup>

The Tasmanian *Mental Health Act* of 1963 (the Act), substantially based on the British *Mental Health Act* of 1959, lacks many of the safeguards to be found in more recent mental health legislation interstate. The scope of its provision is also inconsistent with modern developments in relation to mental illness. While it contains no definition of mental illness, it defines 'mental disorder' to include mental illness, arrested or incomplete development of mind, psychopathic disorder and any other disorder or disability of mind.

On the other hand, the Act establishes a Mental Health Review Tribunal with detailed procedural safeguards and also establishes a Guardianship Board. A comprehensive review of the Act has been undertaken and new legislation drafted. It has not, however, been implemented.

## **Voluntary Admission**

The Act allows 'the patient who requires treatment for mental disorder' to be admitted to any hospital or other institution 'without any application, order or direction rendering him liable to be detained' under the Act and also allows a patient to remain in hospital after he or she has ceased to be liable for detention. In the case of a person between the ages of 16 and 18 years who is 'capable of expressing his own wishes' the Act further provides that arrangements for voluntary admission for psychiatric treatment may be 'made, carried out and determined notwithstanding any right of custody or control vested by law in his parent or guardian.'

## **Involuntary Admission**

Under the Act a person may be involuntarily detained either 'for observation' or 'for treatment'. In either case an application for admission requires the recommendation of two doctors, one of whom is 'approved' by the Minister as having relevant specialist expertise. The medical recommendations must be made in prescribed form and by practitioners who have personally examined the patient within the previous seven days. The Act also prohibits the making of recommendations for admission by doctors who have any of a number of specified conflicts of interest in relation to the application or the person whose admission is sought.

The grounds required for admission for observation under the Act are as follows:

- (a) that the person is suffering from a mental disorder of a nature or degree that warrants his or her detention under observation (with or without medical treatment) for at least a limited period; and
- (b) that the person so ought to be detained in the interest of his or her own health or safety or with a view to protection of other persons.'

The duration of detention for observation on these grounds is up to 28 days. In cases of alleged necessity the Act provides for an emergency application to be made and stipulates that in such cases it is sufficient for the application to be founded on one medical recommendation. The Act does not specify the criteria on which an emergency application must be based. The person may be admitted for up to 72 hours upon the basis of an emergency application and if, during this period, a second medical recommendation is provided and the grounds for an application for admission for observation are made out in the medical recommendations, the person's detention may be extended for up to 28 days.

The criteria for admission for treatment under the Act are substantially the same as those for observation, with the additional requirement that the person to be admitted is suffering either from mental illness or 'severe subnormality' or, in the case of a patient under 21 years of age, from 'psychopathic disorder'. The duration of involuntary admission for treatment under the Act is one year, renewable for a further year and thereafter for periods of two years. Renewal of detention is determined by the hospital authority — based on a report by the responsible medical officer following examination of the patient. The responsible medical officer is required to report on whether it is 'necessary in the interests of the patient's health or safety or for the protection of other persons that the patient should continue to be liable to be detained'. The hospital authority is required to inform a patient of the renewal of his or her detention and the patient is given a right to apply to the Mental Health Review Tribunal.

### **Discharge, Leave, Transfer and Review**

In regard to appeals against mental health orders, the Tribunal has only one power: that of rescinding the order.<sup>55</sup>

Under the Act the patient may be discharged by the doctor responsible for his or treatment; by the hospital authority; by the Minister; or, in the case of admission for treatment, by the patient's nearest relative. However, the nearest relative may not discharge a patient within the first six months of renewal of detention by the hospital authority. Moreover, a relative wishing to discharge a patient must give 72 hours notice to the hospital authority. The hospital authority may veto the discharge if the responsible medical officer considers the patient 'would be likely to act in a manner dangerous to himself or to other persons'.

The Act provides that a patient who is liable to be detained for observation or treatment may be transferred to another hospital or transferred into guardianship 'as if the application [for admission to hospital] were a guardianship application duly accepted at the time when he was originally admitted' to the hospital.

The medical officer responsible for treatment or care of the patient involuntarily detained under the Act may grant that patient leave of absence from the hospital subject to such conditions as are considered necessary in the interests of the patient or the protection of others.

The Act establishes a Mental Health Review Tribunal, consisting of legal, medical and other members appointed by the Governor. The terms of appointment, tenure and grounds for removal from office are not stipulated in



the Act. The Tribunal's jurisdiction is limited to the hearing and determination of applications by patients against their detention, renewal of detention or reception into guardianship. The Tribunal is not given power to itself initiate review of detention orders. Provision is made under the Act for the Minister 'as he thinks fit, to refer to the Tribunal the case of any patient liable to detention or guardianship.' Patients are given the right to apply to the Tribunal within six months from the date of their initial involuntary detention or in relation to any renewal of involuntary detention. The Tribunal has power to direct that a patient be discharged if it is satisfied that the criteria for detention are not met.

The procedural provisions relating to the Tasmanian Mental Health Review Tribunal are contained in Regulations proclaimed in 1964 under the Act. These establish a right to representation for applicants, but no provision is made for payment for such representatives. The Regulations provide for an applicant to make a written application, the form of which requires a special request to be made for a formal hearing. If a formal hearing is not requested the Tribunal is only required to give the applicant the opportunity of an interview. In any case in which an application for review is lodged, the Tribunal is required to notify interested parties. The hospital is required to provide the Tribunal with a statement of the relevant medical history of the patient and the reasons for the order or refusal to discharge. If a formal hearing has been requested, the hospital is also asked by the Tribunal for an opinion whether this would be 'detrimental to the applicant's health.' The Regulations give the Tribunal discretion to determine whether a formal hearing should be conducted. At a formal hearing, the applicant has the rights to: appear; be accompanied by another person; address the Tribunal and call witnesses. The Regulations give both the applicant and the hospital the right to question witnesses. The Tribunal is required to provide its decision and reasons in written form. These may be published, at the Tribunal's discretion.

## **Treatment**

The Act does not make any express provision concerning the nature or quality of treatment to be administered to patients. Nor does it contain any prohibitions on any form of treatment other than 'mechanical means of bodily restraint or seclusion', which are permitted only where 'necessary for the purposes of treatment...or to prevent [a patient] from injuring himself or other persons or destroying property.' The use of seclusion or restraint also requires approval by the medical officer responsible for the patient's treatment. The Act does not contain any reference to ECT or psychosurgery.

In relation to the provisions of the Act dealing with admission for treatment, the need for treatment for mental disorder is the stated reason for detention or for voluntary hospitalisation. While this may indicate an intention that treatment for such mental disorder could not be refused, the words lack the clarity that would normally be required to abrogate common law rights. Furthermore, in the absence of prohibitions or limitations on the form of treatment, it is not clear what scope of treatment a patient admitted for treatment may be required to submit to. In the case of patients admitted 'for observation', the Act expressly states that this may be 'with or without medical treatment'. This seems to leave no basis for argument that the legislation provides for the administration of treatment so as to override the common law right to refuse treatment.

### **Forensic Patients**

Once a mentally ill patient falls into the criminal justice system, then I hold [that] the *Mental Health Act* and particularly the Mental Health Review Tribunal fail to uphold their rights.<sup>56</sup>

The Tasmanian *Criminal Code* contains provisions under which persons may be found by a court to be incapable of understanding proceedings after being charged with an offence or may be found to be not guilty of an offence by reason of insanity. These provisions confer power on the court to order 'that the accused person be dealt with as a mentally disordered person who has become subject to the criminal process.' Such an order authorises the Attorney-General to make a number of decisions concerning the disposition of the person concerned. The Attorney-General has an unfettered discretion as to whether and where to detain a 'mentally disordered person who has become subject to the criminal process'. In practice, most of these persons are placed under 'restriction orders', made pursuant to the Act, in a prison hospital which has been declared a 'special institution' under the *Mental Health Act* for the accommodation and medical treatment of persons detained in conditions of special security.

The *Mental Health Act* also provides for 'restriction orders' and hospital orders to be made by the Supreme Court in respect of persons convicted of offences punishable by imprisonment. A court of petty sessions has power under the Act to make hospital orders or guardianship orders in relation to persons convicted of an offence punishable by imprisonment. The hospital order authorises detention in a specified institution, usually the prison hospital. A restriction order involves a number of limitations on the transfer, reclassification, leave of absence and discharge of a person detained. In particular, the Act requires that someone subject to a restriction order may only be discharged with a

direction from the Governor on the recommendation of the Mental Health Review Tribunal.

The *Criminal Code* provides for the Attorney-General to review fitness to stand trial. Such review must occur at quarterly intervals in the first year and annually thereafter. The Code provides for the Mental Health Review Tribunal to make recommendations to the Attorney General in relation to those found not guilty by reason of insanity and those found incapable of standing trial<sup>57</sup> but the Tribunal does not have power to determine these cases. Their period of detention is subject to determination by the Governor.

### **Monitoring and Complaint Handling Mechanisms**

The Act provides for the Minister to declare a hospital maintained by public funds to be a hospital for the purposes of the Act and also provides for the Minister to declare a place to be a 'special institution' if satisfied that it is 'suitable for the accommodation and medical treatment of persons who may become liable to be detained' under the Act and who need to be detained 'in conditions of special security'. There are, however, no other provisions in the Act relating to the standards or other conditions which need to be maintained by such hospitals or institutions. Administration of psychiatric services was until 1989 the responsibility of the Mental Health Services Commission, established under the *Mental Health Services Act 1967*. Although not yet repealed, this Act no longer operates as the administrative functions of the Commission were transferred in 1991 to the Regional Health Boards.

The *Mental Health Act* does not contain any provisions for monitoring standards of service in psychiatric institutions or handling complaints by consumers.

### **Guardianship and Administration**

The Tasmanian *Mental Health Act* establishes a Guardianship Board consisting of nominees of the Departments of Community Services and of Health, together with three other persons appointed by the Governor. Applications may be made to the Guardianship Board concerning any person suffering or apparently suffering from mental illness. Such a person may be received into the guardianship of the Board itself or of any other person. The grounds on which a guardianship order may be made under the Act are as follows:

- (a) that the person is suffering from mental disorder (being a mental illness, psychopathic disorder or subnormality); and
- (b) that the disorder is of a nature and degree that warrant the reception of the person into guardianship; and
- (c) that it is necessary in the interests of the patient or the protection of other persons that the patient be received into guardianship.

Incapacity is not mentioned as a ground for making a guardianship order. As with an application for involuntary admission, an application for a guardianship order must be supported by the recommendation of two doctors who have examined the person within the previous seven days. Although the decision to make a guardianship order is made by the Guardianship Board, the Act does not contain provision for a hearing or any other process or inquiry preceding the determination to make such an order.<sup>58</sup>

There is also provision under the *Tasmanian Mental Health Act* for orders to be made by the Supreme Court for the administration of a person's affairs or the management of a person's property. The Act provides for the court to appoint the Public Trustee or some other person to administer an estate. The court is also given power to appoint an officer of the court or some other suitable person 'to inquire into the case of the patient or into any matter relating to that person or his property or affairs and furnish to the court a report of his findings' to enable the court to act on those findings in the exercise of its protective jurisdiction. Provision is also made under the *Mental Health Act* for the Public Trustee, upon application, to issue a certificate of incapacity in respect of a person, if satisfied on the basis of affidavits from two doctors, that the person is, by reason of mental disorder, incapable of managing his or her property and affairs. There are no procedural safeguards specified in the Act in relation to the issue of such certificates by the Public Trustee.

### **Anti-Discrimination Legislation**

Anti-discrimination legislation, covering psychiatric disability among other grounds, was introduced into the Tasmanian Parliament in 1991. However, this was not passed and it appears uncertain whether and in what form such legislation will proceed.

## Northern Territory

The NT *Mental Health Act* 1980 is relatively brief and basic in its provisions for hospitalisation of people with mental illness. As in NSW, WA and the ACT the authority for involuntary detention is by Magisterial order. The NT legislation, however, extends the criminal process model further, using the term custody for involuntary detention and relying to a greater extent than elsewhere on warrants and the police force for the purpose of taking people with mental illness 'into custody' for 'care, treatment or control'. The criteria under the Act for involuntary admission are broad and there are no statutory definitions of mental illness or 'a mentally ill person.'

### Voluntary Admission

The NT *Mental Health Act* allows the voluntary admission of a person to hospital and then to be discharged, 'subject to the reasonable rules of the hospital concerning admission and discharge', upon the person's request or, in the case of an infant, the request of the parent or guardian. However, the Act also requires that a person in charge of the hospital notify the Chief Medical Officer (CMO) of voluntary admissions and ensure that individuals so admitted have, within three days of admission, been 'psychiatrically examined by two medical practitioners acting independently of each other'. There is a general requirement that the person in charge shall not permit a person to remain in hospital for more than three days for 'observation, care, treatment or control as a mentally ill person' unless the CMO is satisfied that this is appropriate after sighting the reports of two medical practitioners who have conducted independent psychiatric examinations of the patient. The only exception to this requirement is for a patient who is 'capable of managing himself and his affairs'. The requirement applies equally to voluntary and involuntary patients.

### Involuntary Admission

The Act provides for persons to be taken 'into custody' either by warrant or, in urgent cases, without a warrant and also provides for warrants to be obtained by telephone 'or otherwise' if it is 'impracticable to appear before a magistrate' to apply for the warrant. A magistrate may issue a warrant where, 'after reasonable inquiry', 'it is made to appear' that a person may be suffering from mental illness and, as a result, the person:

- (a) may require care, treatment or control;
- (b) may be incapable of managing him or herself or his or her affairs;
- (c) may be under inadequate care or control; or
- (d) may be likely, by act or neglect to cause death or serious bodily harm to him or herself or another person.

The criteria for a person to be taken into custody under the Act without a warrant are substantially the same — with the addition of the need for immediate custody ‘in his own interest or in the public interest’. The power to take a person into custody under the Act without a warrant is limited to members of the police force and doctors ‘performing duty in or in the vicinity of a hospital’.

The admission procedure for involuntary patients under the NT *Mental Health Act* requires that the CMO apply to a magistrate within three days ‘or as soon as practicable’ after a person is taken into custody under a warrant or, in the case of a person taken into custody without a warrant, within 24 hours or ‘as soon as possible’. The CMO is required to give the magistrate a report on the following matters:

- (a) the mental health of the person taken into custody;
- (b) the care being given to and the control being exercised over that person;
- (c) the treatment, if any, that has been given to that person and whether that treatment was given as ‘recognised standard treatment or on the authority of a magistrate, or as an emergency measure’; and
- (d) steps taken by the CMO to ascertain the existence of a near relative or other person who should be notified before an order is made for the person to be held in custody.

The magistrate, ‘after reasonable inquiry upon an application’ in this form by the CMO, may make an order that the person be ‘kept in custody for a period of observation, care, treatment or control’ where it has been made to appear that the criteria for custody, as set out above in relation to the warrant, are satisfied. There is no express provision regarding the standard or onus of proof. Under normal rules of construction the onus will lie with the CMO, as applicant. However, whether the term ‘made to appear’ imports the civil standard (balance of probabilities) is less clear.

### **Review, Discharge and Transfer**

Provision is made under the NT *Mental Health Act* for the CMO to review the cases of all patients, voluntary and involuntary, at intervals of not more than six months to determine whether they should be permitted to remain ‘for

observation, care, treatment or control' as mentally ill persons, on the basis of the reports of two doctors who have made independent psychiatric examinations of the patients.

The Act also contains a requirement for the CMO to appear before a magistrate, at intervals of not more than six months for each patient, to report in the same terms as in the original application for custody and 'to apply for such further order, if any, as may be necessary to continue to keep the person in custody'. In relation to both the initial orders and any subsequent orders, the magistrate is empowered to decide that the person be kept in custody under the Act for a period of up to six months at any one time.

The NT Act provides for review by the Supreme Court of any order made by a magistrate. An application may be made to the Supreme Court by the person who is the subject of the order, by the CMO, by a guardian or specified close relative of the person, or by any other person 'who in the opinion of the Supreme Court has by reason of tie by friendship or any other reason bona fide interest in the welfare of the person who is subject to the order'. The Supreme Court has power to rehear the application made before the magistrate and to exercise all relevant powers exercised by the magistrate in relation to such applications. The Supreme Court is required to ensure the representation of all persons considered by the court to have an interest in the application, unless the court is satisfied in the circumstances that such representation is unnecessary.

There is no specialised review body for mental health matters under NT legislation.

The procedural provisions for hearing applications under the NT *Mental Health Act* incorporate by reference the powers conferred upon magistrates under the Northern Territory *Coroners Act* as if an inquiry under the *Mental Health Act* were an inquest under the *Coroners Act*. In addition to the express requirement for the magistrate or court to require legal representation for parties to an inquiry, the magistrate or court has discretion under the *Mental Health Act* to appoint a legal representative for a person in custody, 'additional to the legal representation that, but for this Section, that person would have.' While the juxtaposition of the terms 'additional to' and 'but for' is rather paradoxical, this provision appears to allow the court to override the choice of legal representation made by a person in custody. Moreover, this provision is followed by another which allows a legal practitioner appointed to represent a person in custody to 'ask a court or magistrate to make or revoke an order under this Act'. This statutory statement of the role of the appointed representative makes no reference to obtaining instructions from the person held in custody. It is not clear whether it is intended that the statutory formulation of the appointed rep-

representative's role displaces the common law right of a represented person to instruct his or her representative. The *Mental Health Act* makes provision for the reasonable costs and disbursements of an appointed legal representative to be paid by the NT Government, at the court's discretion. There is no similar provision for payment of legal representatives chosen by the person in custody.

Because the NT has only recently developed facilities for psychiatric care and treatment, and because it previously relied on services provided outside the Territory, the NT *Mental Health Act* makes provision for arrangements with other States and Territories for the transfer of persons for care, treatment, or control. Transfer of a person from the NT under such an arrangement must be authorised by order of a magistrate. A magistrate must not authorise the transfer of a person from the NT unless satisfied that the person will be returned at the request of the CMO; or that it is in the best interest of that person that he or she should cease to reside in the Northern Territory.

## **Treatment**

The NT *Mental Health Act* confers power upon the magistrate, at any time after the issue of a warrant or making of an order under the Act, to make a further order in relation to that person authorising any of the following:

- (a) a treatment that may be given to that person;
- (b) an operation that may be performed on that person;
- (c) a procedure that may be carried out in respect of that person;
- (d) a method of control that may be exercised over that person; or
- (e) removal of that person from one hospital or place to another hospital or place (including a place outside the Northern Territory).

The Act prohibits the CMO from allowing treatment, surgery, procedures or methods of control in respect of a person held in custody unless this has been specifically authorised by a magistrate, except in cases of emergency or in the case of treatment that is in the CMO's opinion a 'recognised standard medical treatment'. Furthermore, the CMO can only authorise treatment if one or more of the following circumstances apply:

- (a) if the patient is capable of managing his or her affairs;
- (b) if the CMO is satisfied on the basis of reports of two independent psychiatric examinations of the patient that the treatment will not be detrimental to the patient's best interests;
- (c) if the treatment is required urgently; or
- (d) if the treatment is recognised as 'standard medical treatment' and its use has been authorised as a matter of course.



There are no specific provisions in the NT *Mental Health Act* in relation to electro convulsive surgery or psychosurgery. The Act does contain a prohibition on authorisation by a magistrate of treatment or surgery 'except for the purposes of treating an illness.' On the other hand, not only is the potential scope of the term 'standard medical treatment' very broad but the Act also expressly recognises that 'control' may be exercised over patients in the course of their 'custody' and that these concepts are distinct from 'treatment'.

Provision is made under the Act for a person subject to a custody order to be permitted to leave the hospital 'in the course of his treatment'. A person given such leave 'shall not be held to have been released from custody or to have been removed from that hospital by reason that he be only so permitted to leave'. This allows for treatment outside the confines of the hospital while maintaining a measure of control or authority over the person.

### **Forensic Patients**

The Northern Territory *Criminal Code* 1983 contains provisions for acquittal on the ground of 'insanity', resulting in an order for the person to be held in 'strict custody' at the Administrator's pleasure. There is no legislative provision for review of this detention. The Code also provides for an accused person to be found incapable of understanding criminal proceedings because of an 'abnormality of mind'. In such cases, the court has complete discretion to hold the person in custody or to deal with him in some other manner 'according to law'.

Part IV of the NT *Mental Health Act* contains a number of provisions for psychiatric care, treatment or control of persons charged with or accused of criminal offences or in custody under sentence of imprisonment. The Act gives courts the power to adjourn proceedings at any stage while a person is receiving care, treatment or control for a mental illness. The court may also discharge a defendant without proceeding to conviction or, upon conviction without penalty, where a defendant is receiving or has received care, treatment or control for a mental illness. Execution of a sentence may be suspended by a court or a person may be released on a bond on condition that the defendant submit to care, treatment or control for mental illness. These powers all rely upon voluntary treatment. The court also has, however, the power to make an order for the care, treatment or control of a person who has a mental illness and who is in custody on remand or under sentence for a criminal offence. This includes the power to order that a person in such custody be 'cared for and controlled without his consent for a mental illness'. The criteria applicable to the making of such orders are the same as those applicable to involuntary detention of a civil patient. Review of involuntary detention of forensic patients

by the CMO and by the court, at intervals of not more than six months, is also provided for in similar terms to the terms applicable to civil patients.

A special provision is made for a person who is 'in custody, whether or not under sentence of imprisonment' (ie including remand prisoners) and who is in need of care, treatment or control for a mental illness to be the subject of an order by a court or magistrate for such care, treatment or control. Orders may include the following provisions:

- (a) that the person be not kept locked up;
- (b) that the person be not kept under close guard;
- (c) that the person be allowed freedom to leave the hospital at which he is receiving treatment;
- (d) that prison regulations be not applicable to the person while he is in hospital;
- (e) that the person be released on parole notwithstanding that the minimum term of imprisonment was not specified or that he has not completed his minimum term of imprisonment;
- (f) that the person be granted remission of sentence additional to the remissions that would otherwise be granted; or
- (g) that the person be released for a period while he receives care, treatment or control and that period in which he be released be counted as part of his sentence.'

### **Monitoring and Complaint Handling Mechanisms**

The NT mental health legislation contains no mechanism for monitoring standards of mental health care or inspection of mental health services. There are no avenues provided under statute for complaints by consumers concerning such services.

### **Guardianship and Management of Property**

Under the NT *Mental Health Act* there is a provision conferring on the CMO all the powers of a guardian in relation to the person, but not the property, of either a voluntary or involuntary patient who is in hospital for observation, care, treatment or control as a mentally ill person and who, in the opinion of the CMO, is 'incapable of managing himself or his affairs'.

The CMO may exercise powers as guardian provided he or she is satisfied that no other person 'has custody of that patient' or that it would be impractical in the circumstances to contact that other person for reasons such as urgency or because the action to be taken is of a trivial nature. Approval of a court or

magistrate is also required before the CMO exercises guardianship powers, except in the case of an emergency or where the action proposed is of a trivial nature and it is not practicable in all the circumstances to make an application to a court or magistrate in the time available.

The NT *Mental Health Act* also gives Magistrates the power to order the release of a person in custody under the Act on conditions including the exercise by 'a relative or friend or other person' of 'powers of a parent' as though the person released 'were a child'. This is, in effect, a provision for guardianship in relation to release from detention.

The NT *Adult Guardianship Act 1988* makes provision for a scheme of guardianship to be provided through the Magistrate's Courts. However, this legislation is specifically limited to adults with an intellectual disability which is defined as 'resulting from an illness, injury, congenital disorder or organic deterioration or unknown origin' and by reason of which the person appears to be unable to make reasonable judgements or informed decisions relevant to daily living. This is a relatively broad definition which may include certain persons suffering from mental illness. A person who is not covered by this legislation could, on application, be subject to the Supreme Court<sup>59</sup> exercising its protective powers.

The NT *Aged and Infirm Person's Property Act 1979* confers power on the Supreme Court to make orders for the protection of the property of a person who is 'by reason of age, disease, illness or mental or physical infirmity in a position which renders it necessary in the interests of that person or the interest of those dependent on him that his estate be protected.' The Court may appoint the Public Trustee alone, or one or more persons other than the Public Trustee, as manager of the estate to which the order relates. A protection order may be made on such terms and conditions as the Supreme Court sees fit.

### **Anti-Discrimination Legislation**

The Northern Territory *Anti-Discrimination Act* was enacted in November 1992, but had not been proclaimed at the time of writing. The legislation covers psychiatric impairment.

## Australian Capital Territory

The ACT *Mental Health Act of 1983* is the least comprehensive of any mental health legislation in an Australian State or Territory. It is supplemented by the *Insane Persons and Inebriates Act 1936* and the *Mental Health Act 1962*, under which an agreement exists between the Australian Capital Territory and the State of NSW. The effect of these Acts and the agreement is to make applicable to the ACT certain provisions of the NSW *Lunacy Act 1898*. Even with the commencement of the *Guardianship and Management of Property Act 1991* and the *Community Advocate Act 1991*, there are significant areas not covered by Territory legislation.

### Voluntary Admission

The ACT *Mental Health Act 1983* contains no provision for voluntary admission to a psychiatric hospital.<sup>60</sup> Residents of the ACT may be admitted as voluntary patients to psychiatric institutions in NSW under an agreement between the ACT and NSW,<sup>61</sup> pursuant to which residents of the ACT admitted as voluntary patients to psychiatric facilities in NSW are subject to that State's legislation.

### Involuntary Admission

The ACT *Mental Health Act* provides for involuntary admission by way of emergency detention and by way of a custodial treatment order made by a court. In either case the criteria are as follows:

- (a) that a person is suffering from 'mental dysfunction' defined as 'a disturbance or defect, to a severely disabling degree, of perceptual interpretation, reasoning, learning, judgement, memory, motivation or emotion';
- (b) that the condition of the person gives rise to an immediate and substantial risk of actual bodily harm to the person or to another person; and
- (c) that the person will not accept treatment which the medical practitioner or mental health officer reasonably believes is necessary to avert that risk.

The emergency procedures allow for detention of up to 72 hours by a medical practitioner or an authorised mental health officer (a mental health nurse, psychologist, or social worker appointed by the ACT Board of Health). The detained person must be examined by a doctor 'as soon as practicable'. In order to detain a person beyond 72 hours, application must be made jointly by a doctor and a mental health officer for a court to make a custodial treatment order.<sup>62</sup> The Act also provides for emergency detention by a police officer who has reasonable grounds for believing that:

- (a) a person is suffering from mental dysfunction; and
- (b) the condition of the person gives rise to an immediate and substantial risk of actual bodily harm to the person or to another person.

The procedures for emergency detention include authorisation of the police, medical practitioner or mental health officer to enter any premises (by force, if necessary) for the purpose of taking the person into detention. The place of such detention is at the discretion of the Director of Mental Health Services hereafter referred to as the Director. The Act provides that the person detained may be subject to 'such restraint as is reasonable and necessary to prevent the person from doing harm to himself or any other person'. There is also provision for a physical and psychiatric examination to be conducted by a doctor and for 'such treatment (if any) as is necessary to avert any immediate and substantial risk of the person doing harm to himself or to any other person.'

The ACT *Mental Health Act* requires the Director to appoint a 'prescribed representative' as soon as practicable for each person detained under the emergency procedures. There is provision for the detained person to nominate his or her representative and for the person nominated to refuse, as well as provision for the termination of such appointments. There is, however, no definition of the scope of authority or powers of such a representative.<sup>63</sup>

Involuntary admission by way of treatment order requires an application to the Magistrate's Court or, in the case of a 'further treatment order', to the Supreme Court.<sup>64</sup> The application is made jointly by a doctor (a psychiatrist in the case of a further treatment order) and by a mental health officer. If an application is made in respect of a person for whom a prescribed representative has not yet been appointed, the Act requires the Director to appoint such a representative as soon as practicable after the application. The Act also requires the Director to ensure that a written statement is given to the person who is the subject of the application and to his or her prescribed representative, setting out the following particulars:

- (a) the nature of the application;
- (b) the nature and effect of the orders sought;
- (c) the powers and duties of the Director in relation to persons who are subject to treatment orders; and
- (d) the right of the person and his prescribed representative to appeal against the making of any treatment order to apply for the variation or discharge of such an order.'

There is also provision for the Director to ensure that an oral explanation is given to the person or their representative 'as the case requires'. The person who is the subject of the application has a statutory right to appear at the hearing. However, the court has discretion to waive this right if satisfied 'that in the circumstances the presence of the person during the hearing would not be practicable'. There is no statutory right to legal representation. The parties to an application for a treatment order are the applicant; the Director; the person in respect of whom the order is sought; and that person's representative. The court has a discretion to include as a party any other person whose presence is considered desirable for the proper protection of the interests of the person who is the subject of the application.

Before making a treatment order, the Magistrate's Court must be satisfied of the following:

- (a) [that] the person in relation to whom the application is sought is suffering from mental dysfunction;
- (b) [that] by reason of that mental dysfunction --
  - (i) the person has engaged, and is continuing to engage, in behaviour that has resulted, or is likely to result, in actual bodily harm to himself or to another person;
  - (ii) the person is likely to engage in behaviour that is likely to result in actual bodily harm to himself or to another person; or
  - (iii) the person is in a condition of social breakdown; and
- (c) [that] the person has refused adequate treatment for that mental dysfunction, or has failed to accept such treatment within a reasonable time after it is offered to him, or is, in the opinion of the Court, incapable of weighing for himself the considerations involved in making a decision whether to accept such treatment.

The criteria to be considered by the Supreme Court for the purposes of extending treatment orders are similar, the only difference being that the requirements as to treatment relate to the need for refusal, or likely refusal, of continuing treatment.

The Magistrate's Court is empowered to make treatment orders for a period of up to 28 days. The Supreme Court is able to make further treatment orders for an initial period of up to three months and thereafter for periods up to 12 months.

## **Review and Discharge**

The ACT *Mental Health Act* provides that the court which has made the treatment order has the power to vary or discharge the order on the application of the person to whom the order relates, that person's prescribed representative, or a doctor. There is no express power conferred by the Act on the Director or on any doctor to discharge a person from involuntary detention before the expiration of the term of a court order. However, a court order may be made to allow discharge at any time prior to the maximum period capable of being set by the court.

There is provision under the Act for an appeal to the Supreme Court against a treatment order made by the Magistrates Court.

The ACT mental health legislation does not make any provision for leave to be granted to a patient while detained under a custodial treatment order.

## **Treatment**

Among the miscellaneous provisions of the ACT *Mental Health Act* is a requirement that doctors, police officers, mental health officers and the Director (but not the courts) ensure that restrictions on freedom of a person suffering from mental dysfunction are minimal and that dignity and self respect are subject to derogation 'only to the extent necessary for the proper care and protection of the person and the protection of the public.'

A treatment order made by a Court under the ACT legislation may either direct that the person subject to the order remain in the custody of the Director at premises determined by the Director; or that the person attend such place as the Director determines for the purposes of undergoing treatment.<sup>65</sup> In either case, the Director is ordered 'to administer, or to cause to be administered to [the person] such a treatment for the mental dysfunction suffered by that person as the Director thinks necessary, other than:

- (a) treatment that produces, or is likely to produce an irreversible physical lesion;
- (b) convulsive therapy; or
- (c) treatment that has, or is likely to have, the effect of subjecting the person to whom it is administered to undue stress or deprivation having regard to the benefit likely to result from the administration of the treatment.

The Director is also prohibited from administering 'treatment for the purposes of conducting a clinical experiment or any treatment the effects of which are not known or the beneficial effects of which have not been demonstrated clinically.'

In relation to custodial orders, several coercive powers are conferred on the Director and on medical practitioners or authorised mental health officers for the purpose of conveying a person to premises; subjecting the person to 'such confinement as is reasonably necessary to prevent the person from doing harm to himself or to any other person'; and such other restraint 'as is reasonable and necessary to prevent the person from doing harm...or to permit treatment to be administered to the person.'

The ACT *Mental Health Act* does not contain any express requirements for consent to be obtained for psychiatric treatment, other than ECT or psychosurgery. It does contain a requirement that, where a treatment order is made, the Director or doctor who is to administer treatment shall, before doing so, 'explain to that person the nature and effects including the side effects, if any, of the treatment.' In the case of a person who 'in the opinion of the Director or medical practitioner...would be unable to understand an explanation given', the Act allows the requisite explanation to be given to the prescribed representative of the person.

The administration of ECT under the Act requires authorisation by a Magistrate's Court on the application of the Director or a doctor, supported by evidence from an independent psychiatrist. The Court is required to be satisfied of the following criteria before approving ECT:

- (a) that the therapy will result in a substantial benefit to the person;
- (b) that there is no other form of treatment reasonably available which is likely to result in the same degree of benefit to the person; and
- (c) that the person is either capable of weighing for himself the considerations involved in whether to consent to the therapy and has done so in writing, witnessed by an independent person or, alternatively, is by reason of mental dysfunction incapable of weighing these considerations.

The penalty under the Act for unauthorised administration of ECT is \$1,000.

The performance of psychosurgery under the Act requires the approval of the Director. This may only be granted on the application of a doctor and must be accompanied by a written statement that the person upon whom the surgery is to be performed understands the nature and effects of the surgery and consents



to it. Alternatively, the Supreme Court may consent on behalf of the person. Before the Supreme Court makes such an order, it must be satisfied that the person concerned is suffering from mental dysfunction; has not refused to consent to the performance of the psychosurgery; that there are grounds for believing the person may benefit from the psychosurgery; and that alternative forms of treatment reasonably available failed or are likely to fail to benefit the person. Before the Director approves an application for psychosurgery, such approval must be recommended by a Committee consisting of a psychiatrist, a neurosurgeon, a barrister and solicitor, a clinical psychologist and a social worker.

There is a penalty of \$5,000 or 12 months imprisonment for unauthorised psychosurgery.

There are no express provisions in the ACT mental health legislation relating to medication or the recording of the administration of medication.

### **Forensic Patients**

The ACT *Mental Health Act* 1983 deals only with civil patients, not with forensic patients. Provision is made for residents of the ACT with mental illness and who are accused, charged or convicted of a criminal offence, under a combination of provisions of the *Insane Persons and Inebriates (Committal and Detention) Act* 1936, the *Mental Health Act* 1962 and agreements made under these Acts; and the continuation in force in the ACT of Part V of the NSW *Lunacy Act* 1898 and Section 20B *Commonwealth Crimes Act* 1914. Under NSW and Commonwealth legislation, provision is made for persons to be found unfit to be tried or not guilty by reason of insanity. Acquittal on the ground of insanity results in detention and strict custody at the pleasure of the Governor General. There are no statutory procedures for review of this detention. A person found unfit to be tried must also be held in strict custody. The ACT *Mental Health Act* 1962 provides procedures for a person detained in a NSW institution and committed for trial for an offence against ACT law to be returned to the ACT for the Court in the Territory to determine the person's fitness to plead and, if found unfit to plead, to be returned to custody in NSW.

Because of the lack of specialist facilities for forensic patients in the ACT, the agreement between the State of NSW and the ACT under the *Insane Persons and Inebriates Act* allows for the transfer of forensic patients from the Territory to institutions in NSW. This includes ACT prisoners who develop mental illness during their terms of imprisonment. Once transferred, these persons become subject to NSW legislation.

The *Community Advocate Act* 1991 provides that one function of the Community Advocate is to represent forensic patients before the Guardianship and Management of Property Tribunal or a Court. A broad meaning is given to forensic patient under the Act, including a person apprehended by the police whose behaviour or statements 'indicate to the officer that the person may be suffering from a mental dysfunction'. However, the functions of the Community Advocate do not extend to being present during police interrogation and, as a matter of policy, representation of forensic patients is limited to cases involving serious offences.

### **Monitoring and Complaint Handling Mechanisms**

Part VIII of the ACT *Mental Health Act* 1983 contains provision for the licensing of private mental health facilities. These include requirements as to the physical conditions, staffing and other conditions of such facilities, with power to vary or revoke conditions or to cancel a licence. Provision is also made for inspection of licensed premises and statutory powers are conferred on an inspector. There are, however, no provisions relating to the monitoring of standards or conditions in publicly owned or operated health facilities in the Territory.<sup>66</sup>

No provision exists under general health or mental health legislation in the ACT for processing complaints by consumers. The Office of the Community Advocate under the *Community Advocate Act* 1991 has responsibility for fostering the provision of services and facilities for persons with disabilities; assisting in the establishment of organisations to support such persons; encouraging the development of programs for their benefit; and promoting their protection from abuse and exploitation. The Act also states that the Advocate has 'the power to do all things necessary or convenient to be done in connection with the performance of his or her functions.' However, the Act confers an express power on the Advocate to investigate complaints or allegations concerning the administration of the *Community Advocate Act* itself and to investigate complaints concerning the actions of a guardian or manager acting or purporting to act under an enduring power of attorney. This express provision would appear to limit the Community Advocate's power in relation to complaint handling to the matters specified.

## Guardianship

Since the Inquiry commenced the ACT has introduced the *Guardianship and Management of Property Act 1991*. This Act provides for the establishment of the Guardianship and Management of Property Tribunal to take over the powers exercised by the Supreme Court under the NSW *Lunacy Act 1898*.<sup>67</sup> The new Act gives the Tribunal the power to appoint a guardian where a person is 'unable because of a physical, mental, psychological or intellectual condition

- (i) to make reasonable judgements about matters relating to his or her welfare; or
- (ii) to do anything necessary for his or health or welfare;

and, as a result, the person's health or welfare is, or is likely to be, substantially at risk.'

The Act sets out powers that may be conferred on a guardian including decisions as to where and with whom a person is to live, whether or for whom a person may work and the giving of consent for medical procedures or treatment. There are also certain matters expressly excluded by the Act from the scope of the guardian's powers. These include voting, making testamentary dispositions and consenting to prescribed medical procedures which are defined in the Act to include sterilisation, abortion and contraceptive measures.

The Guardianship and Property Management Tribunal also has power to make an order appointing a manager for all or part of a person's property. If the Tribunal is satisfied that the person is by reason of physical, mental, intellectual or psychological condition legally incompetent to enter into a transaction in relation to a property and decisions need to be made regarding such transactions, the Tribunal may appoint a natural person or the community advocate as a guardian and may appoint the community advocate, a trustee company, or the public trustee as a manager.

The Tribunal, as constituted under the Act, consists of a President and two other members appointed by the Executive. The President is to be a magistrate or legal practitioner of at least five years standing. The other members are to be persons who, in the opinion of the Executive, have appropriate expertise, training or experience in relation to, and are otherwise suitable to deal with, the

needs of persons who because of physical, mental, psychological or intellectual condition need assistance or protection from abuse, exploitation or neglect.<sup>68</sup>

### **Anti-Discrimination Legislation**

Under anti-discrimination legislation passed by the ACT in 1991, discrimination is prohibited in the areas of employment, qualifying bodies, education, access to premises, goods, services and facilities, accommodation and clubs. The grounds on which discrimination is prohibited include impairment which is defined to cover 'an illness or condition which impairs a person's thought processes, perception of reality, emotion or judgment or which results in disturbed behaviour'. This would certainly cover mental illness.

1. Dr John Hoult, Director, Clinical Psychiatry, Glebe Community Care. Oral evidence, Sydney 20.6.91, p409.
2. Thea Bates, Director, Victorian Community Managed Mental Health Services (VICSERV). Oral evidence, Melbourne 8.4.91, p136.
3. Senator Grimes, then Minister for Community Services, in debate on the disability services legislation, as amended in the Senate by the Australian Democrats, 20.11.86, Hansard p2595 1986.
4. The problem that this creates in relation to psychiatric illness was referred to in oral evidence by a number of witnesses including T Bates (op cit, p136) and Margaret Ray (Chairperson, Social Development Committee, Victorian Parliament. Oral evidence, Melbourne 9.4.91, p256). Witnesses pointed out that most clinicians would not describe mental illness as permanent in view of the characteristic fluctuations and remissions.
5. On the other hand, a number of witnesses (eg Liz Dalston, Director, Mental Health Association Resource Centre, Adelaide 22.10.91, p162; Rob Ramjam, Coordinator, Planning, Schizophrenia Fellowship of NSW, Sydney 19.6.91, p324; and Rick Redom, President, Australian National Association for Mental Health, Hobart 12.11.91, p201) referred to the Minister's Statement at the commencement of the legislation that funding of services for psychiatric disability would be a low priority.
6. Dr J Tooth, President, Alzheimer's Association, Tasmania. Oral evidence, Hobart 11.11.91, p40.
7. Evidence to the Inquiry indicated that the HACC guidelines favour those with physical and intellectual disabilities over those with psychiatric disabilities. See, for example, oral evidence given by L Dalston, op cit, p162 and R Redom, op cit, p201.
8. Tony Fowke, President, Mental Health Association of WA. Oral evidence, Perth 11.2.92, p221.
9. The restrictive nature of these Schedules, which do not include many forms of therapy other than traditional psychiatric treatment and which reward doctors most highly for 16 minute consultations, was criticised by many witnesses including Dr Roger Gurr (Clinical Director of Psychiatry, Blacktown Community Health Centre, Sydney 18.6.91, p229); T Fowke (op cit, p221) and L Dalston (op cit, p163).
10. David Pugh, Bendigo Community Support Service. Oral evidence, Ballarat 11.4.91, p587.
11. According to the Act, the relevant determining authority is the Secretary of the Department of Social Security. In practice, the determination is delegated, in the case of Job Search, to a determining officer of the Department and in relation to Newstart, to an officer of the CES.
12. By 1994 it is intended to provide an additional 10,000 places in Commonwealth Rehabilitation Service programs for people with disabilities (including those with psychiatric disabilities) and an additional 6,500 places for people with disabilities in training programs run by DEET (Jobtrain, Jobstart and Job Search). The Disability Services Program will also create an additional 4,000 employment places in supported and competitive employment.
13. Janet Meagher (oral evidence, Sydney 17.6.91, p127) indicated that those who were considered to be 'stirrers' or 'troublemakers' were likely to be refused admission.
14. Anne Davis, former Executive Officer, ARAFMI. Oral evidence, Sydney 18.6.91, p154.
15. There is a requirement in the Act that the certifying doctor not be a near relative of the person to be certified. The term 'medical practitioner' is used in the mental health legislation but for the sake of simplicity 'doctor' will be used in this report.
16. Joy Said, Executive Director, After Care Association. Oral evidence, Sydney 17.6.91, p32.

17. Ramjam (op cit, p327) suggested that magistrates' hearings could be 'absolutely the best or the worst' ways of handling these reviews, depending largely on the magistrates' training.
18. Dr Ronald Barr, Consultant Forensic Psychiatrist. Oral evidence, Sydney 20.6.91, p424.
19. Meg Smith, coordinator, Manic Depression and Depression Association. Oral evidence, Sydney 17.6.91, p87.
20. By order published in the Government Gazette.
21. However, evidence given by Dr John Ellard of the Royal Australian and New Zealand College of Psychiatrists (Sydney hearings 17.6.91, p61) suggested that the legislative provisions were 'too cumbersome' to deal with small fly-by-night private operators.
22. Smith, op cit, former NSW official visitor, remarked that information on 'how to contact the official visitor was one of the State's best kept secrets'.
23. Dr Margaret Leggatt, Secretary, Schizophrenia Australia. Oral evidence, Melbourne 8.4.91, p89.
24. Neil Rees, President, Victorian Mental Health Board. Oral evidence, Melbourne 8.4.91, p32.
25. See oral evidence given by Peter Johnson of the Mental Health Legal Centre (Melbourne 10.4.91, p421) that the 'six hour rule' is used as a 'threat or cajolement'. The same witness referred to a 'practice of putting voluntary patients in locked wards.'
26. Victorian *Mental Health Act* 1986, s.8.
27. These appointments are for set terms, terminable at the Governor's discretion.
28. In practice the appeal may take place one week or more after lodgement, depending on the local availability of the Board. (Frank Hytten, Chairperson, Mental Health Legal Service. Oral evidence, Melbourne 10.4.91, p410.) If the Board finds the admission to have been inappropriate the four to six-week hospitalisation can only be remedied by discharge.
29. The Board issued Guidelines in 1989 for ensuring compliance with the rules of natural justice. However, in oral evidence given by Steven Hird of the Mental Health Legal Service (Melbourne 10.4.91, p426) the practical difficulty of patients getting to know the case against them was discussed.
30. Dr Ian Siggins, Victorian Health Services Commissioner. Oral evidence, Melbourne 8.4.91, p53.
31. On the other hand there was evidence from P Johnson (op cit, p422) that community treatment orders are used 'as cajoling devices to manipulate patients.'
32. Until amended in 1990, the provisions only extended to consent by the authorised psychiatrist or guardian where the patient was not capable of consenting to treatment on his or her own behalf. Dr Siggins, then Victorian Health Services Commissioner (op cit, p54) referred to this amendment as a 'questionable' removal of the distinction between refusal and incapacity and gave examples of the way in which it could lead to inhumanity and disregard for the dignity of patients.
33. Rees, op cit, p16.
34. Siggins, op cit, pp51-52.
35. Queensland *Mental Health Services Act* 1974, s.18.
36. The prescribed form for such medical recommendation is set out in the Mental Health Services Regulations.

37. According to oral evidence given by Gaye Ellis (Cairns 9.8.91, p1104) the 'authorised person' is not invariably present and people being involuntarily admitted are 'treated like criminals'. Similar comments were made in a number of written submissions.
38. This recommendation must also be in the prescribed form.
39. The rights to refuse treatment and to obtain information about treatment to be administered were major themes in written submissions from Queensland. Representative examples included Judy Magub on behalf of the Qld Association for Mental Health; Denis Jones on behalf of the Qld Nurses' Union; Sister Catherine Heffernan on behalf of the St Vincent de Paul Society; and a number of private individuals.
40. Report of the Commission of Inquiry into the Care and Treatment of Patients in the Psychiatric Unit of Townsville General Hospital, Volume I, p435.
41. *Mental Health Services Act*, ss.29A, 29C, 31 and 43.
42. The term of appointment is five years although there is also provision for removal on specified grounds.
43. The Queensland Law Reform Commission is currently examining possible changes to the laws in this area.
44. Although oral evidence given by the Chair of the Mental Health Review Tribunal (Adelaide 23.10.91, p394) indicated that the threat of involuntary detention is used to keep voluntary patients from leaving hospital.
45. However, evidence given by witnesses in Adelaide (eg. Sister Margaret Tulley, 22.10.91, p236 and Julie Felus, 22.10.91, p284) indicated that admission is refused on the ground that a person with 'personality disorder' is not suffering from a condition warranting hospitalisation.
46. However, as was pointed out in evidence given by the Chair of the Mental Health Review Tribunal (op cit, p394), since the Tribunal is part-time, the reviews are usually held only when the initial detention period has almost expired.
47. This, as was pointed out by Anne Burgess, Chief Project Officer, Mental Health Unit (Adelaide 22.10.91, p221), involves 'a lot of dual reviewing...a very circular sort of process.'
48. Dr David Ben-Tovin, Associate Professor of Psychiatry and Director of Mental Health Services. Oral evidence, Adelaide 22.10.91, p219.
49. Burgess, op cit, p220.
50. Dr Malcolm Roberts, psychiatrist. Oral evidence, Perth 12.2.92, p330.
51. The Board, however, has no power to order aftercare, only to discharge outright.
52. Evidence given by the Chairman of the Board of Visitors at Heathcote Hospital (Perth 10.2.92, pp35-36) indicated that the Boards do not tend to actually order discharge, although they consider the option in appropriate cases.
53. Professor Ian Campbell, Associate Professor, School of Law, University of Western Australia. Oral evidence, Perth 11.2.92, p119.
54. Dr Ian Sale, President, Tasmanian Branch of the RANZCP. Oral evidence, Hobart 12.11.91, p187.
55. id.
56. Dr Russell Pargiter, Chairman of the Ethics Committee of RANZCP. Oral evidence, Hobart 12.11.91, p148.

57. Dr Pargiter also cited the case of Dr Thompson whose release had been recommended by the Mental Health Review Tribunal but refused by the Attorney General.
58. Discussed in evidence by Sale, op cit.
59. These powers form part of its inherent jurisdiction.
60. Oral evidence given by Chris Staniforth of the ACT Legal Office (Canberra 19.3.92, p74) provides examples of the tragic problems that can arise where a patient is refused voluntary admission.
61. The agreement is contained in a schedule to the ACT *Mental Health Act* 1962.
62. Evidence given by Karen Fryar of the ACT Legal Aid Office (Canberra 18.3.92, p79) and also in the written submission from the ACT Legal Aid Office, indicates that a patient may be detained for more than one 72 hour period under these emergency procedures without application to the Court but without actually being informed at any point that he or she is free to leave.
63. This scope would not extend to guardianship or management of the estate of the detained person as such functions are currently provided for in the *Guardianship and Management of Property Act* 1991 and were previously covered by the application in the ACT of the NSW *Lunacy Act* 1898. Fryar, op cit, pp81-82, indicated that there is considerable uncertainty surrounding the role of prescribed representatives and some possible duplication with legal representatives.
64. Use of the Courts for this purpose was the subject of strong criticism in evidence given by Libby Steeper of ACTCOSS (Canberra 18.3.92, p25) who, like witnesses in other States, pointed out that the Court process was inappropriate for people who were ill and tended to be confused by criminal processes.
65. According to further evidence given by Fryar, op cit, p80, these orders are not in the form of individualised treatment plans but merely require that the patient be held for 28 days at the direction of the Director of Mental Health.
66. Nor is there, as was pointed out in evidence by Ken Horsham, General Manager, Housing and Community Services Bureau, ACT Correctives Services (Canberra 19.3.92, p150), any provision for monitoring the conditions for ACT patients in NSW institutions.
67. Parts VII, VIII and IX of the *Lunacy Act*.
68. The President is to hold office for a renewable term of five years. Other members are to hold office for a renewable period of three years. Although the Tribunal is a specialist body with a measure of independence, it is not 'freestanding' in that it is administered by the ACT Magistrates Courts. This point was clarified in evidence given by Brendan Bailey, ACT Community Advocate (Canberra 19.3.92, p139).



## Chapter 5

# MENTAL HEALTH SERVICES

## The Government Sector

Although we are becoming more skilled in the perception, the description, the diagnosis and the treatment of [mental illness], where are the psychiatrists to treat those with severe psychotic illness...who may be too difficult to treat in any other setting than a public psychiatry unit?<sup>1</sup>

This century has seen a dramatic shift in government mental health policy and service provision. The 'asylum era' that dominated mental health policy in the nineteenth century has given way (gradually, initially, and rapidly since the 1960s) to less custodial and segregated approaches — culminating in the prevailing preference for community-based care.

The concept of asylum was initially premised on the view that the most appropriate way to care for people with mental illness was in a protected, segregated environment. Inevitably, population growth outpaced the capacity of the asylums and the limited treatment regime meant that very few people ever moved back into the community. Any advantages that asylums may have offered were outstripped by the disadvantages of confinement, exclusion, stigmatisation, overcrowding and lack of personal freedom.

Nevertheless, it was not until the mid twentieth century that social pressure for reform — abetted by advances in medical technology and concerns about the financial burden imposed by large institutions — contributed to the major change in policy direction known as 'deinstitutionalisation'.

The discharge of patients formerly resident in psychiatric hospitals<sup>2</sup> and the growth of community psychiatry — where individuals are more likely to receive community or outpatient treatment and community-based rehabilitation — have gained momentum over the past 30 years. Unfortunately, hospital and community services have tended to compete for funds and have generally proved unwilling to co-operate in service provision. In addition, the promise of more, and more effective, community-based services has yet to be realised.

The policy of 'mainstreaming', as espoused in the *National Mental Health Policy*, attempts to address this situation by ensuring that mental health services are co-located with general health services, 'while retaining the internal integration of specialised services to ensure continuity in clinical management.'<sup>3</sup>

The success of this radical policy shift to mainstreaming, and of the *National Mental Health Plan*, remains to be demonstrated in practice. However, it is important to note that the debate about distinctions in policy has tended to divert attention — away from the endemic under-resourcing that has characterised mental health services. Lack of resources has bedevilled community-based care in much the same way that inappropriately allocated resources contributed to the ineptly executed demise of the large institutions. Clearly, resources and effective coordination are imperative if mainstreaming is going to work.

## **Funding**

According to estimates for 1991-92, the Commonwealth spent \$2,582 million on identifiable mental health services. Expenditure by the States and Territories in 1990-91 was \$871 million. This is a total of \$3,450 million, or \$201 per capita.<sup>4</sup>

Of the Commonwealth expenditure, \$20.5 million is identified as funding through the Disability Services Program. It does not include recent 'incentive' payments from the Commonwealth to the States and Territories as part of the devolution of disability services under the Commonwealth-State Disability Agreement (CSDA).<sup>5</sup>

A further \$120 million is identified as expenditure through the Home and Community Care (HACC), Supported Accommodation Assistance Program (SAAP), and Housing Programs of the Commonwealth. Again, it is difficult to identify how much of this expenditure relates at all directly to people with mental illness and psychiatric disability.

By far the greatest proportion of the Commonwealth's 'mental health' expenditure (\$1,444 million) relates to income security payments. Other benefits to or for individual recipients include \$79 million for pharmaceutical benefits, \$405 million for nursing home benefits, and a puzzling \$14 million for 'emergency relief'.

State expenditure varies significantly — from \$40 per capita in Queensland to \$63 per capita in Victoria.<sup>6</sup> Amounts spent in each jurisdiction in 1990-91 were as follows:

State	\$ million	\$ per capita
NSW	266	46
Victoria	277	63
Queensland	119	40
WA	85	51
SA	88	52
Tasmania	21	46
NT	6	33
ACT	9	31

### *National Mental Health Policy Funding*

The *National Mental Health Policy and Plan* were developed by the Commonwealth, State and Territory Governments over a three-year period and launched in May, 1992.

The aims of the Policy are to:

- Promote the mental health of the Australian community and, where possible, prevent the development of mental health problems and mental disorders;
- Reduce the impact of mental disorders on individuals, family and the community; and
- Assure the rights of people with mental disorders.

The *National Mental Health Plan* specifies strategies designed to assist in the implementation of the Policy by the Commonwealth Department of Health, Housing, Local Government and Community Services and State and Territory health departments.<sup>7</sup>

The Commonwealth is providing \$135 million to implement the Plan over the next five years. (Additional funding has also been allocated for capital works.) Of the \$135 million, approximately \$106 million will be allocated directly to the States and Territories as part of the renegotiated Medicare Agreement — to assist with the policy of integrating mental health services with the general health system. The \$10 million allocated during 1992-93 will be followed by:

1993-94	\$14.1 million
1994-95	\$19.1 million
1995-96	\$19.6 million
1996-97	\$20.7 million
1997-98	\$22.8 million

Clearly, the States and Territories are the primary providers of services for people affected by psychiatric disability. Most face significant difficulties in closing outmoded and expensive institutions, where most of their resources still lie, and developing an adequate level of community and acute hospital mental health services to accommodate patients currently in institutions and many others who will, at some stage, need acute care.

Theoretically, the *National Mental Health Policy* funding will allow introduction of additional services and facilitate the transfer of patients to community-based care. The intention is that this will facilitate further rationalising of institutions and the release of funds which can then be redirected to the community sector. Funding is also intended to be used to upgrade specialised psychiatric facilities for people in need of inpatient care and for mainstreaming acute psychiatric services into recognised hospitals.

The balance of Policy funding is to be used to support a program of structural reform at the national level, research, innovation in service delivery and evaluation.

## **Government Mental Health Services**

### *Resource Allocation*

This brief summary of expenditure and funding commitments does not purport to describe the extent of government involvement in the provision of services for people with mental illness. In most States — especially NSW and Victoria — there has recently been a significant redirection of government effort. However, while government mental health services are now much wider in range and impact than they were previously, the fact remains that State government funding is still, very largely, ‘institutionally based’.

While mental health services now offer specialised services — including assessment, crisis intervention, acute inpatient services, community outpatient clinics, mobile treatment teams, domiciliary services and rehabilitation and living skills programs<sup>8</sup> — there is still a fundamental imbalance between the number and distribution of these services, the extent of community needs and the resources available to meet those needs.

Although the figures vary from State to State, the overall picture is disturbingly uniform. In Victoria, for example, in the latest year for which the Inquiry could obtain figures (1990-91) 97.7 percent of that State’s mental health budget was used directly by government services. If the figures are further disaggregated, most States present a picture in which government services not only predomi-

nate, they effectively monopolise the limited resources available and apply those overwhelmingly to treatment and care in institutional settings. In Queensland, for example, of the total funds of \$119 million available for mental health services in 1990-91, over half (51 percent) was spent on just three psychiatric hospitals. A further 36 percent was spent on psychiatric units in general hospitals. Only 10.5 percent was allocated to 'community services' — and only 1 percent allocated to carer and consumer organisations (ARAFMI, Schizophrenia Fellowship, GROW etc) which provide a great deal of support to consumers and carers alike.<sup>9</sup>

### *Types of Services*

The following service components are regarded by the NSW Health Department as essential to an integrated mental health services system:<sup>10</sup>

- adult mental health teams (providing assessment and ongoing treatment and management services);
- mobile assertive case management teams/mobile treatment teams (providing intensive case management services to clients with special difficulties);<sup>11</sup>
- crisis/ extended hours services (providing assessment, acute treatment and management services, preferably on a 24-hour basis);
- community-based treatment beds;<sup>12</sup>
- accommodation services;
- mental health inpatient services;
- general hospital psychiatry services (principally providing acute admission services and servicing defined catchment areas);
- psychiatric hospitals (providing a regional service for acute patients who cannot be managed in general hospital units, tertiary assessment, long term care for chronic patients with severely intractable chronic mental illness not manageable in the community or other facilities, specialised rehabilitation services, and specialised containment for both civilian and forensic patients);and
- specialised services for children, adolescents and older people.

Other States are adopting similar systems according to population size and special needs. (Chapter 9 — Community Care and Treatment, provides a detailed description of the components of comprehensive mental health services.)

## *Hospital Services*

At present there are no uniform national data concerning:

- the relative numbers of beds in specialist, stand-alone psychiatric facilities compared with psychiatric units;
- designated beds in general hospitals; or
- acute treatment beds and beds for long-stay or so-called chronic patients.
- beds occupied by old people with mental health problems. (Some States include psychogeriatric and dementia beds; others exclude these categories.)

This makes it impossible to accurately tabulate the provision of inpatient services on a State by State basis. However, the States and Territories are currently implementing systems, to be linked into a national mental health minimum data set, which will have the capacity to identify service patterns and costs.

At the Commonwealth level, the only hospital services for people with psychiatric conditions are those provided by the Department of Veterans' Affairs. A process of transferring these hospitals to the States is under way.

It should also be noted that private hospitals offer some beds to public patients with mental illness. As an example, a submission from the Australian Catholic Health Care Association nominated three private psychiatric hospitals among the 36 private and 22 public hospitals throughout Australia represented by the Association. The Association stated:

All our major Catholic public hospitals throughout Australia are involved to some degree in care of various psychiatric illnesses, often through accident and emergency departments, in specialised units, general wards and outpatient clinics.<sup>13</sup>

Private inpatient services are discussed in more detail later in this chapter.

As mentioned earlier, the policy of mainstreaming or amalgamating psychiatric inpatient services with general hospitals will have major implications for the future of hospital services for people affected by mental illness.

The success of mainstreaming will depend not only on more — and more equitably allocated — resources, but also on more enlightened attitudes by the medical profession and health administrators.

The Inquiry was presented with a wide range of views concerning the effects and desirability of mainstreaming public psychiatric services. On the one hand, bringing acute psychiatric treatment into the main stream of hospital services was seen as an essential way of improving the status of psychiatric medicine, and as a means of removing the prevalent stigma still associated with mental illness.

The integration of psychiatric services into the mainstream would force psychiatric hospitals like Lakeside to...stand on their own and become hospitals in the true sense as we know them in the public sector.<sup>14</sup>

Integration enables barriers to be broken down between psychiatry and other disciplines. By thus countering the tendency towards isolation of psychiatry, integration can reduce the stigma attached to mental illness and open its principles and practices to broader scrutiny.<sup>15</sup>

In addition, mainstreaming was seen by some as a way of significantly improving medical care for people affected by mental illness.

There is a large degree of overlap between psychiatric and physical ill health. Roughly 30 percent of patients in general hospital beds have co-existing psychiatric disorders. A similar figure (25-30 percent) applies to patients in primary care. Likewise, 30-50 percent of psychiatric inpatients show evidence of concurrent physical illness. It follows that integrated health care ought to improve the quality of care by providing better access to modern diagnostic and therapeutic procedures together with enhanced interdisciplinary consultation and collaboration.<sup>16</sup>

However, many witnesses to the Inquiry feared this radical policy shift will result in mental health budgets being eroded and funds redirected to the larger and more expensive health services in general hospitals, which have been stretched, sometimes to breaking point, in most States over the past few years. This could actually lead to diminished status and funding, and even greater risks of discrimination and stigmatisation.

It is essential to ensure that funding earmarked for psychiatry is in fact delivered to psychiatric services and not diverted to competing areas of health care. And I think, on that point, there has almost been a trial run of mainstreaming in Western Australia since the closure of the Mental Health Services Department some six or seven years ago, and its incorporation into the Health Department. Whilst probably facilities and services have not yet been reduced, on the other hand...they have not been proportionately increased and so psychiatry has actually fallen behind other areas of medicine.<sup>17</sup>

Another concern related to the possibility that mainstreaming could lead to psychiatric care becoming more closely aligned with the 'medical model' of care — at the expense of broader psychosocial approaches to treatment.<sup>18</sup> The apprehension and ambivalence of many witnesses was concisely summarised in a submission from one professional association:

The policy direction of integrating mental health services with general health services is commendable, first, in attempting to address the problem of so many inpatient psychiatric services being so removed from the patients' local communities, and secondly, in attempting to destigmatise mental illness by associating its treatment with general health services... However, there is a potential for mental health services to be overshadowed by general health care areas, [because they tend to be] more expensive and more prestigious.<sup>19</sup>

Several submissions to the Inquiry advocated an even greater degree of integration in order to 'normalise' mental health services.

Outpatient clinics are conducted within the precincts of the acute facilities... We believe that outpatient clinics, day centres and rehabilitation services should all be situated out in the community where people live. The established general community health centres could be used for this purpose on specified days.<sup>20</sup>

Whatever the outcome, it is clear that with the introduction of mainstreaming, training must become a higher priority if general hospital staff are to adapt to the particular demands of dealing with people affected by psychiatric disorders in an appropriate, empathetic manner.<sup>21</sup>

### *Community Services*

We do need staff in the community, but no more than we are currently employing in the hospitals... The real challenge is to develop training programs... We are talking about a thousand community mental health workers — psychologists, social workers, nurses, psychiatrists — none of whom have had a lot of training for the new jobs we are asking them to do. It's a problem of changing roles and us forgetting to reskill them.<sup>22</sup>

Notwithstanding the relatively slow reallocation of resources referred to above, submissions from State and Territory governments expressed a unanimous commitment to greater government involvement in direct service provision at a community level. The *National Mental Health Policy* calls for 'comprehensive mental health service systems' offering an appropriate service mix that recognises the need to cater for 'acute episodes and long-term needs'.<sup>23</sup>

Government submissions received by the Inquiry clearly acknowledged that people with mental illness, like people with any other illness, are best treated and cared for in a familiar environment, where they have access to both organisational and informal supports. The *National Mental Health Plan* and State strategic plans<sup>24</sup> acknowledge this; but they vary in the degree of explicit commitment to action that will correct continuing imbalances in resourcing.

Clearly, from the evidence presented to the Inquiry, there are a number of problems preventing the transition from institutional care to community care proceeding effectively.



Major impediments identified by witnesses included:

- failure to transfer financial resources to community mental health services;<sup>25</sup>
- lack of staff in the community to care for people after discharge;<sup>26</sup>
- inefficient organisational arrangements to integrate community services with hospitals;<sup>27</sup>
- lack of retraining for hospital-based mental health professionals, particularly nursing staff;<sup>28</sup>
- existence of industrial barriers to moving staff out of hospitals;<sup>29</sup>
- lack of procedures to involve families in the community treatment process.

These issues are discussed in more detail in Chapter 9 — Community Care and Treatment.

### *'Specialist Services'*

While there are many accommodation, rehabilitation and continuing care services that have special expertise and a specialised focus, this section is confined to clinical services — an area which is the exclusive preserve of government.

Concerns about the effects of mainstreaming are particularly pronounced in relation to specialist services. Evidence presented in later chapters of this report indicates that there is a chronic shortage of specialist services for particularly vulnerable groups such as children and adolescents, Aboriginal and Torres Strait Islander people, refugees, survivors of torture and trauma, the homeless and those with multiple disabilities. Older Australians are especially disadvantaged:

As we get older we know there's a greater chance of having a psychiatric disorder. We know, for example, that 25 percent of people over the age of 75 can suffer from a depressive disorder and it can go unrecognised and therefore untreated — put down to the ageing process — when it's a treatable condition... We will be a sicker population because of the increased incidence of psychiatric disorders in the aged...and the significant increase in our [elderly] population.<sup>30</sup>

Those specialist services that do exist are currently concentrated in a handful of large cities — generally the State capitals. While this is understandable in a political and economic sense, the failure to provide even basic services outside our major urban centres must be a matter of serious concern in a country with such a widely dispersed population.<sup>31</sup> (See also Chapter 22 — People in Rural and Isolated Areas.)

### **The Most Disabled**

Nowhere else in medicine does it occur that the sickest receive the least time of the most highly skilled. Have we largely abandoned these people?<sup>32</sup>

In opening this chapter reference was made to the traditional concept of 'asylum' — and the rapid decrease in the number of 'institutional beds' (from 281 per 100,000 people in the 1960s to 40 per 100,000 in 1992). While few would oppose deinstitutionalisation as a concept, there are disturbing signs that some States may be on the verge of closing down all institutions without providing any viable alternatives for some of the sickest and most vulnerable in our society — those for whom some type of 'asylum' in the traditional sense is essential. There are also a small number of individuals who are, in reality, so dangerous to the community that there are compelling human rights arguments for their continued confinement. These facts may be unpalatable — but they cannot be ignored. Nor can governments realistically look anywhere else but to government funded facilities for provision of the requisite care.

However, the Inquiry found little evidence of appropriate planning to effectively cater for the needs of such people. One US study conducted in the 1980s indicated that there is an 'irreducible minimum' of approximately 15 institutional beds per 100,000 people — to cater for the needs of the severely mentally ill elderly, intellectually disadvantaged, brain injured, dangerous and endangered.<sup>33</sup> Clearly proper provision for such people must be made — both to protect themselves and, in the case of the chronically dangerous, the community at large.

### **Prevention and Early Intervention**

Australian governments have committed themselves to promoting a better understanding of mental health issues and to secondary (early intervention) and tertiary (rehabilitation) prevention of psychiatric disability.

The efficacy of primary prevention measures has not been demonstrated for most severe mental health problems and mental disorders... The evidence in support of the effectiveness of...early intervention and...rehabilitation prevention is stronger, and the provision of such measures is regarded as central to mental health care. Early diagnosis and intervention are particularly effective, as are programs which assist people to deal with life events which may place their mental health at risk.<sup>34</sup>

To date, very little systematic attention has been given to this important objective. While the Inquiry acknowledges the importance of programs such as the Early Psychosis Centre at Parkville, Melbourne, the 'prevention' effort seems to have been directed at broader mental health issues. (See Chapter 27, Prevention and Early Intervention, for a more detailed analysis.)

## The Private Sector

I would be quite happy to go on the record as being extremely critical of the role of private psychiatrists in the provision of services to psychiatric patients in the community. In our position we are frequently put in the situation where a psychiatrist will not see anyone after hours, even if it is their own patient... This is in a background where I believe...that about 80 percent of the State's psychiatrists are in private practice... I would suspect that very, very few of them provide a locum service or an after-hours service, and...virtually none would ever visit a patient at home. So the situation there is they are confining their treatments essentially to neuroses. Once it comes to a psychosis they don't want to know about it.<sup>35</sup>

The Inquiry received very little evidence from the private sector. Publicly available information indicates, however, that there are a significant number of private psychiatric services operating in the capital cities, particularly Sydney and Melbourne.

It is also well recognised that private therapists, working as sole practitioners or in clinics, provide treatment and counselling services — especially in the child, adolescent and family therapy fields.

### Private Sector Psychiatric Services

#### *Outpatient Management*

There are approximately 1800 psychiatrists in Australia. Psychiatrists see approximately 75 percent of patients in office-based private practice and 25 percent in public practice.<sup>36</sup> Psychiatrists in private practice are less likely to see people with severe mental illness and, according to government figures, approximately 60 percent of their patients suffer from neuroses or personality disorders.<sup>37</sup>

However, there is considerable doubt that the remaining 40 percent are affected by what are clinically defined as 'mental illnesses'.

A large number of psychiatrists have taken the soft option and set up a practice which discriminates against the seriously mentally ill. If someone really ill turns up, they're shunted off to the nearest government facility.<sup>38</sup>

The point comes into sharper focus when the figures for Commonwealth expenditure on mental health are analysed. In 1990-91 the Federal government paid out approximately \$400 million in medical benefit rebates. This is a very substantial sum — and dwarfs, by comparison, the amounts paid to support other important elements of the mental health care system.<sup>39</sup>

Clearly psychiatrists — including those in the private sector — have a central role in any coherent mental health system. But if, at the same time that governments are closing institutions at an unprecedented rate, many psychiatrists are declining to treat the most seriously mentally ill, our professionals (and the governments which substantially finance their practices through the rebate system) are fundamentally failing many who need them most. (Also see Chapter 6 — The Role and Training of Health Professionals and Others, for further discussion of this issue.)

In theory, it is possible for any individual to see a private practitioner — as long as the psychiatrist is prepared to accept the Medicare rebate as total payment for their services. While it is true that long term involvement with one private psychiatrist has distinct benefits, this form of treatment is really only suitable for people who are compliant with treatment, are willing and able to attend for consultations, and have the external supports to assist with management and linking into rehabilitation services.

Patients who consult a psychiatrist in private practice have the advantage of continuity of practitioner, the knowledge that the practitioner is fully qualified and the opportunity to change doctors if they do not have confidence in a particular one. On the other hand they usually get a medical service only, without the wider professional services which are provided through the public sector. Many private practitioners will not provide any information or support to family members out of respect for confidentiality, and families are thus left without the assistance needed to care for the person with the identified illness. There is some anecdotal evidence that those who can afford to use the services of the private sector may in fact be more isolated in their illness, or their distress, than those in the public sector.<sup>40</sup>

The major concern in this area rests upon the fact that many people treated by private psychiatrists have no access to support and rehabilitation services. For example, there is no one to follow up on medication, which is a major factor in the prevention of relapses.<sup>41</sup>

It has been suggested that the present arrangements for reimbursement of private psychiatrists under the Medical Benefits Schedule system have contributed to this situation.<sup>42</sup> People with mental illness have multiple needs which vary over time. At different stages many will need services which are not usually provided by a psychiatrist or GP — such as assistance in finding accommodation and obtaining other forms of support. Psychiatrists are not reimbursed for time spent making arrangements such as these or for maintaining referral networks.

Indeed, there are no incentives for private psychiatrists to give priority to people with chronic mental illness at all. Nevertheless, the Inquiry did hear from family members who were pleased with the service provided by their private psychiatrists, as the following case illustrates:

Now, there can't be many doctors in this world who would take a distraught call from a person eight times during the day. He gives me his holiday number, his private home number and his clinical number and I think it's good to be able to note — it gives us hope, even though they are pretty hard to find and it took us 14 years to find him — that there are people who are willing to do that.<sup>43</sup>

### *The Relationship Between the Public and the Private Psychiatric Systems*

In most States, private psychiatrists do not have visiting medical officer rights in public hospitals. Under the present arrangements a private psychiatrist cannot be reimbursed through the Medical Benefits Schedule for continuing to treat patients in this setting.

Private patients who are referred to public hospitals because they do not have private health insurance generally 'lose' their psychiatrists when they enter the public mental health system. In many cases the psychiatrist is not even notified when the patient is discharged from hospital.

Some private hospitals offer beds to public patients affected by mental illness (a subject addressed in more detail in the previous section on Government Services).

### *Private Psychiatric Inpatient Services*

Only 12 percent of acute psychiatric beds are in the private hospital system.<sup>44</sup> Similarly, a lower proportion of people with the more serious mental disorders are private inpatients. A recent Queensland study found that the proportion of hospital patients with schizophrenia and other psychoses was lower in private psychiatric hospitals than public hospitals: 26 percent (private) and 40 percent (public); as was the case with affective disorders: 22 percent (private) and 31 percent (public).<sup>45</sup>

In NSW, patients in private hospitals represented 13 percent of residents in mental health facilities at the 1990 Census. NSW private hospital psychiatric bed numbers have decreased in recent years — to 564 beds in October 1991 — a proportion of which are designated as drug and alcohol treatment beds.<sup>46</sup>

Private inpatient psychiatric care is out of the question for people who do not have private health insurance. Furthermore, evidence to the Inquiry indicated that some major health insurance funds unjustifiably discriminate against people with mental illness, either by imposing special rates on patients admitted to private psychiatric facilities,<sup>47</sup> or by establishing tables which exclude psychiatric hospitalisation. These tables are often directed towards young adults — on

the basis that they will not need inpatient psychiatric care — when in fact they are in a high risk category.

We are most concerned by the establishment of health insurance tables specifically excluding psychiatric hospitalisation. Such tables have been established in the past year by major health funds. These tables are often directed towards young adults on the basis that they will not need such care, when in fact they are in a high risk category. Schizophrenia commonly starts between 15 and 25 years of age, and major mood disorders commonly between 25 and 45 years. To claim that psychiatric hospitalisation will be unnecessary is a fraud which can succeed because it caters to people's denial and prejudice.<sup>48</sup>

This is clearly a major problem which must be effectively addressed (see also Chapter 20 — Children and Adolescents).

Other financial issues affecting people with mental illness are discussed in more detail in Chapter 9 — Community Care and Treatment.

### **Other Private Practitioners**

Psychiatrists are not, of course, the only practitioners offering services in the private sector. However, for reasons which are addressed in the following chapter (*The Role and Training of Health Professionals and Others*), the services of psychologists and other health professionals are only available in the private sector on a very limited basis to individuals and families affected by mental illness.<sup>49</sup>

## **The Non-Government Sector**

I have singled out the ways in which GROW has helped me. Some of these had to do with the special kind of sickness I had and my own peculiar delusions and disturbed behaviour. Others (like the need to regain an ordinary pattern of daily living, to be free of drugs and to get back to work) are common to the majority of stories of recovery from severe breakdown... GROW helped me to understand and manage pretty well every aspect of my life — the care of my physical health and personal appearance, all kinds of personal relationships, religion, human inadequacies, the wear and tear of life and even the prospect of death, including the death of loved ones.<sup>50</sup>

Evidence presented to the Inquiry clearly established that a wide range of non-government services (not-for-profit, non-hospital services) are central to effective realisation of the rights of people with mental illness. Equally clearly, such services are frequently regarded as incidental or peripheral to the 'real' effort of psychiatric treatment and rehabilitation. (The most recent comprehensive examination of psychiatric services in Australia confines non-government services to an essentially secondary role.)<sup>51</sup>

Compared to their involvement in other fields of human service, the participation of non-government organisations (NGOs) in the mental health field is, on the whole, relatively recent.<sup>52</sup> Nevertheless, there is now general acceptance that non-government, not-for-profit organisations are critical to the provision of a wide range of accommodation, advocacy, rehabilitation and support programs for people with psychiatric disabilities.<sup>53</sup>

Australia has a tradition of utilising such organisations for the provision of a range of health and community services. They are typically supported financially by Government to undertake functions regarded as not appropriately or efficiently performed within the public service system. These groups constitute the non-government sector.

Increasingly, NGOs have specialist know-how — and considerable experience — in the care and support of people who would previously have been thought to require treatment in psychiatric institutions. Non-government services offer a blend of professionally trained and qualified staff; staff who bring special qualities and life experience to their role; volunteers; and people who have themselves experienced at first hand the impacts of mental illness and psychiatric disability.

Evidence to the Inquiry indicated that NGOs frequently demonstrate qualities of concern, commitment, innovation, advocacy and tenacity — qualities sometimes lacking in Government services. They can be more immediately responsive and flexible than statutory services. They are able to advocate for and with people with psychiatric disabilities in ways denied to staff of Government agencies. Further, they are more likely to be seen as an acceptable part of the fabric of the community, without the unfortunate overtones which often accompany bureaucratic procedures.

The range of services that can accurately be described as ‘non-government’ is extremely broad, encompassing the whole gamut of formal and informal programs conducted by agencies, groups and individuals who assist people with mental illness and psychiatric disabilities.

While there are substantial variations among NGOs, they share the following characteristics:

- The non-government sector does not provide medically based clinical or treatment services. It does, however, offer a range of ‘therapeutic’ rehabilitation and support services.
- Many organisations have a major advocacy and lobbying role.

- In general, non-government organisations offer services that deal with disability — the functional consequences of an illness or impairment — and not with the illness or impairment itself.<sup>54</sup>
- Many non-government services provide valuable links between the public psychiatric services and community health sector, and the non-government community services sector.<sup>55</sup>

The term 'voluntary' is still sometimes applied to the varied collection of non-government services. However, because few mental health services are in fact run entirely by unpaid volunteers, this terminology is not used in this report.

(Throughout the report, there is reference to the vital contribution of informal care networks — made up of people with psychiatric disabilities themselves, their relatives and friends — which are critical to the wellbeing of people with mental illness. This is the true 'voluntary' care and support sector.)

There is a growing category of services, described as **community managed**, which places particular emphasis on consumer participation and community control. A peak body for organisations with this orientation described their contribution as follows:

*Non-government, community-managed organisations have been traditionally recognised as essential to the provision of high-quality, cost-effective community and health services... Whether as service providers, self-help, carer or advocacy organisations, they are critical to the success of any truly integrated human services system. They are also the vehicle by which members of the community can participate in the planning, management and delivery of services which they have decided are essential and to which they are prepared to make commitments of time and resources.*<sup>56</sup>

The special characteristics of the sector were described to the Inquiry in the following terms:

- the community managed sector has built up a set of philosophies, principles and practices that have proved their cost-effectiveness over many years.
- the community managed sector does four things especially well:
  - a) it works in and is part of the wider community, accessing a wide range of community resources: this is true integration and mainstreaming;
  - b) it accepts people as individuals, and doesn't 'treat' them as 'patients';
  - c) it takes risks (not at the expense of people with mental illness, but on their behalf); and
  - d) it educates, increases awareness, and advocates the cause of people with mental illness in a far less threatening way than can the public sector, which inevitably has authoritarian overtones.



- not only does this result in cost efficiencies: it is the essential 'humanising' and real-world factor that often is missing from public services.
- most importantly, the sector is a key safeguard against monolithic medical-administration control over the lives of people with psychiatric disability that is one of the dangers of the mainstreaming of public general health and psychiatric services.<sup>57</sup>

It is unclear whether the increasing dependence on the non-government, not-for-profit sector stems from economic rationalism — such services typically operate at between one third and one fifth the cost of directly comparable government services — or from a recognition of the benefits provided by the flexibility and responsiveness which characterise these services.

Certainly, the requirements of deinstitutionalisation, and philosophies of normalisation or social role valorisation,<sup>58</sup> with their emphasis on 'a valued social role for every devalued person', have highlighted the role of non-government services.

The traditional boundaries between government and non-government psychiatric services seem to be increasingly blurred. This is partly as a result of uncertainties accompanying mainstreaming and the amalgamation of public psychiatric and general health services. It may also be related to changes in funding and accountability requirements and procedures, to inadequate communication and consultation about policy, and to the changing perceptions each group of services has of the other.

### **What They Do**

The...[non-government] mental health sector has been a critical supplier of support to generic mainstream services who are struggling to adapt to the massive influx of clients with associated psychiatric disabilities seeking access to generic services following 'deinstitutionalisation' and 'normalisation' policies being implemented.<sup>59</sup>

The Inquiry received oral and written submissions from many non-government organisations. This evidence was supplemented by submissions from peak councils and coordinating bodies in each State and Territory. Evidence presented by governments also confirmed there are a large number of NGOs supporting and providing services to people affected by mental illness and psychiatric disability around Australia.

This number increases substantially if NGOs assisting the homeless and those with dementia are included. An enormous amount of assistance is given to people with mental health problems, and those caring for them, by organisations with broad community service charters, such as the conferences of the St

Vincent de Paul Society, the Salvation Army, Uniting and other church agencies, and other religious and secular organisations.

Among the extensive range of descriptive labels attached to this wide variety of non-government services, the following are commonly used: accommodation support, advocacy, carer group, clubhouse, community education, community outreach, community support, consumer group, crisis support, day services, day support, employment training and placement, living skills development, outdoor adventure, psychosocial rehabilitation, respite, recreation, self-help, supported accommodation, supported employment, and transitional accommodation.<sup>60</sup>

The Australian Psychiatric Disability Coalition Inc (APDC)<sup>61</sup> is funded by the Commonwealth Government as the peak body of non-government organisations working with people with psychiatric disabilities. The Coalition proposed a typology of services based on four factors — who provides the service and for whom; what service is provided; how the service is provided; and where services are provided. After analysing the extensive material made available by many NGOs, the Inquiry concluded that the major suppliers of services in the non-government sector can usefully be divided into five main categories.

In the first category are organisations formally constituted to offer programs and services directly to people with mental illness which were not traditionally available in the public sector. Such organisations employ staff, place minimal or no reliance on volunteers, and regard themselves as professional providers, whether or not staff have formal professional qualifications. Typical of this category are the Richmond Fellowships — operating in all jurisdictions except South Australia and the Northern Territory; the After Care Association and the Psychiatric Rehabilitation Association, both operating only in NSW; and Casson Homes in Western Australia. These organisations provide accommodation or accommodation support, employment and activity services for people with psychiatric disabilities.

A second group of organisations are dedicated to assisting those who experience the direct impacts of psychiatric illness — individuals themselves affected by mental illness, their relatives and friends. These organisations provide support, information, advocacy and other services to and for their members. They may also offer specific programs and services akin to those of the first category, but this is not their primary purpose. Increasingly, these organisations employ skilled and experienced staff in management and coordinating positions, and to train and support volunteers. Among such organisations are the Schizophrenia Fellowships around Australia, the Associations of Relatives and Friends of the

Mentally Ill (ARAFMI), and the Alzheimer's Disease and Related Disorders groups (ADARDS).

Closely related is a third category of self-help and mutual support organisations. These vary — from organisations such as GROW, which has professional staff and significant administrative support, to specific-diagnosis bodies, such as the bi-polar mood disorder associations (including the Depressive and Manic Depressive Association of NSW and Self Help Mood Disturbance Prevention in SA); to very small support groups (such as those described to the Inquiry at hearings in Albany, Alice Springs, Cairns, Devonport, and Port Lincoln) for people with a wide range of mental disorders and psychological problems.

Fourth, there are organisations which specialise in providing outreach services for people with mental illness. Examples of this type of service are the Macaulay Community Support Service and the Western Region Outreach Service in Melbourne, and a range of smaller organisations in NSW, Western Australia, Queensland and Tasmania.

There is a fifth category of organisations which operate as research, advocacy and information sharing bodies, whether on a 'peak' basis (such as the Sydney-based Alliance for the Mentally Ill, Australia) or as a voice for consumers in a variety of forums (such as the Victorian Mental Illness Awareness Council). An important group of this type which has recently been established is the National Community Advisory Group, chaired by Ms Trisha Goddard.

### **How They Operate**

There is an important initial distinction to be made between non-government organisations that operate on a mainly volunteer basis, and those that employ staff. Understandably, volunteer services are more likely to be found in the area of mutual support, information sharing and advocacy than in the provision of accommodation, employment or outreach services requiring significant levels of external funding and rigorous accountability.<sup>62</sup>

It is now a requirement of government funding that non-government organisations be incorporated and be registered as charitable bodies. In the case of small services (such as 'Youth Link' in Cairns or the 'Oasis Community Centre' in Hobart) there may be an outrider arrangement, with a formally structured agency acting as auspice for the smaller organisation or group.

Data in the community health and welfare field are notoriously unreliable, and the Inquiry could not obtain a complete picture of all sources of funding for non-government psychiatric services. Nevertheless, it is clear there are great

variations in the levels and types of support provided. (For example, in NSW in 1991-92, 21 NGOs were funded at different levels by the Health Department to provide mental health services. Eighteen additional organisations received no funding from the Department but were recognised as being 'active in the mental health field'.)<sup>63</sup>

According to evidence presented to the Inquiry, the Commonwealth, for some years, refused to fund non-government psychiatric services under the *Disability Services Act*, but is giving this area some priority now that funding of most disability services has been transferred to the States.<sup>64</sup>

Non-government services generally place a strong emphasis on membership, with maximum participation and direction by members. Most programs concentrate on developing or reaffirming the skills of daily living, interpersonal and social relationships, leisure and recreation. Priority is also given to making the transition to independent living options through the development of personal and social support networks.

NGOs often refer to the people with whom they work as participants or members, consumers or users: they rarely talk of people being patients.<sup>65</sup> (The Schizophrenia Fellowships refer to 'sufferers'.) This choice of terminology is much more than mere semantics. The terms involved are seen by consumers, carers and non-government providers as characterising a fundamentally different attitude to the involvement and empowerment of people who have long experienced blatant discrimination, stigmatisation, marginalisation, and even victimisation.

As already noted, non-government services tend to focus on providing support and rehabilitation. They give particular attention to group interaction and dynamics within a non-institutional setting — to help people gain a sense of security and purpose and to become confident both within themselves and in their relationships with the wider community.

Although efforts are being made in some States (especially NSW and Victoria) to gather accurate data on staffing, there is still no detailed analysis of categories of staff employed in the non-government sector. In selecting staff, many NGOs told the Inquiry they place equal importance on personal qualities and professional qualifications and experience. This is a key area of difference with both public psychiatry and the private sector. Non-government organisations see themselves as attracting staff from a variety of backgrounds, with a wide range of experience, skills and expertise.

Nor do Federal or State governments have accurate data on the numbers of volunteers used by non-government organisations. It is known, however, that organisations such as the Schizophrenia Fellowships, Lifeline, the Society of St Vincent de Paul, the Red Cross and the Salvation Army are all heavily reliant on the direct involvement of volunteers in service delivery. The level of such reliance understandably tends to be greater in self-help and mutual support and advocacy organisations.

Many, if not most, NGOs have considerable indirect volunteer involvement in fund-raising, administrative assistance, public relations, information and advocacy activities. They also rely on 'help in kind' by way of donations of time, equipment and expertise from the corporate sector.<sup>66</sup>

## **Resources**

Notwithstanding the increasingly important role played by NGOs, the vast majority of resources are still devoted to public psychiatry.

In most of Australia the rights of one group can only be satisfied at the expense of other groups, and the reason I put to you is the maldistribution of resources — that more than 80 percent of the mental health budget of the States goes to hospitals who deal with less than 5 percent of the people with mental illness. 95 percent of the mentally ill have to make do with less than 20 percent of the budget.<sup>67</sup>

This disparity is even more obvious in terms of funding for NGOs. In Victoria, which offers more direct support to non-government services than any other State, only 2.3 percent of Government funding for mental health and psychiatric services was allocated to non-government organisations in 1991-92.<sup>68</sup> Yet Victorian Government figures also clearly show that non-government services cater for at least as many 'primary' clients as do government psychiatric facilities.<sup>69</sup>

In Queensland, it was not until 1990-91 that the then Division of Psychiatric Services established a separate funding program for non-government organisations. Funding has almost doubled since the Inquiry began (increasing from \$559,561 in 1990-91 to \$966,999 in 1992-93).<sup>70</sup> However, this is still a tiny fraction (approximately 1 percent) of the State mental health budget.

NSW provided a total of \$2,330,550 to community organisations in 1991-92, a mere 0.7 percent of its mental health budget.<sup>71</sup>

It has clearly emerged from evidence presented to the Inquiry that, in every State and Territory, non-government services are the poor cousins of public psychiatric service provision throughout Australia. As a result, there is a

tendency for not-for-profit services to 'make do' — both in terms of numbers of staff and remuneration levels, and in relation to the costing of overheads.

- [Governments have] recognised the value of the non-government sector by entering into funded contractual arrangements with both support groups and service providers and self help groups in an effort to ensure that the individual and family receives ongoing support in integrated services. However, many of the groups still go unfunded and there is a need for much greater resourcing in that area.<sup>72</sup>
- We handle anything between 30 and 50 people per day. We offer them a meal at a very reasonable price, continuous tea and coffee, a social atmosphere... Our biggest problem, of course, is finance — as with any community based organisation — and we find we do not have the money to meet the programs we would like to provide for those who come to us.<sup>73</sup>
- There is an awful lot of energy going into raising money when the demands on our services in terms of counselling, education, support and direct service provision are so great. I feel it is a great shame that we are having to put so much [effort] into just trying to keep our heads above water financially.<sup>74</sup>

On the basis of the evidence there is an urgent and compelling need for more, and more adequately resourced, non-government services. This applies equally to the scope, distribution and quality of such services.

## Scope

Self-help and mutual support is the most common type of service provided by NGOs. This ranges from very localised mutual support services that may be sponsored by a church or community group (including a few through multi-purpose neighbourhood houses) to major support networks, such as those managed by the Schizophrenia Fellowships, ARAFMI and GROW.

Accommodation and support services appear to be the dominant category in terms of Government funding. In NSW, for example, 54 percent of its 1991-2 non-government organisation budget was allocated to accommodation and support services.<sup>75</sup> The Victorian Office of Psychiatric Services indicated that 44.2 percent of its 1991-92 allocations to NGOs was attributed to 'accommodation services', defined as 'residential rehabilitation, supported housing, homebased/outreach housing support and respite services'.<sup>76</sup>

It was widely accepted by witnesses giving evidence to the Inquiry that secure, affordable accommodation, with support appropriate to the needs of individual residents — including access to complementary rehabilitation programs — is fundamental to the rights of mentally ill people. Lack of secure accommodation and appropriate support was generally identified as a major cause of readmission to hospital.

The next most common form of service in this sector appears to be what NSW categorises as 'support and self-help' (consuming 24 percent of the Health Department budget for NGOs in 1991-92).<sup>77</sup> In NSW, this category includes day programs of various types. There are no directly equivalent figures available for Victoria: the minimum data set there reports 18.2 percent of the Office of Psychiatric Services budget for NGOs as allocated to 'support and advocacy services', identified as including 'mutual support/self-help groups, other support groups, individual advocacy and system advocacy/education services.'<sup>78</sup>

There are fewer non-government services specifically aimed at employment and employment opportunities for people with psychiatric disabilities. In NSW, for example, 13 percent of the Health Department's 1991-92 budget for non-government organisations was allotted to 'work and living skills' programs.<sup>79</sup>

The Schizophrenia Fellowships have commenced 'Clubhouse' programs (see Chapter 12 — Employment, for more detail); and several of the Richmond Fellowships have successfully piloted work and living skills services. Specialist organisations such as the Psychiatric Rehabilitation Association in Sydney and the Outer East Council for Developing Services for the Psychiatrically Disabled in Melbourne have provided work programs over many years.

Fewer NGOs offer outreach services aimed at assisting people at risk of mental disorder who resist formal treatment and support services. Nevertheless, there have been significant initiatives taken by a few organisations, such as the Macaulay Community Support Service operating in the inner urban area of Kensington in Melbourne; and the Richmond Fellowship of Victoria, which has initiated a pilot outreach service for young homeless women at risk of psychiatric illness and disability.

There is also less involvement by NGOs in the provision of independent case management or coordination. While the principles of case management seem well accepted — and the Inquiry received impressive evidence of the benefits of systematic planning and follow-up for the users of services<sup>80</sup> — there was limited evidence concerning the role of non-government services in this regard. Certainly, Australia does not seem to have many independent 'brokerage' services such as those developed in parts of North America.<sup>81</sup>

Clearly, there is not only an urgent need for more accommodation and support services, but there is also an opportunity for a broader range of services that might appropriately be managed in the community by non-government organisations.

Such services could include respite and emergency accommodation, both for individuals with mental illness needing a change of setting and for those caring for people with psychiatric disability in their own home; a significant expansion in early intervention and outreach services, seeking to prevent unnecessary and inappropriate readmission to hospital; employment services specifically geared to recognition of the episodic nature of much psychiatric disability; information and referral services that draw on a variety of community resources; and creative leisure and recreational programs.

## **Distribution**

It is particularly disturbing that there are so few non-government (or indeed government or private sector) services outside our capital cities. And the situation is worse if other major population centres are excluded.

This maldistribution was clearly illustrated in evidence given in places such as Cairns and Townsville, Port Lincoln, and Albany. During the Inquiry's Townsville hearings, for example, Mrs Margaret Herring, President of the Schizophrenia Fellowship of North Queensland, pointed to alarming imbalances in the availability of the whole range of community support services in metropolitan, provincial and rural centres of Queensland.

Resources are so lacking in North Queensland that significant numbers of people with schizophrenia are denied access to adequate care... Of the total of 290 psychiatrists in Queensland, 160 work in Brisbane. There are 46 between Brisbane and Mackay, there are 14 north of Mackay. North Queensland, therefore, with 17.6 percent of the population has 6 percent of the psychiatrists... As well as the staff placement in rural areas, there needs to be the necessary professional development and support to ensure continuity of service. On a recent visit to Innisfail one of our workers was horrified at the conditions for people with schizophrenia and their carers in that town... When [assistance] does occur it tends to centre on medication — with very little on-going support given as a general rule.<sup>82</sup>

Moreover, the distribution of services even within metropolitan areas is extremely uneven. Material provided to the Inquiry by the Victorian Community Managed Mental Health Services Inc exemplifies the concentration of acute treatment facilities in most States, and the consequent 'clustering' of non-government providers — which must have ready access to treatment and crisis intervention services.<sup>83</sup>

## **Examples of Effective Non-Government Services**

The activities and programs of a number of excellent non-government organisations (including ARAFMI and ARAFEMI; the Schizophrenia Fellowships; the Mental Health Associations; the Richmond Fellowships; the



Alzheimer's Association; Bromham Place Clubhouse; the After Care Association; the Manic Depressive support groups; PALA; The Post and Ante-Natal Depression Association (PanDa) and Christian communities such the Salvation Army, the Society of St Vincent de Paul, Emmanuel Centrecare in Perth and the Prahran City Mission in Melbourne) are mentioned elsewhere in this report. However, the following programs are briefly described at this point to give specific examples of a variety of effective non-government programs, often in areas which have been otherwise neglected.

*Charmian Clift Cottages (Outer Western Suburbs, Sydney)*

Charmian Clift Cottages in Sydney's western suburbs provide supported accommodation for women with a psychiatric disability and dependent children. It is one of the few crisis facilities in Australia which accepts women with children and is unique in the range of services it offers. Most importantly, programs allow women to interact with their children while receiving care and support from staff. The programs include personal development, parenting groups, child development, playgroups and a pre-schoolers' program.

The growing number of residents now living at Charmian Clift confirms the need for similar services 'to provide safe, secure, non-judgmental support whilst clients and their children regain the ability to overcome their fears, manage their illness and reside independently in the community.'<sup>84</sup>

*Macaulay Community Support Association (Inner Melbourne, Victoria)*

The Macaulay Community Support Service was established as a result of concerns by residents and a range of community and tenant groups in North and West Melbourne, Kensington and Flemington — a densely populated area with many residents accommodated in public housing. These concerns included the isolation and lack of support for people with psychiatric disabilities, together with the difficulties being experienced by their neighbours in high rise flats.

Macaulay provides an outreach service using community support workers who engage with people in the ordinary, everyday environment. Participants not only learn and practise community living skills in familiar surroundings, they also have the benefit of support through face-to-face contact with local officials (including Social Security or Housing department personnel), neighbours and local shopkeepers.

The Service began operations in 1987. Since that time it has been able to report substantial reductions in hospital admissions for those who had participated; major changes in the extent to which participants were engaged with local

community services important to their needs; and improvements in quality of life and personal satisfaction.<sup>85</sup>

#### *June O'Connor Centre (Perth)*

The June O'Connor Centre in Subiaco is the only drop-in centre in Perth. It offers support services and recreational activities to young people with a serious mental illness who live in the community.

People may attend as frequently or infrequently as they choose. Activities do not require daily or weekly attendance, and although participation is encouraged it is not mandatory.

Monthly attendance has exceeded 600 and referrals have had to be refused in order to deal with the number of clients. Ninety percent of people have a diagnosis of schizophrenia and all clients have follow up care at community health centres.<sup>86</sup>

#### *Outcare: Civil Rehabilitation Council of Western Australia*

Outcare provides a range of support services to offenders, ex-offenders, and their families. One important service is the provision of short-term accommodation to newly released prisoners. Increasingly, Outcare is dealing with mentally disordered offenders.<sup>87</sup>

Outcare emphasised in evidence to the Inquiry that all people released from prison without adequate support face the very real risk of reoffending. For those with psychiatric disabilities this risk is compounded not only by their health problems, but also by the lack of suitable community care.<sup>88</sup>

#### *The Outer East Council for Developing Services in Mental Health (Victoria)*

The Council services the outer eastern region of Melbourne (covering the areas of Nunawading, Ringwood, Croydon, Lilydale, Healesville, Upper Yarra, Sherbrook and Knox) and provides three main programs, Halcyon, Crest and Groundwork.<sup>89</sup>

**Halcyon**, situated in Ferntree Gully (an outer suburb of Melbourne), has become an accepted part of the community and is not seen as 'different'. Apart from a normal name plate at the front door there are no other signs to distinguish it from surrounding homes.

Programs focus on participants' personal development and cover the areas of stress management, confidence building and physical challenge. A computer training program is also provided.

About 20 people attend each day. They are expected to make a commitment to their personal program and each is allocated a worker with whom they can evaluate progress and discuss day to day problems.

**The Crest** supported accommodation project comprises four group homes, five two bedroom units and four single units. They accommodate 29 residents in the region, each with a project worker available from 9am to 5pm.

The houses in Bayswater, Croydon, Ringwood and Lilydale are suburban family homes, supplied by the Victorian Housing Department. Residents pay 20 percent of their pension towards rent and make a contribution toward living and household expenses. Each person has a program and together with the worker sets individual goals and regularly assesses progress.

**Groundwork** was established in 1989 as Australia's first specialist employment placement service for people with psychiatric disabilities. Groundwork provides a service for approximately 50 clients. The average waiting period for new clients seeking assistance is approximately nine months.

The project's success is demonstrated by the fact that in the six months up to February 1993, 26 clients had undertaken vocational training courses and 11 clients had secured employment. (Given the depressed labour market and the increased competition for positions, this is an impressive achievement.)

#### *Link-Up (Queensland and NSW)*

Link-Up is an Aboriginal organisation that works with Aboriginal adults who were separated from their families as children. These children were either institutionalised, fostered or adopted. Link-Up offers assistance to people who want to be re-united with their natural families and communities or who want to regain their Aboriginal identity.

For some clients, follow-up counselling has continued for many years. The process of recovery prior to and following the initial reunion lasts as long as Link-Up's clients need their services.<sup>90</sup>

### *Out Doors Incorporated (Victoria)*

Out Doors Inc is a Victorian community managed mental health service which provides a Statewide, outdoors-based rehabilitation program for people with mental illness.<sup>91</sup>

Out Doors manages a number of programs, most notably the Going Places outdoor adventure education project. Going Places works with 12 participants and 12 support people at a time. The program normally runs for four months and participants attend four days per week. They participate in a range of half and full day activities in the urban environment, as well as several five-day camps in bush and wilderness settings.

Going Places aims to provide an opportunity for people to develop a more positive self image, to practice social skills and gain new insight into their potential capabilities by participating in interesting, challenging and socially valued activities. Activities offered include bushwalking, camping, orienteering, environmental education, canoeing, rafting, abseiling, rockclimbing, caving and cross-country skiing.

### *Sandridge Program (Victoria)*

The Sandridge Program, run by the Richmond Fellowship Victoria, is an innovative service for homeless young people between the ages of 16 and 25. It aims to provide:

- a) a program which addresses a range of issues for young people who have experienced severe abuse or have been subject to some form of life trauma;
- b) early intervention in the lives of young people who have become inappropriately involved with the psychiatric system and to prevent chronic psychiatric disability developing.

After approximately 12 months, residents of Sandridge House can move into Sandridge Extension. This is a block of ten one-bedroom flats, supported by two workers and a live-in 'caretaker.' The emphasis is on supporting the young people in developing a satisfying lifestyle and future directions. Developing a sense of community between the members of the Extension is also seen as an important means of mutual support.

## *Schizophrenia Fellowships*

The Schizophrenia Fellowships throughout Australia aim to promote the welfare of schizophrenia sufferers, their friends and relatives.<sup>92</sup>

Originally established as self-help organisations where members (primarily relatives) offered each other information and support based on the sharing of experiences, the Fellowships now employ full-time and part-time staff and many volunteers in a wide range of programs. Schizophrenia Fellowships run a wide range of activities and provide extremely important support to their members. Although services vary from State to State, they include:

- Information and support services
- Rehabilitation programs
- Accommodation facilities
- Community education
- Advocacy and lobbying for improved legislation, treatment, hospital and community care and research.

## **Conclusion**

The Inquiry considers three points need to be made about non-government services for people affected by mental illness in order to place their contribution in context and in proportion to the needs they are addressing.

First, the effects of deinstitutionalisation and other recent policy changes mean that non-government organisations are being asked (and are attempting) to provide expanded services with extremely meagre (and in some cases dwindling) resources.

Second, the peak bodies of non-government organisations presented convincing evidence that their members are constantly asked to offer assistance to people who are regarded as 'non-treatable' within the public (Government) psychiatric system.

Third, State and Territory governments need to make a much greater effort to relate effectively with non-government services.

In particular, mental health services planning needs to take into account the important distinctions between:

(a) treatment and treatment-related services that are necessarily (in a medico-legal sense) going to be medically oriented — and which in a medical setting are necessarily addressing acute episodes;

(b) on-going care that is an extension of the treatment regime (and is analogous to palliative care);

(c) rehabilitation that is an extension of and related to treatment regimes;

(d) what are termed ‘psychosocial’ services that combine ‘asylum’ (transitional accommodation), rehabilitation/skills development and enhancement, and offer support, encouragement and confidence-building through a wide range of programs and activities.

There are further distinctions to be made between those services that are directed to the person with mental illness (primary); those that support relatives and carers who are themselves supporting people with mental illness (secondary); and tertiary services that foster better attitudes/improved access of people with mental illness (and their carers) to services they need.

Given the present poor status of mental health services throughout Australia, State and national mental health plans must urgently undertake:

(a) to substantially increase resources allocated to primary, secondary and tertiary non-government services;

(b) within these allocations, to ensure that there is a substantial increase of currently available ‘places’ (whether residential, day, or home support);and

(c) to substantially improve access to non-psychiatric government programs and services, such as HACC, Housing Agreements, SAAP etc, under which non-government bodies can improve their provision of services to people with mental illness and their carers.

1. Extract from an article by Dr Norman James, former President of the Royal Australian and New Zealand College of Psychiatrists, quoted in 'Don't crack up in public', *The Bulletin* Aug 3, 1993, p30.
2. The population of psychiatric inpatients in Australia has declined from 281 beds per 100,000 in the early 1960s to 40 beds per 100,000 in 1992 — an 86 percent reduction.
3. National Health Strategy, *Help Where Help is Needed: Continuity of Care for People with Chronic Mental Illness*, Issues Paper No5, AGPS, Canberra 1993, p22.
4. *ibid*, p46.
5. Figures provided to the Inquiry by officials of the Victorian Department of Health and Community Services suggest that approximately 5 percent (\$400,000 out of \$7.8 million) was allocated last financial year as CSDA 'transitional funding', for the enhancement of existing psychiatric services. However, some 28 percent (\$750,000 of \$2.7 million) has been nominated as 'growth' funding, for services expansion to meet identified needs. Current projections are that at the end of the three-year period, about 10 percent of total CSDA funding in Victoria will be allocated to psychiatric disability services.
6. *Help Where Help is Needed*, *op cit*, p46.
7. 'The ambit of the Plan does not include matters more properly covered by existing Commonwealth/State arrangements/Agreements, such as the Commonwealth/State Disability Agreement and the Commonwealth/State Housing Agreement. It is noted that both these agreements have responsibility for providing non-discriminatory services to the community, including people who have a mental disorder or mental health problem.' Australian Health Ministers' Conference, *National Mental Health Plan*, AGPS, Canberra 1992, p5.
8. *ibid*, p22.
9. The remaining 1.5 percent was allocated to administration expenses for bodies such as Review Tribunals etc.
10. Adapted from the NSW Mental Health Services Strategic Plan, *Leading the Way: A Framework for Mental Health Services 1991-2001*, NSW Health Department, 1992. Other analyses studied by the Inquiry include those from the Office of Psychiatric Services, Victoria; the Area Integrated Services Standards Project in NSW (also see Chapter 9 — Community Care and Treatment); the Australian National Association of Mental Health; and the Australian Psychiatric Disability Coalition (formerly the National Coalition of Mental Health and Psychiatric Disability Groups). Reference is made elsewhere in the report to Prof G Andrews' findings in *The Tolkien Report: A Description of a Model Mental Health Service*, Sydney 1991, which offers a slightly different perspective.
11. According to this model, there should be ten mobile community health workers per 200,000 population. (Current numbers fall far short of this.)
12. A minimum of 20 beds per 200,000 population.
13. M J Pavone, Australian Catholic Health Care Association, Victoria. Submission.
14. John O'Neill, Administrator, Lakeside Hospital, Ballarat. Oral evidence, Ballarat 11.4.91, p547.
15. Prof Vaughan Carr, Department of Psychiatry, University of Newcastle. Submission, p3.
16. *id*.
17. Dr David Lord, consultant psychiatrist, Fremantle Hospital and representative, WA Branch, RANZCP. Oral evidence, Perth 11.2.92, p137.
18. 'Thus reducing awareness of the person's total wellbeing and the need to establish [a concept of health] that incorporates social, vocational and leisure aspects.' Lisa Brophy,

Association of Mental Health Social Workers, Victoria. Submission, p3. This subject is also considered at greater length in Chapter 9 – Community Care and Treatment.

19. id.
20. Marcia Fawdry and Julie Roach, Tasmanian Community Health Association. Submission, p2.
21. See Chapter 6 – The Role and Training of Health Professionals and Others.
22. Prof Gavin Andrews, Professor of Psychiatry, University of NSW and Director of Health Services Research Group, Clinical Research Unit for Anxiety Disorders, St Vincents Hospital. Oral evidence, Sydney 17.6.91, pp46,47.
23. *National Mental Health Policy*, op cit, p20.
24. Including *Leading the Way: A Framework for NSW Mental Health Services 1991-2001*, op cit, and Office of Psychiatric Services, *Policy and Strategic Directions for Public Psychiatric Services in Victoria*, Melbourne, 1992.
25. See, for example, Dr John Hoult, Director of Clinical Psychiatry, Glebe Community Care, NSW. Oral evidence, Sydney 20.6.91, p408.
26. O'Neill, op cit, p544: 'We need to increase the number of psychiatric nurses working in the community [so] we can provide day hospitals, day care, long-term hostels and a range of services to enable our former patients to live with some dignity in the community.'
27. ibid, p540, 'There is no process...whereby we can facilitate the transfer of staff...to other areas.'
28. Andrews, op cit.
29. ibid, p50. See also O'Neill, op cit, concerning resistance to reforms in Victoria.
30. Prof Graham Burrows, Chairman of the Mental Health Foundation of Australia. Oral evidence, Melbourne 9.4.91, p233.
31. Evidence on this point was given by a series of witnesses at Inquiry hearings in Cairns, Townsville, Albany and Port Lincoln.
32. James, op cit, p30
33. The study, conducted in Massachusetts, concluded that the number of long term beds required was approximately 150 per one million people (ie approximately 2,550 beds would be required for Australia's population of 17 million). The categories of individuals requiring such intensive institutional care were:

	Beds per 1,000,000
The elderly	30
The intellectually disadvantaged	30
Those with acquired brain damage	15
The psychotic and assaultive	25
The chronic psychotic, disruptive and endangered	50
	<b>150 Total</b>

Andrews, op cit (p2), contends that we need 10 long stay and 15 acute beds per 100,000.

34. *National Mental Health Policy*, op cit, p24.



35. Dr David Wells, Head of the Office of Forensic Medicine, Victoria. Oral evidence, Ballarat 11.4.91, pp595-596.
36. Also see Chapter 6 — The Role and Training of Health Professionals and Others, which cites the findings of a survey which indicates that psychiatrists see 77 percent of their clients in private practice and 23 percent in the public sector.
37. Information from *Help Where Help is Needed*, op cit, pp103-104. Also see Chapter 6 — The Role and Training of Health Professionals and Others.
38. Dr Jonathan Phillips, Director of Postgraduate Training, RANZCP, quoted in 'Don't crack up in public,' *The Bulletin*, Aug 3, 1993, p31.
39. See previous section on Government Services.
40. Elizabeth Bleby, social worker, Guardianship Board of South Australia. Submission, p6.
41. Robin Gurr, President, Council of Social Service of NSW. Submission, p6.
42. *Help Where Help is Needed*, op cit, pp106-107.
43. Win Leslie, carer. Oral evidence, Ballarat 11.4.91, p627.
44. *Help Where Help is Needed*, op cit, p107.
45. *ibid*, pp107-108.
46. NSW Health Department, *Leading the Way: A Framework for NSW Mental Health Services 1991-2001*, Sydney, 1991, p26.
47. Correspondence to the Inquiry from Dr Sandra Hacker, psychiatrist in private practice.
48. Information provided to the Inquiry by Dr Bill Pring, representing the Section of Psychiatry, Australian Medical Association, Victoria.
49. Various aspects of this issue are discussed in Chapter 6 — The Role and Training of Health Professionals and Others, and Chapter 9 — Community Care and Treatment.
50. From 'Joannie's Story' — information provided to the Inquiry by the GROW association. The Inquiry heard from members and representatives of GROW at its Sydney and Darwin hearings.
51. P Eisen and K Wolfenden, *A National Mental Health Services Policy: Report of the Consultancy to Advise Commonwealth, State and Territory Health Ministers*, Department of Health, Housing and Community Services, AGPS, Canberra 1988.
52. There are exceptions (such as the After Care Association of NSW, founded in 1907). However, the Victorian Community Managed Mental Health Services Inc (VICSERV), for instance, states that 'non-government organisations have been providing services and support to people with psychiatric disabilities in Victoria, and their carers, for over 25 years.' (From 'The Non-Government Psychiatric Disabilities Sector: Strategies for the Future', in *New Paradigm*, VICSERV Newsletter, Sept 1992, pp11-18.) This contrasts with general welfare services, where non-government organisations have been the major providers for well over a century.
53. The term 'rehabilitation' has many applications in the psychiatric services field. For community managed organisations, it refers to a wide range of programs with 'psychosocial' objectives, ranging from basic living skills through to complex independent living goals. In the public psychiatric system, it is likely to relate to the immediate post-acute phase of a treatment plan.
54. The nature of psychiatric conditions is such that the distinctions are far more blurred than in, say, the physical and sensory disability areas.

55. 'These links are long-standing, and form part of an informal, integrated network with mainstream community health and generic community support services.' Submission by VICSERV relating to the report of the National Mental Health Task Force, January 1992.
56. 'The Non-Government Psychiatric Disabilities Sector: Strategies for the Future', op cit.
57. From material provided to the Inquiry by The Richmond Fellowship of Victoria, July 1992. An extended analysis of the characteristics and benefits of non-government community managed services is provided in the VICSERV paper quoted above.
58. These concepts owe a great deal to work undertaken over many years by Wolf Wolfensberger, initially focussing on the integration of people with intellectual disability into the general community. (A 1989 booklet produced by the Research and Advocacy Unit of Wesley Central Mission in Melbourne, *Changing Lives, Changing Communities*, is a useful introduction for those interested in the principles of social role valorisation).
59. Submission by VICSERV relating to the report of the National Mental Health Task Force, January 1992.
60. As indicated elsewhere in this report, many NGOs provide a combination of these services.
61. Formerly the National Coalition of Mental Health and Psychiatric Disability Groups.
62. The point should be made that reliance on external funding can affect an organisation's effectiveness as an independent lobbyist or watchdog. See, for example, Liz Dalston, Director of the Mental Health Association Resource Centre. Oral evidence, Adelaide 22.10.91, p165.
63. *Leading the Way*, op cit, p26 and Appendix G.
64. Note, however, that employment services remain the direct funding responsibility of the Commonwealth.
65. There are exceptions. Representatives of the Victorian Mental Illness Awareness Council, then representing 32 consumer self-help and advocacy groups across the State, whilst vehemently opposed to the labelling of people with psychiatric illness, were relaxed about use of the term 'patient' and indicated that many of their members preferred this to 'consumer' or 'client'. Oral evidence, Melbourne 9.4.91, p271.
66. The Australian Psychiatric Disability Coalition Inc has informally estimated that such assistance could amount to the equivalent of a 10 percent increase in the budget of most government-funded non-government organisations.
67. Hoult, op cit, p408.
68. 'The Non-Government Psychiatric Disabilities Sector: Strategies for the Future', op cit. This figure of course refers only to not-for-profit services. Profit-oriented mental health and psychiatric services are 'subsidised' through the public purse only in regard to Medicare health benefits.
69. Office of Psychiatric Services, *Minimum Data Set Summary Report*, op cit; and *Policy and Strategic Directions for Public Psychiatric Services in Victoria*, January, 1992.
70. *Help Where Help is Needed*, op cit, p78.
71. NSW Health Department, *Annual Report 1991-92*, Sydney 1992, pp65,143.
72. Joy Said, Executive Director, After Care Association of NSW. Oral evidence, Sydney 17.6.91, p33.
73. Chris Pollard, Oasis Community Centre, Hobart. Oral evidence, Hobart 11.11.91, p124.
74. Dalston, op cit, p165.
75. It is assumed that this figure includes funding of what in some States are known as 'transitional residential rehabilitation services'. *Leading the Way*, op cit, Appendix G, p65.

76. Office of Psychiatric Services, Victorian Department of Health and Community Services, *Non-Government Services Minimum Data Set Summary Report: Draft Version for Non-Government Workshops*, Oct 1992, p8.
77. *Leading the Way*, op cit, Appendix G, p65.
78. *Minimum Data Set Summary Report*, op cit, p8.
79. *Leading the Way*, op cit.
80. The *Project Focus* program of the Office of Psychiatric Services in Victoria has thoroughly documented both the principles and practice of case management in the public psychiatric services system, and has recently worked with non-government organisations to extend its analysis. See Office of Psychiatric Services, Victorian Department of Health and Community Services, *Project Focus — Manual for Psychiatric Services in Victoria*, Melbourne 1992.
81. The Independent Living Foundation of Vancouver and several services in Wisconsin are examples. The Inquiry is also aware of a number of Commonwealth Government pilot projects which are trialling a brokerage model of community care for people with dementia.
82. Margaret Herring, President, Schizophrenia Fellowship of North Queensland. Oral evidence, Townsville 12.8.91, p1244.
83. 'The Non-Government Psychiatric Disabilities Sector: Strategies for the Future', op cit.
84. Nan Allen, Chairperson, in the *Charmian Clift Cottages Fifth Annual Report, 1990-91*.
85. Information provided by Mary Wynne, Chairperson of the Macaulay Community Support Association, in her submission to the Inquiry.
86. Information provided to the Inquiry by Anne Parker, Coordinator, June O'Connor Centre, Perth.
87. For an explanation of the increasing demands in this area, see Chapter 25 — Forensic Patients and Prisoners
88. Information from a submission made by Marion Leach, Manager Support Services, Outcare, Western Australia.
89. Information from a submission made by Maurice Mead, Executive Director, The Outer East Council For Developing Services in Mental Health, Victoria.
90. From a submission by Carol Kendall, Coordinator, Link-Up, NSW.
91. Information provided to the Inquiry by Vic Issell, Coordinator, Going Places Project, Out Doors Inc, Victoria. Submission, pp1-2.
92. Rosemary Webster, President, Schizophrenia Fellowship of Victoria. Submission, pp1-3.

## Chapter 6

# THE ROLE AND TRAINING OF HEALTH PROFESSIONALS AND OTHERS

As part of my job as Senior Clinician within a hospital, at any one week, I'm on duty for seven days and on call for 24 hours. Each of my colleagues tells me at the end of a seven-week period that they have usually written out their resignation two or three times because of the frustration that they have experienced. And the frustration largely relates to resource problems. It is a terrible business to be on the receiving end of these calls for help and not to be able to respond; to be juggling for a catchment area of half a million people, with 160 beds, and have only one or two beds available, if you're lucky, on each day. That's an extraordinarily frustrating experience...it is not what we were trained for and most of my colleagues say... 'I'm not going to put up with this for much longer'.<sup>1</sup>

## The Views of Health Professionals

### Psychiatrists

The quality of psychiatric treatment and care has an enormous impact on the welfare of many individuals affected by mental illness — and the profession, until recently arguably among the most complacent, has been getting the message.

Psychiatric treatment available to people should be of a high standard. In this regard the Royal Australian and New Zealand College of Psychiatrists has recently expanded its structure to include a Board of Practice Standards which embraces the issues of quality assurance and peer review, and is involved in contributing to the maintenance of adequate standards and public confidence in these standards.<sup>2</sup>

Witnesses and submissions to the Inquiry expressed concern, however, that no formal national mechanism for the regulation and maintenance of standards of psychiatric care currently exists.

To my knowledge, I am the most isolated psychiatrist in the world... In the past 4½ years, neither the Health Department nor the College have ever lifted a finger to audit my performance... As regional psychiatric services spread, this will become more of a problem... At my first branch meeting as a member of the College (February 1978) I proposed that members should be re-examined every seven years or so as a means to maintaining standards. Since then, the College has fiddled around with various peer review or continuing education schemes but these have mostly been insipid and non-threatening. Patients deserve a guarantee that their psychiatrist has not just passed his Fellowship, but is actively continuing his education.<sup>3</sup>

This lack of self-regulation is due, in part, to the lack of regulatory powers enjoyed by the Royal Australian and New Zealand College of Psychiatrists. While the profession has made attempts to address the issues of psychiatric standards, quality of care and professional conduct,<sup>4</sup> evidence to the Inquiry repeatedly emphasised that these issues need to be clearly articulated, reflected in appropriately defined standards and enforced in a nationally uniform fashion.<sup>5</sup>

One might well deduce that you can't trust the medical profession...to regulate itself, not because they are intrinsically wicked but because...the medical profession has no power. Unlike the law, where lawyers conduct their own inquiries into themselves and have the power to regulate, the Royal Colleges...or the Australian Medical Association...really can't do anything except approach statutory bodies and ask them to do something — and if they do nothing, nothing is done.<sup>6</sup>

The Inquiry heard many allegations — including several concerning the conduct of certain psychiatrists employed on behalf of insurance companies. It was alleged some psychiatrists were used by insurance companies to intimidate compensation claimants:

The doctors used by insurance companies have been picked out...for their hard line against compensation claimers and many patients have complained to me about the brutal manner (in which they have been treated)... A code of conduct for medico-legal examinations should be instituted... Some psychiatrists were quite upset at my...suggestions that...they were in fact abusing and mistreating patients in doing legal reports. They felt that it was their job to take an adversarial approach and in fact carry out what is virtually an inquisition into the patient... Their attitude was that unless the patient was distressed or upset they weren't likely to obtain the truth in the consultation. This of course is to the detriment, in my opinion, of the patient's mental health and is quite unethical.<sup>7</sup>

Other issues also concerned members of the profession or had a significant impact on their perception of themselves or their professional roles.

The relatively recent transition from hospital-based treatment and care to community-based care has substantially altered the traditional role and functions of mental health professionals. Witnesses and submissions to the Inquiry indicated that working in a multidisciplinary community-based environment has caused, and still causes, certain psychiatrists some confusion and disquiet. Other mental health professionals can and do perform many of the functions that were, formerly, exclusively the domain of psychiatrists.

I'm a great believer in the multidisciplinary therapeutic team and I think that there are few areas in which only one branch of the mental health professions must [work] in isolation... For example, a psychiatrist might happen to be very good at psychotherapy, but in my opinion, that can often be done by psychologists or a psychiatric nurse if they're interested and skilled in that area. I think leadership is another issue. It usually ends up that psychiatrists are the people in

charge of multidisciplinary teams. I personally think that the person who has leadership qualities should be utilised, whether they're a psychiatrist or whether they are a social worker, psychologist or what have you.<sup>8</sup>

Because psychiatrists now treat the majority of patients in the community rather than in hospital,<sup>9</sup> it is necessary to clarify the community treatment role and functions not only of psychiatrists but also other mental health professionals. Some psychiatrists are concerned about the lack of clear career structures and financial incentives:

The problem is the lack of rewards inherent in such a system, for in the absence of any career structure that provides for rapid occupational advancement in return for expert service, there is little inducement for skilled personnel to work hard in a community service.<sup>10</sup>

In addition, evidence to the Inquiry suggested that the role of psychiatrists in supporting professional caregivers in community-based care is not adequately recognised in the structure of Medicare rebates.

[Professional] caregivers and community groups need to be supported in their role to attempt to minimise the impact that mental illness has on the individual's family and the community. In each case Medicare funding for psychiatric consultations with support givers is only available for a limited number of consultations. In the treatment of individual patients consideration must therefore be given to the value of providing consultations to those affected by the mentally ill and to more appropriate funding of such consultations.<sup>11</sup>

The Inquiry also heard that there has been a steady (and in some States, such as South Australia, alarmingly rapid) movement of psychiatrists from the public sector to private practice.<sup>12</sup> Poor financial rewards and lower job satisfaction in public sector employment were often cited by psychiatrists as the main reasons for this disturbing trend.

Psychiatrists in the public sector obviously make a number of sacrifices to stay there, not the least working with the frustration of under-serviced and stigmatised systems which are over-bureaucratized with patients with the most severe and often intractable disorders... The financial disparities of course, are also an issue... [Psychiatrists work in the public sector] because they have, I believe, a commitment, at times even a passion, for the rights of the mentally ill.<sup>13</sup>

The Honorary Secretary of the Royal Australian and New Zealand College of Psychiatrists suggested that to entice psychiatrists back to the public sector, their role needs to be reviewed and clarified.

The role of the psychiatrist in the process of psychiatric treatment within the public sector is no longer clear and is constantly being challenged... To restore adequate participation of psychiatrists in Australian public psychiatric facilities a review of the role of the psychiatrist in those facilities is required, ensuring that there is sufficient job satisfaction, adequate financial incentives, etc.<sup>14</sup>

Evidence to the Inquiry clearly indicated that the recent movement of significant numbers of psychiatrists from the public to the private sector has restricted the access of many Australians affected by mental illness to effective psychiatric management — due to the substantially greater costs of private treatment. (Also see Chapter 5 — Mental Health Services, concerning the role of the private sector in the treatment of mental illness.)

In view of dramatic changes in the distribution of psychiatrists (and to a lesser extent ancillary services) from the public to private sector, and the resultant decline of public psychiatric facilities in Australia, many of the chronically mentally ill have minimal access to psychiatric management.<sup>15</sup>

From the perspective of professional responsibilities and training, this shortage of psychiatrists in the public sector places additional burdens on mental health facilities and quite unreasonable demands on staff.

The shortage of psychiatrists in the public sector [makes it difficult to] provide for leave relief, both recreational and study and conference leave, as well as increasing pressure on the on-call roster. The College of Psychiatrists has also expressed concern at the lack of opportunities for ongoing education for psychiatrists, due to their inability to take leave easily.<sup>16</sup>

A recent survey of psychiatrists illustrates the extent of this movement and the impact it has had on the role and functions of psychiatrists. The survey was conducted to determine whom psychiatrists saw and what treatments they carried out.<sup>17</sup> With regard to patient consultations, 77 percent of patients were seen in private practice. Only 23 percent were attended to in the public sector.

Evidence also confirmed what was obvious throughout the Inquiry — that public sector patients suffered from more serious mental illnesses than the private sector patients.<sup>18</sup> Approximately 60 percent of patients seen in private practice suffered from a neurosis or personality disorder. (Only a quarter of the public sector patients received one of these diagnoses.)<sup>19</sup>

Patients in the public sector were also twice as likely to be prescribed drugs — especially anti-psychotic medication — whereas private sector patients were twice as likely to be in psychotherapy.

Private patients were seen twice as often and were expected to receive two and a half times as many consultation hours as patients in the public sector.

If one estimates the number of patients in care and not the number of consultations, then a psychiatrist's case load in terms of diagnoses is 40 percent psychoses, 40 percent neuroses, 6 percent personality disorders and 6 percent children's disorders reflecting both the prevalence of these disorders in the community and their perceived seriousness.<sup>20</sup>

The Inquiry heard that some psychiatrists (in spite of their extensive training at public expense) have abandoned both the public sector and the treatment of patients with serious mental illness. One professional witness suggested<sup>21</sup> that if many psychiatrists do not wish to work with these patients within the public sector, then psychologists and psychiatric nurses who are prepared to do so should be given special training and allowed to prescribe psychiatric medication.

The Inquiry also heard that the separation of mental health care funding from the overall health system has an adverse impact on mental health professionals — in that it contributes to their marginalisation and to professional isolation and alienation.<sup>22</sup>

[There are] difficulties inherent in having different funding systems for psychiatric services and general health services in Australia. Such differentiation results in alienation of psychiatry from the mainstream of medicine and medical specialities, and contributes further to alienation of the mentally ill from the community at large. Consideration should be given to the appropriateness of providing adequate and equitable funding for psychiatric services, under the same Commonwealth/State arrangement as for other public health facilities.<sup>23</sup>

## Nurses

The comfort, health, and recovery of the patients depend, in a great measure, upon the manner in which...nurses perform their duties, and it is a great mistake to suppose that these duties are of a light or easy character, or can be performed in a routine manner. They are of an anxious and responsible nature; [need] to be carefully learned; are frequently irksome and disagreeable; and demand almost unceasing activity and vigilance.<sup>24</sup>

Nursing requires extensive training, an understanding of human development and behaviour, diagnostic skills and therapeutic techniques. Nurses often work closely with clients and their families to achieve the best possible results. The role of nurses working within the mental health sector is fundamental in nurturing and caring for individuals affected by mental illness.

- When people are unable to take care of their most basic needs, [nurses] take up the slack, and encourage, model and support new behaviours.<sup>25</sup>

- I try to help people gain insight into their illness: insight into why they are here and some acceptance of it. I try to encourage people to ask questions about their treatment and to look at goals for the future, perhaps to think about independence and maybe prevention and not coming back here again.<sup>26</sup>

- I encourage people to be realistic... I [also] try to encourage them to learn what they need to do to manage their disability... I like people to reflect on the things they've done and realise that past behaviour has been inappropriate and point out the unrealistic [nature] of their behaviour and perhaps of their paranoia. The whole game is about empowering.<sup>27</sup>



In caring for those affected by mental illness, nurses require effective communication skills. Indeed, their particular insights can often result in more appropriate treatment options for people with mental illness.

Nurses...perform the role of liaison, openly communicating their clinical observations, treatment plans and feelings. This is done in informal discussions, and team meetings, to gain and give feedback... A policy of frank discussion between staff members develops self-awareness in the staff and...enhances the chances that staff will be more realistic, optimistic and creative in management style.<sup>28</sup>

Nurses believe they can also play an important role as educators — as an informal and accessible source of information for people affected by mental illness and their families. They can provide details on an individual's illness, the prescribed medication and its effects, and government and non-government community assistance programs.

As the client moves towards discharge the nurse will need to assume the role of educator. Of particular importance for inpatients and their families, is education about the medical aspects of their problems... Patients can, with education, understand and give meaning to past behaviours and present difficulties. By educating clients about the medications prescribed to them, their wanted and other effects, clients can be involved in their treatment and give valuable feedback... Clients can also benefit from learning what they need to do for themselves in terms of financial assistance, accommodation, leisure and meaningful activity, and what resources exist in the community to help them.<sup>29</sup>

The working environment can have an important impact on mental health nurses' roles and the discharge of their responsibilities. The Inquiry heard that the use of a formalised medical model in mental health settings can make it difficult to foster a sense of independence in patients.

At times and in some places there is a disturbing tendency to treat patients with little regard to their dignity and respect... I feel that [this] occurs because of a resurgence of the medical model which means that the doctor is in charge, the 'patient' is 'sick', and the nurses do work which arises out of doctors' work. This model is extremely problematic in the mental health setting. Firstly it concentrates control and responsibility in the role of 'Doctor'. This in turn denies the patient an opportunity to take some responsibility for their own behaviour and to explore their own solutions to the problems they experience, as they must remain in the sick role. All of this negates or makes unnecessary the varied role of the specialist mental health nurse, whose role is designed to facilitate as much independence in the client as possible.<sup>30</sup>

In addition, evidence indicated that management structures which support this traditional medical model may impede the development of wider roles for nurses.

Within a hierarchically arranged structure where those professionals with the greatest power are also seen to be those with the greatest therapeutic contribution, the nurse's role can become compressed and distorted, so that 'doing to' is all that is tolerated and 'doing with' is viewed

as insubordination... The result can be a custodial style of care where nurses are seen as the keepers of the keys and guardians of the cigarettes, and therapeutic relationships may be little more than a barter system of favours.<sup>31</sup>

The level of staffing in mental health facilities clearly affects the role of health professionals and the quality of care and treatment. Witnesses and submissions to the Inquiry stressed that as nurses are at the 'front line' of providing health services to those affected by mental illness, adequate staffing levels are fundamental in ensuring appropriate care. Concern was expressed, however, that in many health services, nurse staffing levels were inadequate.

Things which stop us from being effective are poor staffing levels; staff are very busy during the day. We think that mingling with the patients is very important but this is not always possible. We are not always available to do this because of our other duties, mainly admin work.<sup>32</sup>

The Australian Nursing Federation emphasised the importance of staffing levels and the impact on quality of care of the additional administrative and ancillary functions that nurses are frequently expected to perform.

In contrast to general health services, there have not, to our knowledge, been attempts to establish optimum staffing levels and skills mix in the mental health services... Staffing has therefore been a matter largely based on a rule-of-thumb and subject to cost constraint. To be blunt, the resulting skill mix is usually the least that can be got away with, without causing actual harm.<sup>33</sup>

Non-nurse ward staffing levels (for so-called 'hotel services') will vary widely in institutions. Where an independence model of care is in place, bed-making and housework will be functions carried out by patients themselves... The degree to which clerical work is performed by nursing staff is also difficult to quantify. However, in both cases, it is clear that the requirement by employers for nursing staff to provide services which are clearly not nursing activities must influence the quantity and quality of nursing care.<sup>34</sup>

Evidence to the Inquiry generally indicated that work environments which do not sufficiently recognise or value the contribution of nurses to the delivery of an effective system of mental health care, promote poor work practices and undermine standards of care. In addition, the evidence suggested that in such working environments the potential for exploitation and abuse is increased.

Where the model of care is such that nurses act as therapeutic agents, successful interaction with clients will be influenced by constant interruptions to attend to telephones, serving of meals and similar tasks... Research undertaken in the general health system, for instance, demonstrates the increased risk of nurses making medication errors if they are interrupted on 'medication round' to attend to other work.<sup>35</sup>

Systems which employ nurses who are disempowered, poorly educated, or out of date, where systematic reflection on nursing practice is not valued, are setting the parameters which breed poor practice.<sup>36</sup>

## **Psychologists**

It was clear throughout the Inquiry that the general public has little understanding of the various roles of psychologists and is confused about the distinction between functions performed by psychologists and those performed by psychiatrists.

In general, the community at large is ill-informed and confused in relation to the role played by psychologists and the responsibility for this must rest, largely, with the psychological profession, as well as the existing myths surrounding and stigma attached to 'mental illness'. Certainly, there is an overlap in the various roles of health professional groupings leading to some confusion amongst themselves, and competition amongst these groupings has, both in the past and currently, led to psychologists' skills being under-utilised and overlooked.<sup>37</sup>

The Inquiry heard that appropriately trained psychologists are equipped to contribute to the treatment of individuals with mental health problems by providing assessments of the degree and type of cognitive and functional deficits, by minimising the effects of mental illness through early intervention programs and by assisting individuals back into the community and into employment through counselling and therapy.<sup>38</sup>

Psychologists can provide three main intervention services to affected individuals and their families — assessment; therapy and counselling; and skills training.<sup>39</sup> Described alternatively:

Psychologists...contribute to mental health...at three levels:

- (i) Primary — a preventative role through identifying of those at risk and high risk situations;
- (ii) Secondary — minimising the effects of mental problems by early recognition and intervention; and
- (iii) Tertiary — providing rehabilitation of those affected.<sup>40</sup>

Psychological assessment can assist individuals affected by mental illness by identifying problem areas directly and indirectly associated with their illness — thus assisting development of the most effective intervention programs and maximising opportunities for reintegration into the community. Services can include neuropsychological testing; vocational testing, guidance and counselling; diagnostic assessment (intellectual, psychological and vocational); and educational testing and guidance.

Therapy and counselling services which may assist people affected by mental illness and their families in dealing with the effects of the illness include

personal counselling; psychotherapy; hypnotherapy; marital counselling; and family therapy.

Skills training can assist by changing inappropriate patterns of behaviour; by helping individuals to approach situations differently; and by restructuring their learning patterns and teaching them more effective ways of coping. Psychological skills training services can include communication and social skills; assertiveness training; stress management; developing self esteem and motivation.

Psychological interventions include programs to develop personal skills.<sup>41</sup>

The psychologist's intervention technique is distinguished by providing people affected by mental illness with new skills and strategies... The emphasis of such intervention is on the long-term change of inappropriate patterns of behaviour.<sup>42</sup>

The development of psychology as a discipline and as a profession has seen the emergence of major specialisations, including clinical psychology, neuropsychology and counselling psychology — together with a number of specialist subdisciplines.

These specialist subdisciplines include health, community, industrial, organisational, educational, forensic, social and experimental psychology. While some of these are more concerned with research and others with its application their common element is the desire to gain a better understanding of the complexities of mental processes and behaviour.<sup>43</sup>

The specialisations of clinical psychology and counselling psychology are particularly relevant to the treatment of people with psychiatric disabilities. (Clinical psychology originated largely in the older psychiatric hospitals or clinics and counselling psychology emerged primarily from educational settings.)<sup>44</sup> Practitioners of both these specialisations offer mental health services and often work closely with other mental health professionals, especially psychiatrists and psychiatric social workers, in multidisciplinary teams.

Clinical psychologists are equipped to provide treatment interventions for addictive behaviours, psychosomatic illnesses, anxiety disorders including various phobias, depression, obsessive-compulsive disorders, eating disorders, post-traumatic stress disorders and clinical stress management. These lists are not exhaustive...[but only] providing examples which illustrate the potential contribution that psychologists may make in the treatment of the mentally ill...

Because of their specialised understanding of human behaviour and the brain-behaviour relationship...clinical psychologists and clinical neuropsychologists are ideally equipped to provide support services to brain-impaired patients (including the dementias) and their family and carers. This support can include not only didactic contributions but also the implementation of rehabilitation programs as part of a health care team.<sup>45</sup>

In analysing the contribution psychologists can make in the treatment of individuals affected by mental illness, witnesses emphasised the distinction between 'psychologists' generally and 'clinical psychologists'. The training of clinical psychologists enables them to play a substantially more specialised treatment role.

'Psychologists' and 'clinical psychologists' should be distinctly defined... Clinical psychologists have distinctive skills.<sup>46</sup>

'Clinical psychologists' possess diagnostic and treatment skills on the same footing as psychiatrists, except that psychologists cannot prescribe [medication]... Clinical psychologists can often more accurately measure function, point to origins and set about assessment and treatment with patient participation... As such, clinical psychologists should take key roles in clinical and administrative structure and policy-making.<sup>47</sup>

The Inquiry heard, however, from both psychiatrists and psychologists, that clinical psychologists are under-utilised in our mental health care system.

My view is that the number of clinical psychologists working in mental health services [is insufficient]... Our best estimate is that they have about three staff per 100,000 population... We should double that... If you look overseas they are double that number.<sup>48</sup>

The Australian Psychological Society believes that financial constraints operating in both the private and public sectors have led to the under-utilisation of psychologists and other mental health professionals in the prevention, identification and recognition of mental illness, and in interventions to minimise the effects of mental illness, as well as assistance in the rehabilitation of mentally ill persons... The basic rights of mentally ill people to proper care, treatment and rehabilitation are not being met. Resource constraints and structural and cultural barriers exist which inhibit the provision of vital services.<sup>49</sup>

But the number of psychologists available in the mental health system is only one of several problems.

Evidence to the Inquiry highlighted the fact that the role and accessibility of psychologists in the treatment of people with mental illness is seriously limited by distinctions in the health insurance system. Witnesses agreed that psychologists generally charge between \$80 and \$120 an hour and psychiatrists generally charge an average of \$150 an hour for consultations. But rebates under Medicare are provided only for psychiatrists' fees. Services provided by psychologists and other qualified practitioners who are not doctors (such as marriage guidance counsellors and family therapists) receive no rebates from Medicare and few rebates from private funds.

Services by clinical psychologists and clinical neuropsychologists are not rebatable through Medicare. Therefore access to these services is confined to those with top of the range private health cover or to those receiving hospital treatment.<sup>50</sup>

There is limited access to psychological treatment through the public health system. Access to privately practicing clinical psychologists is restricted by cost, the only financial support coming through private health insurance. This is usually beyond the means of those on sickness benefits or invalid pensions. There is no Medicare cover for psychologists, as there is for psychiatrists and other doctors.<sup>51</sup>

Given consultation costs, the distinctions in Medicare rebates and the costs associated with 'full cover' private health insurance, the majority of individuals affected by mental illness (many of whom are poor)<sup>52</sup> have extremely restricted access to psychological services.

This [distinction]...renders psychological services from private practitioners largely unavailable to both the general public and the disabled... The growing health costs in Australia and the increase in mental illness will be exacerbated unless there is full utilisation of available resources.<sup>53</sup>

Most mentally ill people, whatever their needs or wishes, do not have access to clinical psychologists or other psychologists. In order to give them their right to proper care, they need this access. There needs to be some form of financial support for the mentally ill to obtain psychological treatment. Where this is the appropriate treatment, costs should be covered similarly to Medicare coverage of psychiatric care. Access to appropriate care is both a human right, and ultimately a social benefit in terms of reduced disability and improved capacity to cope for those suffering mental illness.<sup>54</sup>

It is clear from evidence presented to the Inquiry that the restriction of access to psychologists results in important treatment options being denied to many individuals affected by mental illness. Perhaps even more importantly, preventive counselling and effective rehabilitation opportunities are being squandered.

We are constantly placed in a position where we have people who want to come, or continue coming to us for therapy, but can't afford to do so... The fact is that many highly qualified professionals, such as solicitors and general practitioners are faced with a dilemma when needing to refer a client for psychological assistance or counselling. Under the present system, unless the client is wealthy...many feel obliged to refer to a psychiatrist for counselling, even where a psychologist may be more appropriate... The net result of this is twofold. First of all, an unnecessarily heavy burden on the taxpayer and limited government resources — given that psychologists properly charge less than psychiatrists. And secondly, and more important, many individuals who need counselling and assistance for depression and other mental health problems are denied appropriate treatment or any treatment at all.<sup>55</sup>

Not everybody suffering from an emotional disorder or psychiatric disorder needs to see a psychiatrist. A good psychologist can, in some cases, more appropriately deal with the problem. But the people who are calling out for help haven't got the funds to pay for a private psychologist. I think it would be reasonable to ask that psychologists were able to bulk bill or be part of the health care insurance system just as psychiatrists are... People have to go to somebody who can bulk bill because they just can't afford to pay privately.<sup>56</sup>

The inequities inherent in such a system clearly impact most heavily on many of those already most disadvantaged in our community.

There is an anomaly that patients, particularly in public hospitals, are often provided with clinical psychological and clinical neuropsychological expertise but that this freedom of access does not persist into the community... It often happens that because psychological services are not readily available, disabled people are forced to seek alternative practitioners who are not adequately trained in that discipline thereby making treatment less effective and often inappropriate. In addition, these services are often more costly therefore putting a greater burden on the public health system.<sup>57</sup>

This restriction of access may mean that available treatment options are inappropriate, or lead to increased health care costs to the community — or both.

Research to date indicates...that the appropriate use of psychological services as an integral part of a health care system results in reduced expenditures for unnecessary and, at times, inappropriate hospital and medical services, thereby significantly reducing health costs.<sup>58</sup>

Such a system is not only incompatible with human rights principles — it is economically unsound.

### **General Practitioners**

General practitioners play a critical role in the treatment of mental illness — because individuals affected by mental illness often consult them as their first point of contact with the health system.<sup>59</sup>

When we are dealing with patients with depression, sometimes it is really obvious what the problem is... They will walk in...and burst into tears... Sometimes, however, people will come in with a more physical type problem which they are quite happy to tell you about, and then when the consultation is about to finish, it will all come out... I find that a lot of times people actually present with numerous physical symptoms...but you have a gut feeling that you are dealing with someone who is depressed.<sup>60</sup>

General practitioners play a critical role as 'gate keepers' to specialist health services and treatment options.

There are certain situations where I would feel that I could not handle a patient... And I would feel that I am out of my depth and it would be detrimental to the patient for me to continue to care for them. In these instances I would need to enlist the help of a mental health team.<sup>61</sup>

While evidence presented to the Inquiry emphasised the need for closer links between GPs and mental health professionals working in the community,<sup>62</sup> there is no doubt that general practitioners could and should play a more direct and effective role in the treatment of many people affected by mental illness.

This is largely a matter of appropriate education and continuing training in mental health — issues which are addressed in detail below.

### **Other Health Professionals**

Occupational therapists and social workers employed in the mental health field fulfil specific and important roles in the treatment of individuals affected by mental illness. As with other health professionals, however, the movement to multidisciplinary, community-based treatment services has modified the traditional functions these professionals perform.

The clinical staff of a community mental health centre consists of nurses, social workers, counsellors, occupational therapists and psychologists, as well as psychiatrists. But, whereas in a hospital ward the doctor is the primary therapist and requests other disciplines to help as necessary, in a community centre many of the patients will be 'case-managed' by one of the other disciplines and the psychiatrist is a consultant to that case manager.<sup>63</sup>

As more and more people with serious mental illness live in the community, the need for services provided by allied health professionals is growing. It is the...social workers and occupational therapists who are best prepared to meet the needs of mentally ill people as people.<sup>64</sup>

With the movement to community-based treatment, the roles of these allied health professionals have expanded. Some now take leadership roles in multidisciplinary mental health services and act as carers, organisers and educators.

The nature of social work has changed dramatically, the skills of social workers have been extended as their duties and responsibilities have increased.<sup>65</sup>

Evidence to the Inquiry indicated that individuals affected by mental illness generally supported multidisciplinary, community-based treatment.

There was universal support for more staff and funding to community mental health services... Most people made positive comments about extended hours and crisis teams, saying the staffing tended to be more stable and they usually responded when they were needed... Among positive comments was the view that mental health team workers spent more time with people, giving more information and support beyond medication only. They were also thought to be less threatening.<sup>66</sup>

The Inquiry heard, however, that benefits associated with the transfer to community-based treatment are jeopardised if appropriate levels of funding are not forthcoming. The Association of Mental Health Social Workers stated that:

The policy commitment to deinstitutionalisation has...resulted...in increasing numbers of people living in the community who require treatment from community-based services. However members of our association are consistently concerned regarding the resource problems in



Mental Health Services... A large proportion of funding...remains tied up in inpatient services, whilst community based services are inadequate... This is incongruent with the large numbers of people who attend community-based services...in comparison...[to] people who are admitted to psychiatric hospitals annually.<sup>67</sup>

Another important issue canvassed in evidence was the need to ensure that community-based professionals are appropriately registered. The Australian Association of Occupational Therapists expressed the view that the registration process is essential in ensuring quality of care and treatment:

Without registration, any unscrupulous individual may hold out to be an occupational therapist and practice occupational therapy. Removal of registration will result in the consumer having to judge the therapist's competence to practice. By definition, in time of need the client is in a crisis situation and is not necessarily able to make an informed and dispassionate assessment of the practitioner or the treatment. In the past, statutory regulation of health professionals tacitly recognised this imbalance of power in the practitioner-client relationship and, by registration, sought to provide to the client a reassurance of quality and professionalism. Functioning as an efficient and effective channel for minor and major complaints, the Registration Boards provide a low or zero-cost means of achieving resolution (as opposed to costly private legal action)... [The Association] is afraid that removing the legislative regulation of occupational therapists will create a major barrier to access to safe health services for the community.<sup>68</sup>

## **Professional Training and Education**

People with serious mental illness have very specialised needs and these can only be provided by those who are professionally trained and highly skilled.<sup>69</sup>

At present, practising psychiatrists are likely to spend 40 years in practice yet are not required to participate in any continuing education that would keep them abreast of new developments.<sup>70</sup>

The training and education of mental health professionals determines, to a large extent, the quality of care afforded Australians affected by mental illness. A mental health workforce comprising well trained individuals who regularly update their knowledge and skills through continuing education programs would provide a solid foundation for the delivery of appropriate medical and support services.

Evidence to the Inquiry indicated, however, that the education and training needs of many mental health professionals (and many health professionals routinely called upon to assist the mentally ill — particularly general practitioners) are not adequately met. Consequently, mental health services for Australians with a psychiatric disability are often sub-standard.

The training of community mental health professionals is seriously deficient. There is no agreed Australian code of practice, no text book of community mental health practice, and throughout Australia there are only two small graduate courses teaching the necessary skills (with 20

graduates a year they cannot hope to remedy the educational deficits of 3,000 community mental health workers). It is not surprising that morale among staff and their managers is frequently very low. Continuing education for hospital staff is only just beginning.<sup>71</sup>

## **Access to Courses**

To meet individual needs and achieve equity of access, a full range of educational offerings should be provided through a variety of programs and modes.<sup>72</sup>

Inadequate access to education and training programs means that many mental health professionals are denied the opportunity to adequately establish and subsequently broaden their skills. At one level the problem is attitudinal (for example, with respect to the necessity for adequate training for general practitioners). More tangible and equally significant problems include the costs associated with training and education programs, the timing of courses and their impact upon occupational demands, the lack of back-up staff to 'cover' for staff wishing to attend training, the limited number of 'places' available for those wishing to undertake courses and the costs — in terms of travel, time and money — particularly for rural workers.

Providing inservice training and continuing education for staff can depend upon the distance staff need to travel to obtain training; the availability of vehicles and resources to get to training venues; the numbers and locations of tertiary institutions; and the availability of those skilled to teach.<sup>73</sup>

Evidence presented to the Inquiry indicated that the priorities of their employers and the demands of their jobs frequently prevent mental health workers attending continuing education programs.

Employers...discussed the shortages of staff...and whilst they appreciated the needs for staff inservice training and continuing education, they also stipulated that releasing staff was a problem... They proposed that one or two-hour sessions conducted on site and at lunch time or cross-shift [were] more convenient.

Staff stated that the advantages of attending longer courses (five to ten days) were that they were able to obtain more intensive skills training; that valuable contact was made with other workers, thereby widening networks; and 'time out' from busy work commitments was appreciated, enabling a concentration on educational input, and a new enthusiasm when they returned to their work area.<sup>74</sup>

Many individuals working in mental health services emphasised the importance of support from their employers to enable them to undertake appropriate education and training.<sup>75</sup> However, a number of employers and service providers, while recognising the value of continuing education and training, emphasised the financial and administrative difficulties in providing that support. The creation of a work environment which values the importance of

continuing education and training was generally accepted as an essential step in achieving adequate standards of service delivery.<sup>76</sup>

Professionals working in rural and isolated areas find it particularly difficult to participate in education and training courses.

The training program in Western Australia does not extend beyond the metropolitan area. There is a need for accredited, funded training posts in rural regions.<sup>77</sup>

This absence of education and training opportunities and associated interaction with colleagues constitutes an important contributing factor to high staff turnover in isolated areas in all States and the Northern Territory.

It is an established goal of the Department to attract and retain sufficient numbers of adequately trained and experienced staff, and to establish staff development and training policies to provide opportunities for professional development.

Substantial problems occur in recruitment and retention of mental health professionals, particularly psychiatrists, outside of the Brisbane metropolitan area.<sup>78</sup>

Evidence clearly indicated that the development of training opportunities, along with other benefits, would assist in redressing the maldistribution of psychiatric facilities and psychiatrists across Australia — thereby facilitating better access to mental health services for our increasingly beleaguered rural population.<sup>79</sup>

Inducements to encourage trainee and qualified psychiatrists and appropriate support personnel to work in such disadvantaged areas need to be developed. Such inducements should include financial incentives as well as the provision of appropriate facilities, availability of other professionals and continuing medical education opportunities... The Royal Australian and New Zealand College of Psychiatrists has established a continuing medical education committee which is currently involved in looking at ways of improving access of its geographically isolated Fellows to continuing medical education activities.<sup>80</sup>

In addition to expanding formal training programs, dissemination of appropriate information through other channels was also considered important in ensuring that isolated professionals have access to up-to-date information.

Written materials, simple guideline documents on how to deliver services, audiotapes and videotapes were...seen as invaluable, especially for those who do not have access to training.<sup>81</sup>

### **Number and Type of Courses Available**

While professional colleges, associations and institutes, universities and governments are all involved in the provision of training, evidence to the

Inquiry demonstrated that both the number and range of courses available to mental health professionals is inadequate.<sup>82</sup> Particular needs include the expansion of inservice training courses and workshops; continuing education programs conducted by both tertiary institutions and professional bodies; postgraduate courses in mental health; educational packages by way of external studies; and more comprehensive on-the-job training.

Experts as well as carers emphasised the need for intensive training in specialised fields such as rehabilitation, family intervention, residential care, crisis intervention and management.<sup>83</sup>

Expert evidence presented in our two most populous States also highlighted the critical lack of education and training opportunities for professionals in the important areas of child and adolescent and geriatric psychiatry.

There is a considerable dearth of professionals trained to work with children and adolescents. In many of the areas where under-servicing is the biggest problem, the staff are either totally untrained in mental health work or if they have some background in mental health work, they've had no specific training in child and adolescent work. The gap between staff and services and particularly trained staff and services and the needs of the clients is most acute in these areas because many of these areas are hot spots of mental health problems... I can say for NSW that if by some miracle funding were made available to provide even just a half of the services that we need, we simply would not at the moment be able to staff those services with qualified professionals. If the rights to treatment for children and adolescents with mental health problems are to be met...[then there is an] urgent need for the training of professionals.<sup>84</sup>

The Honorary Secretary of RANZCP also acknowledged the results of this lack of specialist training.

Both child and geriatric psychiatry are still understaffed; resulting in moves by the Royal Australian and New Zealand College of Psychiatrists to expand training facilities and establish special interest groups in these areas.<sup>85</sup>

### **The Impact of Deinstitutionalisation and Associated Issues**

With the process of deinstitutionalisation and the development of community-based services, many individuals working both in institutions and the community requested intensive education and training in community-based service delivery skills.<sup>86</sup> Comprehensive community mental health services require the development of specialised skills, such as case management. An integrated approach to educating and preparing staff to work in the community-based environment is therefore essential.

In the climate of deinstitutionalisation it is very important the issues of attempting to live in the community with chronic psychiatric disorder are addressed in a training program. This will mean greater flexibility in training posts and also within services or regions.<sup>87</sup>

This change in educational approach needs to be reflected in both formal undergraduate and graduate programs and incorporated into continuing education courses. In particular, practising professionals currently employed in institutional facilities need to be trained in the skills associated with delivery of community-based services.

The critical need in community mental health today, and this will become even more acute when additional staff currently working on psychiatric hospital inpatient units are transferred to work in the community, is for high level training and supervision.<sup>88</sup>

Practising clinicians needed to adopt a new...approach to the way in which they were working... In particular, staff who had worked in state psychiatric institutions for several years needed to be educated about the development of community-based services and how institutions should be integrating and linking their services with the local community... In addition, community-based staff needed to accept the important role that institutions and hospitals played, and to determine ways in which to work with these services.<sup>89</sup>

Professionals in positions of seniority who were moving into community-based services indicated the need for training in a range of leadership skills — such as conflict resolution, team building, team management, computerisation, priority setting, and resource budgeting. Staff already employed in community-based services emphasised that time must be allocated for initial inservice training, team building and general skill acquisition for new employees.

New staff [should] have time to build up their caseload over a two to three week period. A major problem identified in many services was that new staff were usually 'thrown' into their job on the first day with no time being allowed for induction and orientation to [the] service, for getting to know the team, or the local environment in which staff would be working. The long-term problems that this creates are enormous as staff try to cope with large caseloads whilst obtaining basic information that they need to do their work.<sup>90</sup>

Evidence to the Inquiry also indicated that the emphasis on development of multidisciplinary teamwork should be more adequately reflected in undergraduate courses than is presently the case.

Students rarely learn to realistically view the multidisciplinary team as a functioning critical mechanism for service.<sup>91</sup>

Multidisciplinary teams employ people from a variety of professional backgrounds, including nursing, social work, psychiatry, occupational therapy, psychology and other fields. These individuals have a range of qualifications

and special skills in addition to a basic set of core skills. If all disciplines are to share tasks in community-based service delivery and work towards the goal of providing quality care for the seriously mentally ill, students should have greater opportunities to work directly with other students in related disciplines.

### **Consumer Concerns**

The evidence from individuals affected by mental illness and their families indicated that many consumers had experienced insensitive and even callous treatment from mental health professionals.<sup>92</sup>

Too often we have seen a breakdown of care due to lack of understanding by professional staff. A system of care is only as good as its operators!<sup>93</sup>

Some witnesses suggested that consumers should participate in the development of training courses for mental health professionals and that programs should highlight what mental illness means to the individual, what it is like to be admitted to hospital and what individuals need from professionals when they are patients in hospitals.

There is a definite barrier between staff and patients in psychiatric hospitals which is a barrier of prejudice and fear and not of therapy... There is a real need for change in the ways that clinical staff in the psychiatric system are selected and trained... During their training, staff could benefit from a focus on the development of empathy. We suggest that this could be done in the following ways:

- a) guided exercises which help the students to imaginatively experience mental illness;
- b) contact with psychiatric patients who are not in the acute stages of their illnesses and who are able to articulate their experience of mental illness. This should occur in informal settings to encourage the exchange of experience and insights;
- c) emphasis on the history and sociology of mental health care;
- d) exposure to a variety of schools of thought about the therapy of mental illness;
- e) personal assistance from a 'mentor' or therapist to enable staff to deal with their own emotional and psychological issues as they arise, especially those which arise from their work.<sup>94</sup>

It was also suggested that mental health professionals need to work more closely with family members to appreciate their needs and to explain aspects of each individual's illness and treatment.

Training programs should also encourage trainee psychiatrists in their roles with families and the community. They should be aware of the stigma of psychiatry, the need for patient rights, and so be constantly aware of their own role in addressing these issues, and as appropriate encouraged to attend community groups etc.<sup>95</sup>

In addition to these general themes, the Inquiry heard more specific evidence concerning the education and training needs of psychiatrists, general practitioners, nurses, social workers, psychologists and occupational therapists.

## **Psychiatrists**

Perhaps one of the most important functions...is to develop and maintain postgraduate training programs in psychiatry and continuing education programs. With the progression of knowledge, psychiatric assessment and treatment has become increasingly complex and the training necessary for a skilled psychiatrist is considerable... The adequacy of psychiatric treatment will be closely related to the adequacy of the training of...psychiatrists.<sup>96</sup>

Evidence presented to the Inquiry frequently emphasised the importance of continuing education programs in maintaining high standards of psychiatric care. However, a number of witnesses underlined the shortcomings of the existing system:

The first remedy invoked is usually that of Continuing Medical Education (CME). It is honourable, very helpful for those who make use of it, and not particularly expensive, although the College of Physicians might believe otherwise. The central problem is well known to those who contribute to it. One meets the same eager faces repetitively, but those most in need of education rarely present themselves. There are also the ineducable: those who know all the answers or who are unaware that there are any questions. New knowledge arises, and one is inclined to forget that already acquired: CME is a necessity for us all.<sup>97</sup>

Some witnesses suggested that re-registration of psychiatrists (and other mental health professionals) should be conditional on undertaking and gaining accreditation for continuing education programs.

Clearly there is a particular need for psychiatric training in a variety of specialised fields — generally the ‘difficult’ areas of mental health where the need for adequate services is particularly important.

There are few training posts in areas of need. For example it is often difficult to fill posts in psychogeriatrics. There are no posts per se in rehabilitation, no designated forensic training posts, no posts with Aboriginal Medical Services, no post with an Alcohol and Drug Authority and only limited contacts with low socioeconomic areas. Without experience in these areas, and other similar areas, the graduating psychiatrist is at risk to remain ignorant or to feel inadequate to work within the area.<sup>98</sup>

The Honorary Secretary of RANZCP emphasised the need for specialised training and increased resources in forensic psychiatry:

Forensic services in Australia are particularly in need of attention. Studies in this area demonstrate that there is a high incidence of severe mental illness among prisoners. Provision of psychiatrists and psychiatric services in Australian prisons is severely limited, and appears

to be the result of a lack of adequate training resources and lack of job satisfaction for those working in these areas. Consideration must be given to the development of appropriate career structures within the prison psychiatric system, the upgrading of forensic psychiatry, provision of academic chairs, and improvement of working and living conditions within the prison system.<sup>99</sup>

The Inquiry repeatedly heard evidence concerning the loss of psychiatrists from the public sector and the depletion of resources for treatment of the chronically mentally ill. In this context, it was suggested that the career decisions psychiatrists make at the completion of their training are often determined by their initial experiences. If their first exposure to public mental health facilities is negative, trainee psychiatrists may decide at that point to pursue a career in private psychiatry.

Many training experiences — especially in very busy general hospitals and in particular in the large psychiatric hospitals — can become one of service rather than training. Trainees frequently leave such a service vowing never to return. Funding such units to allow trainees to work with optimum patient numbers... would allow, I believe, a significant change in perspective.<sup>100</sup>

The absence of role models and good clinical training... may explain why many young psychiatrists do not find those with chronic mental illness an attractive group to treat... More student units are needed and a range of training sites identified particularly in community-based services.<sup>101</sup>

The six monthly rotation of trainee psychiatrists (referred to elsewhere in this report)<sup>102</sup> was consistently criticised.<sup>103</sup> Many witnesses felt they could not establish any real relationship with trainee psychiatrists and believed their treatment suffered as a consequence. In addition, the lack of continuity of care means that trainees simply don't have the opportunity to develop the skills gained from treating patients over an extended period.

The training experience does not allow for continuity of care. It is desirable for trainees to have a broad experience and so rotate through many units, but often this is at the expense of not experiencing the long term effects of mental illness.<sup>104</sup>

The need for interpersonal skills training for psychiatrists (and other mental health professionals) was repeatedly raised in evidence to the Inquiry by people affected by mental illness.<sup>105</sup>

The staff here can be both informal and intimidating... The social workers and psychiatrists do not seem sincere. Things could be better if... there was some personal involvement from them. There is no feedback from doctors and there is no human level of relationship with them.<sup>106</sup>



## General Practitioners

[The health system] does not identify the mental health area as a special skill in preparing medical graduates for general practice. As the first point of contact by a mentally ill person is usually a GP, this omission is staggering.<sup>107</sup>

The level of understanding by general practitioners is deficient and there are a couple of recent studies to show that... There's a gap in education. We know that the major complaint from carers is that GPs are unable to give them information about diagnosis or about management... [We need] to look at education at all levels, at primary health care providers, and particularly at general practitioners.<sup>108</sup>

Evidence presented to the Inquiry clearly established that the training of general practitioners with respect to mental illness is inadequate. General practitioners are frequently the first point of contact with the medical system for people affected by mental illness. This is partly because they are generally accessible — due to the availability of Medicare benefits — but also because symptoms of mental ill health are not always obviously just that. It has been estimated that general practitioners spend 10 percent of their time dealing with patients whose primary reason for consultation is an emotional or psychiatric problem and an additional 10 percent of their time with patients with mental health problems who are actually seeking treatment for a physical illness or have concurrent physical conditions.<sup>109</sup>

We should develop better education facilities...for doctors... We should make sure GPs in particular...know how to identify [psychiatric problems] and how to make sure that [patients] are referred to psychiatric services.<sup>110</sup>

General practitioners fail to identify mental illness in a significant proportion of patients.

[It's quoted] that 10 percent of people with mental health problems are seen by GPs. Well probably 20 percent are seen by GPs [but] only 10 percent are correctly diagnosed. Again it seems to me it points out the need for competent professional services.<sup>111</sup>

However, they have a profound influence over the use of other health services. They initiate referrals to specialists and allied health professionals and they can directly influence treatment options.

[General practitioners] are often thought of as the 'coordinators' of health care. In this role they can ensure the best treatment for their patients through prescribed medications or referrals to medical specialists, or allied health services... However, the effectiveness of this role can be diminished by insufficient awareness of local community resources.<sup>112</sup>

General practice is seen as poorly integrated with the rest of the health system...<sup>113</sup>

Effective integration of general practitioners in our health care system is essential if their services to people with psychiatric disabilities are to be more effective. Since the Inquiry began, the Federal Government has increased efforts in conjunction with the Australian Medical Association and the Royal Australian College of General Practitioners to promote greater integration.<sup>114</sup>

With effective integration, general practitioners could play a more significant role in the management of people affected by mental illness. They currently care for large numbers of such people, many of whom have little contact with specialised mental health services. This is particularly the case in remote areas where few specialised services of any variety are available.

[People with mental illness] still want to have an ordinary general practitioner and they accept that as a reasonable way of making contact with the [mental health] care system. They in fact value that because this person is not a psychiatrist, not part of the formal mental health system and I think they look towards that person as being on their side... [This presents us with the opportunity to] use general practitioners more as agents of care and support of people's mental illness.<sup>115</sup>

If general practitioners are to be used more effectively in providing mental health services, however, it is essential that they receive more comprehensive mental health education. They need to substantially improve their skills not only in diagnosis and the management of people affected by mental illness but also in developing close links with community-based mental health professionals.

It just amazes me when I look at the training program for doctors in NSW how little emphasis is placed by the universities at the undergraduate level on building in core training subjects relating to psychiatry... It is my belief that there needs to be far greater input at the undergraduate level and the postgraduate level to help [GPs] develop and maintain skills that will make them far more effective practitioners in this area.<sup>116</sup>

More specific deficiencies in the training of our general practitioners are addressed in other chapters of this report.<sup>117</sup>

## **Nurses**

The effectiveness of mental health services is dependent on an adequate supply of highly trained professionals... The training of specialist nursing staff to work in the mental health area is of crucial concern. It is extremely important that governments and tertiary training institutions ensure that nurse education includes adequate basic and post basic training in psychosocial and biomedical aspects of health care.<sup>118</sup>

In recent years, the education of mental health nurses has moved away from hospital-based courses to generalist tertiary based programs. The three-year tertiary courses provide a curriculum designed to equip graduates to work in

medical-surgical; mental health; and developmental disability settings. According to the Australian Nursing Federation:

The curriculum for pre-registration nurse education is to be comprehensive in nature to enable graduates to function as beginning practitioners in a variety of health care and community settings, in order to meet society's needs.<sup>119</sup>

The Australian Nursing Federation contends that pre-registration nursing programs which are generalist [will] allow graduates to emerge sufficiently well equipped to withstand the pressures applied when they embark on a post-registration career in mental health. We believe that separate education which focusses on either the 'body' or the 'mind' encourages the socialisation of students into separate cultures. This is to the disadvantage of mental health clients.<sup>120</sup>

While this change has been welcomed by many in the mental health nursing sector, it has also caused concern. In particular, there are serious reservations regarding the transfer of mental health nursing education to a generalist tertiary program and the possible loss of specialist nursing skills.

Within the psychiatric nursing field there is considerable disquiet and demoralisation because of the clear trend in marginalisation of psychiatric/mental health nursing theoretical content and clinical experience in tertiary curricula...<sup>121</sup>

In NSW the move of nursing education to the tertiary sector has seen the disappearance of hospital-based schools of nursing and the dispersion of staff who had previously worked in and developed those schools... It was the intention that a comprehensive basic curriculum would [be developed]... That was the intention...[but] many mental nurse academics in NSW are sure that this has not happened.<sup>122</sup>

Some evidence suggests that in practice the educational demands of medical-surgical nursing have been given priority over the training needs of psychiatric nursing:

There are some around who would want to see psychiatric nursing in particular shoved into the postgraduate domain and others who want to see developmental disability nursing shoved right out of nursing altogether. This would give more time in the present three-year curriculum for what is believed to be medical-surgical nursing. I believe this would be a disaster.<sup>123</sup>

Many nursing faculties have at the moment too few mental health nursing academics on their staff -- in some places it is under 10 percent.<sup>124</sup>

Obviously there is a need to ensure that all basic nursing education contains an appropriate level of mental health training.

Education institutions must ensure that education for work in all health services includes education for mental health work. Graduates of health faculties should have achieved a level of

competence which prepares them for work as beginning practitioners in health, both physical and mental.<sup>125</sup>

However, continuing education is also essential with respect to nursing techniques and treatment methods.

As mental health nurses, we need to keep ourselves well educated and abreast of the changes in psychiatry and nursing. We can be active in publishing our own work, conducting research, and reading about the work of our contemporaries.<sup>126</sup>

The Australian Nursing Federation highlighted the necessity for the 'provision of appropriate, regular inservice education opportunities for all staff for the maintenance and enhancement of skills' to ensure proper standards of nursing care.<sup>127</sup>

Evidence presented to the Inquiry also established that there are significant differences in nurse education in each State and Territory — and that these differences affect the standards of treatment for individuals affected by mental illness.

The differing State/Territory legislation, the differences in funding and the variety of educational opportunities for personnel mean that clients are subjected to differing standards throughout the country.<sup>128</sup>

This situation impacts both directly and indirectly on those involved. The Secretary of the Queensland Nurses Union commented upon the variation in educational requirements and standards and the impact this had on the number of nurses available.

The Queensland Nurses Union does not accept that mental illness is resourced to the same standard as physical illness. Our concerns in particular go [to] the...educational preparation of mental health nurses... There is extraordinary variation across the States in terms of the ways that psychiatric nurses are currently prepared... These variations, apart from being educationally and professionally unacceptable, also have profound effects on the supply side of the mental health nursing labour market...<sup>129</sup>

Beyond addressing these difficulties, however, there is also clearly a growing need for appropriate adaptation of existing health services to more effectively deploy the talents of psychiatric nurses — particularly in rural and regional areas, where the very real and in some cases very urgent needs of many thousands of Australians living in smaller population centres need to be imaginatively and effectively addressed.

## **Other Health Professionals**

The Inquiry heard that other health professionals working in the mental health field — psychologists, social workers, and occupational therapists — have specific training needs, including in the field of community-based service delivery. The development of community-based educational programs and the promotion of continuing education courses in these areas were seen as essential.

The real challenge is to develop training programs... I mean, at the moment in NSW we have the Institute of Psychiatry...our own University [of NSW] is developing a Masters of Psychotherapy program...and there's the University of Wollongong and...a small program in Canberra. We are talking about 1000 community mental health workers, psychologists, social workers, nurses, psychiatrists, none of whom have really had a lot of training focussed on the new job we're asking them to do; it's a problem of changing roles and forgetting to re-skill them.<sup>130</sup>

One significant education and training provider is the NSW Institute of Psychiatry. The Institute is independent of any individual university or teaching institution and is the only organisation of its type in Australia and New Zealand.<sup>131</sup> It has three broad objectives: education of doctors and allied mental health professionals; fostering research; and promotion of community education in the mental health field. While the Institute initially concentrated on the training of psychiatrists in NSW, it now conducts training programs for a range of health care professionals and consumers.

In the child and family field there are courses now running to train psychiatrists, there are multidisciplinary courses for people who are working with adolescents, and there's a course for the early childhood nurse. In the cross-cultural area the Institute conducts courses for interpreters, ethnic health workers and bilingual counsellors...and a course for health professionals who work in the cross-cultural area.<sup>132</sup>

The Institute also provides courses for those working with the seriously mentally ill, leadership skills development in mental health services, the psychiatry of old age, crisis intervention and management skills and rehabilitation systems. In its community education role the Institute conducts seminars throughout NSW for both professionals and consumers.

While the Institute has limited resources and is far from adequately meeting the needs outlined in this chapter, its existence means that mental health professionals in NSW have access to a greater range of formal and continuing education than their colleagues in other States. The lack of similar organisations elsewhere in Australia needs to be addressed as an initial step to improve training opportunities for all workers in the field of mental health.

I think [the Institute] is a good idea, in the sense that it allows the best expertise from all sources to be drawn together in its teaching programs. Because we're not part of any one particular university or teaching institution, it gives us a degree of independence, so that we can draw on all academic resources, plus the private and public resources, as well as consumer resources. Now having said that, I think that's a strength — but it also means we are vulnerable in terms of being the only Institute in either Australia or New Zealand. We are often asked why should we have one...and so far we have been able to respond to that in such a way that we haven't been cut out altogether but certainly sometimes they see this thing as a luxury. I certainly don't see it as a luxury.<sup>133</sup>

## **Other Professionals Who Work with People Affected by Mental Illness**

Ignorance and misinformation underlie the alienation of the mentally ill from the mainstream of the community. There is a marked lack of understanding of mental illness by the population at large.<sup>134</sup>

The Inquiry heard that many professionals — including government employees, police and ambulance officers, teachers, lawyers and journalists — need training to deal with people affected by mental illness, and issues relating to them, in an appropriate manner.

People with psychiatric disabilities need information or assistance from a variety of government services — including employment and rehabilitation, education and training, transport, health and accommodation. However, the evidence presented to the Inquiry indicated that staff in relevant agencies are simply not equipped to meet these needs.

The overwhelming conclusion about government departments and programs is that access to them is difficult and inequitable. It is recommended that there needs to be ongoing...training of all government workers, particularly counter staff who deal directly with consumers.<sup>135</sup>

In 1990 a study of 23 NSW State Government departments<sup>136</sup> was conducted to determine what training government employees were receiving relating to a range of disabilities.<sup>137</sup>

Staff of government and non-government organisations had limited knowledge of, and were not sensitised to, the needs of people with intellectual, physical, sensory and psychiatric disabilities. Those with severe disabilities were often denied access to information, education, employment, recreation, leisure, home care and support, transport, housing and other community services.<sup>138</sup>

The study concluded that the majority of government departments did not provide any training for their staff — either because staff development time was limited or because staff development officers did not have adequate resources or knowledge of disability issues in general. Beyond this:

Staff were particularly unsure of people with psychiatric disabilities, had limited knowledge of mental illness or how to cope with difficult or unusual behaviours.<sup>139</sup>

Government services must become accessible to people affected by mental illness. The provision of educational programs for government workers will assist in raising awareness of the needs of the mentally ill and dispelling fear and ignorance. (This point is also relevant to non-government organisations which provide services to people with psychiatric disabilities.)

Evidence to the Inquiry also indicated the need to provide adequate training to police and ambulance officers — who frequently deal with people affected by mental illness in stressful and traumatic situations.<sup>140</sup> Police officers, for example, are often called to forcibly transport mentally ill individuals to hospital or detention.<sup>141</sup> The provision of appropriate training is essential in ensuring that the rights of people with mental illness are respected.

There are personnel trained and employed by some authorities who are poorly equipped to deal with the mentally ill from the aspects of compassion and confidence in managing a sufferer. They are either anxious, patronising or rude. I refer in particular to some members of the... police force... Consideration should be given to further extending the educative process in mental illness to encompass the disciplines peripheral to mental health workers.<sup>142</sup>

A recent questionnaire completed by 97 members of the Victorian Police Service revealed that 84 percent of respondents did not think they knew enough about mental illness to work effectively with consumers, and 55 percent believed they would benefit from training in this area.<sup>143</sup>

### **School Children and Students**

The Inquiry also heard that educators are inadequately trained to identify mental health problems in childhood and adolescence.<sup>144</sup> Teachers, lecturers, tutors and other education professionals often have inaccurate notions about mental illness and little understanding of the problems individuals face in coping with episodes of illness and trying to study.<sup>145</sup> Beyond this, the potential of our schools for addressing the widespread ignorance which feeds discrimination against people affected by mental illness has, until very recently, been ignored.

A national school education program would ensure that young people throughout Australia gain insight into the needs of a person with a mental illness, be they someone known to them at school, a relative or a person on the street.<sup>146</sup>

Community education can start in schools — acquainting students with mental health and mental ill health and how to be supportive. Generally, secondary school children at the year 10 onwards are the most receptive and have the capacity to understand schizophrenia, anorexia nervosa, bulimia and depression. Co-operation between State education departments [and] health

departments, with joint funding, could provide packages for both secondary and tertiary institutions.<sup>147</sup>

The Association of Relatives and Friends of the Mentally Ill (ARAFMI) has developed a national schools education program, first tested in NSW, for children in years 7 and 10 of high school. Young people participating in the program receive a comprehensive range of information on mental illness, mental health, the effects of illness on family members and the community support available to people with mental illness.

At present this program is run by volunteers. We've researched our method of presentation and we now know that it would take 650 volunteers working for two years to cover only the initial lesson...to blanket NSW high schools. As a result ARAFMI is working very hard to have the program written into the curriculum of NSW Schools so that each class will automatically have access to the program.<sup>148</sup>

Since this evidence was presented to the Inquiry, the Australian Youth Foundation<sup>149</sup> has made a grant of \$460,000 to ARAFMI to assist in the expansion of its education program to schools in all States and Territories.

Education is the only way...to ensure a caring and committed population with an insight into the effects of mental illness and the ability to grant those suffering from this illness the same rights as every other human being. [It] is the only way to make an attempt to remove the stigma attaching to mental illness. The removal of the stigma is probably the most important step towards the community seeing people with a mental illness as people.<sup>150</sup>

The importance of introducing mental health education programs into tertiary institutions was also echoed in other submissions to the Inquiry.<sup>151</sup>

[The tertiary sector should conduct] public education about the 'rights' model of community development. Such education should occur as an intrinsic component of tertiary and higher education, not only in courses designed for the human services sector. Community education is a key role for recipients of higher education and such basic 'rights' philosophies...are sufficiently complex to require transmission by a consistent, deliberate and wide ranging process of community education.<sup>152</sup>

## **The General Community**

Education is the main weapon we can employ to ensure that the mentally ill are granted their rights at all times: education of the sufferers, their families, the professionals, but most of all the community at large. People have to be made to view mental illness as an illness, something that can be treated and in many cases cured. Even those who do not achieve a complete cure can lead a much better life if they're allowed to function to the utmost of their ability.<sup>153</sup>

Evidence to the Inquiry confirmed that the level of understanding in the community about mental illness is abysmal. There is widespread fear about the



behaviour of people affected by mental illness — based largely on ignorance, misconceptions and myths. This fear is sometimes reflected and reinforced by selective reporting in the mass media, which contributes to stigmatisation, marginalisation and discrimination.

- Mental health is at the point that the anti-smoking program was at 20 years ago. Not many people [have] considered the issue... The community at large still retains quite erroneous notions about mental illness. Fears about rape, violence etc surface when community residences are proposed. The reality is that these behaviours are not common among people with psychiatric illness — especially among people receiving treatment.<sup>154</sup>
- The general public are threatened by mental illness, both by the frightening nature of the illness and by the unfortunate and often sensational way it is reported in the media.<sup>155</sup>
- Ignorance and misinformation underlie the alienation of the mentally ill from the mainstream of the community. There is a marked lack of understanding of mental illness by the population at large, including employers, industry, the media and government. Stereotypic and often prejudicial views do not match the reality of mental illness... Such lack of understanding needs to be addressed by appropriate educational and information programs.<sup>156</sup>

This situation has a profound and often destructive effect on the lives of individuals affected by mental illness.

Attitudinal and structural discrimination towards those with mental illness is far more prevalent and far-reaching than most would believe.<sup>157</sup>

We have all experienced a great deal of degrading treatment and isolation in the community as a result of the stigma of mental illness. We do not always appreciate being herded together in rehabilitation and social activities because of the wider community's need to not see us. There is a great need for education of the community about mental illness so that barriers of fear and ignorance can be dismantled.<sup>158</sup>

The impact of this ignorance and discrimination affects not only people with mental illness but also their families and friends.

Families [also] suffer...the stigma of mental illness. A lack of understanding of psychiatric issues in the general community means the families not only watch their relatives discriminated against and marginalised by society but [also] endure personal discrimination, criticism and social isolation. Community education programs that seek to destigmatise mental illness may restore dignity and a place in society to the mentally ill and their families.<sup>159</sup>

There is clearly an urgent need to effectively disseminate information about mental illness that dispels the common myths and misinformation.

The Association of Relatives and Friends of the Emotionally and Mentally Ill (ARAFEMI) Victoria is of the opinion that...one of the principal barriers to the human rights of people with

mental illness being respected is the lack of knowledge amongst the general public, legislators, public servants and medical officers about mental illness... Adequate and accurate information about mental illness... is not available in a form which makes it freely accessible. The stigma attaching to mental illness is clearly the result of fear and prejudice and affects the general public and mentally ill people alike.<sup>160</sup>

Experts, carers, professional organisations and consumers contended that one of the most effective methods of educating the public would be through a national campaign:

- Given that mental illness affects such a large proportion of the population, such a project would need to be large scale, well funded, coordinated, and have the involvement of Federal and State governments and private enterprise. In most states there have been campaigns on smoking, drinking, fitness, cancer, AIDS; so a similar campaign on mental illness is quite appropriate.<sup>161</sup>
- The general community needs to be educated about mental illness through targeted campaigns aimed at different segments of the population, using multi-media approaches.<sup>162</sup>
- [There is a] need for community education programs in all educational institutions including primary schools. Employers, general medical practitioners, employment agencies, real estate agents, legislators, public servants and journalists should be included as targets for such programs. All forms of media should be used to disseminate information, inform and educate. Information must be freely available in hospitals, general practitioners' waiting rooms, community health centres and other information centres. This information should take the form of leaflets, pamphlets, and books, as well as cassettes, videos and films.<sup>163</sup>

The development, design and implementation of community education programs should be undertaken in consultation with those affected by mental illness. Where possible, consumers should also be actively involved in disseminating information.<sup>164</sup>

It has been found that rehabilitation programs are effective if they have client involvement in the design. Community education is similar, the best advocates are ex-clients if they are able to stand the stress of public exposure.<sup>165</sup>

It was suggested that in any community education campaign, similarities between mental illnesses and other illness should be emphasised as a way of demystifying and de-stigmatising mental illness and addressing community fears.

Public education in relation to mental illness needs to reinforce similarities between mental and other illnesses, rather than differences... A great deal of education is needed for the public to overcome its fear of mental illness. It is unfair that other 'physical' illnesses attract so much public sympathy and support... Public attitudes... have always been a negative force in my experience.<sup>166</sup>

Effective community education, complemented by appropriate anti-discrimination and affirmative action programs, is clearly an essential step in combating the fear and stigma so closely associated with mental illness. It is an indictment of our lack of concern that such widespread ignorance still exists. A national campaign to effectively address and dispel it must clearly be a high priority.

1. Dr D Leonard, Director of Clinical Services, Royal Park Psychiatric Hospital. Oral evidence, Melbourne 10.4.91, pp341-342. Dr Leonard resigned from his post shortly after giving this evidence. (Given the circumstances he described, the fact that he persisted to the point he did is a tribute to the commitment of those psychiatrists left in the public sector.)
2. Dr N McLaren, Senior Consultant Psychiatrist, Kimberley Region, WA. Submission, p10.
3. *ibid*, pp1-2.
4. The Royal Australian and New Zealand College of Psychiatrists released its first Code of Ethics in August 1992. The Code of Ethics is a guide to good professional conduct — not a legally enforceable document. The Code identifies nine fundamental principles:
  1. Psychiatrists shall have respect for the essential humanity and dignity of each of their patients.
  2. Psychiatrists shall provide the best possible psychiatric care for their patients.
  3. Psychiatrists shall hold information about the patient in confidence.
  4. Psychiatrists shall obtain consent from the patient before undertaking any procedure or treatment.
  5. Psychiatrists shall not allow the misuse of their professional knowledge and skills.
  6. Psychiatrists shall continue to develop their professional knowledge and share this knowledge with colleagues and other relevant health professionals.
  7. Psychiatrists shall share the responsibility of upholding the integrity of the medical profession.
  8. Psychiatrists conducting clinical research shall adhere to those relevant ethical principles embodied in national and international guidelines.
  9. Psychiatrists in their societal role shall strive to improve the quality of psychiatric services, promote the just allocation of these services and contribute to the education of society regarding mental health.
5. Also see Chapter 28 — Accountability.
6. Dr J Ellard, NSW Branch of the RANZCP. Oral evidence, Sydney 17.6.91, pp59-60.
7. Dr B Boettcher, psychiatrist, NSW. Submission, p2.
8. Dr J Wooldridge, Consultant Psychiatrist, Cairns Community Mental Health Service. Oral evidence, Cairns 9.8.91, pp1055-1056.
9. G Andrews, *The Tolkien Report: A Description of a Model Service*, 1991, p5.
10. G Andrews, 'Health Services Research and the Future of Australian Psychiatry', *Australian and New Zealand Journal of Psychiatry*, 24, 1990, p5.
11. Dr B Kenny, Honorary Secretary, RANZCP, Victoria. Submission, p6.
12. In 1987 it was estimated that there were 1428 qualified psychiatrists in Australia or 8.8 psychiatrists per 100,000 population. 55 percent were predominantly in private practice and 45 percent were in the public sector. This disproportion is now almost certainly greater. See Chapter 5 — Mental Health Services.
13. Leonard, *op cit*, p348.
14. Kenny, *op cit*, pp7-8.
15. *ibid*, p6.
16. Dr B Kerr, Director of Psychiatric Services, Northwest Region, Tasmania. Submission, p19.
17. Andrews, 'Health Services Research and the Future of Australian Psychiatry', *op cit*. The survey of psychiatrists also found that people in private treatment were significantly more likely to be female, of working age, in the workforce, and living with a spouse. Only 4 percent of private sector consumers were inpatients. In comparison, 80 percent of public

sector consumers were of working age but only 18 percent were in the workforce. Forty percent were on pensions, significantly more lived in hostels and 37 percent were inpatients at the time of the survey.

18. Another recent study, made available to the Inquiry by its author, has questioned the conventional wisdom about the relative degrees of illness and impairment of patients in the public and private sectors. Direct evidence to the Inquiry, however, indicated that the people with serious mental illness are generally being treated in the public system.
19. Also see the discussion of the role of the private sector in the treatment of mental illness in Chapter 5 — Mental Health Services.
20. Andrews, 'Health Services Research and the Future of Australian Psychiatry', op cit, p2.
21. Andrews, *The Tolkien Report*, op cit, pp6-7.
22. The separation of mental health services from general health care is reflected in other ways including, for example, in industrial awards. Mental health nurses do not have uniform union coverage and work under a variety of awards. In some cases nurses and ancillary workers in mental health services are covered by the same union. Often, mental health nurses and general nurses belong to separate unions. This has had a considerable influence on the manner in which mental health services and education policies have developed in different States.
23. McLaren, op cit, p11.
24. G Curry, Senior Lecturer, School of Nursing, University of Technology, NSW. Submission, p10.
25. L Cox, Society of Mental Health Nurses, NSW. Submission, p16.
26. M McGuiness and Y Wadsworth, 'Understanding Anytime — A Consumer Evaluation of an Acute Psychiatric Hospital,' Victorian Mental Illness Council, Melbourne. Submission, p32.
27. id.
28. Cox, op cit, p18.
29. *ibid*, p19.
30. *ibid*, p2.
31. M Vidovich, Assistant Federal Secretary, Australian Nursing Federation, Victoria. Submission, p1.
32. McGuiness and Wadsworth, op cit, p31.
33. Vidovich, op cit, p1.
34. *ibid*, p2.
35. id.
36. E Crowther, Director of Nursing Services, Royal Park Hospital; 'Changes in the Nursing Profession', Address to the Australian College of Mental Health Nurses 18th National Convention, 1992, Submission, p17.
37. R Laver, Chairperson, Australian Psychological Society, Tasmanian Branch. Submission, p3.
38. *ibid*, p2.
39. Evelyn Field, Australian Psychological Society, Victorian Branch. Submission, p8.
40. id.
41. Laver, op cit, pp2-3.

42. Field, *op cit*, pp7-8.
43. *ibid*, p7.
44. *id*.
45. Laver, *op cit*, pp2-3.
46. Dr T Avery, Tasmania. Submission, p3.
47. *id*.
48. Prof G Andrews, Director of the Health Services Research Group, Clinical Research Unit for Anxiety Disorders at St Vincents Hospital. Oral evidence, Sydney 17.6.91, p49.
49. M McMahon, Australian Psychological Society, Victorian Branch. Oral evidence, Melbourne 10.4.91, pp381-382.
50. H Clausen, Chairperson, Board of Clinical Neuropsychologists, Victoria. Submission, p1.
51. J Manners, State President, Institute of Private Clinical Psychologists of Australia, Western Australia. Submission, p1.
52. See also Chapter 18 – Homeless People.
53. Clausen, *op cit*, p2.
54. Manners, *op cit*, p2.
55. E Field, Australian Psychological Society, Victorian Branch. Oral evidence, Melbourne 10.4.91, p381.
56. G Holland, Senior Community Psychiatric Nurse, Cairns Community Mental Health Service. Oral evidence, Cairns 9.8.91, p1058.
57. Clausen, *op cit*, p2.
58. Laver, *op cit*, p3.
59. It has been estimated that 10 percent of general practitioner consultations are with individuals with psychiatric disabilities and a further 10 percent are with individuals who have mental health problems but are actually seeking treatment for a concurrent physical illness. Andrews, *The Tolkien Report*, *op cit*, pp20-21. See also Chapter 5 – Mental Health Services.
60. Dr L Barnes, general practitioner. Oral evidence, Alice Springs 23.7.92, pp189-190.
61. *ibid*, p190.
62. T Alexander, Sydney. Submission, p2.
63. Dr J Hoult, 'Community Psychiatry', *Institutionalisation and Community Psychiatry*, NSW. Submission, p318.
64. Alexander, *op cit*, p2.
65. K Stanick, senior social worker, Tasmania. Submission, p2.
66. C Flynn, Policy/Administrative Director, Mental Health Coordinating Council, NSW. Submission, p14.
67. *ibid*, p1.
68. L Oke, President, Australian Association of Occupational Therapists Inc, Victoria. Submission, p1.
69. W Weir, *Education and Training Programs for Mental Health Professionals*, A report to the Churchill Trust of Australia, 1989, NSW. Submission, p44.
70. Andrews, 'Health Services Research and the Future of Australian Psychiatry', *op cit*, p3.
71. Andrews, *The Tolkien Report*, *op cit*, p7.

72. Australian Nursing Federation, *Standards for Nurse Education*, Victoria, 1989, p3.
73. Weir, *op cit*, p6.
74. *ibid*, p57.
75. See for example, McLaren, *op cit*.
76. The introduction by the Federal Government in 1990 of the 'Training Guarantee Levy' should significantly assist in ensuring the delivery of work related training and education opportunities in sections of the mental health sector. The Training Guarantee Levy is a legal obligation on employers to invest a minimum amount each year on training. Employers are subject to the Training Guarantee levy if their annual national payroll is equal to, or above, a threshold figure. The threshold is indexed annually to 'Average Weekly Earnings' and for the 1992-93 financial year, the threshold was \$222,000 (there is no legal requirement to provide a minimum level of training if an employer's payroll does not meet this indexed threshold amount). Currently, eligible employers must spend a minimum of 1.5 percent of their payroll on net training expenditure (in the first two years of operation — 1990-91 and 1991-92 — the minimum expenditure was 1 percent of payroll). Within a broad definition of training, employers are free to choose whom they train and the type of training offered.

Not all employers in the mental health sector whose payroll is equal to or exceeds the threshold amount, however, are subject to the Training Guarantee obligation. 'Public benevolent institutions' (except public hospitals) are exempted from the Training Guarantee levy. 'Public benevolent institution' is a legal term which refers generally to an institution, not carried on for private gain, whose object is the relief of poverty, sickness, distress, misfortune, destitution or helplessness. Such an institution is defined as being for the benefit of a section or class of the public where relief is available to every member of that section or class without discrimination. (Public benevolent institutions are also exempt from Fringe Benefits Tax and Sales Tax.)

77. Dr S Lutton, Acting Director, Postgraduate Centre for Psychiatric Research and Education, RANZCP, Western Australian Branch. Submission, p2.
78. P Stanley, Under Secretary, Queensland Department of Health. Submission, p19.
79. For further information on the problems associated with rural and isolated areas, refer to Chapter 22 — People in Rural and Isolated Areas.
80. Kenny, *op cit*, pp8-9.
81. Weir, *op cit*, p56.
82. See for example, Andrews, (oral evidence and *The Tolkien Report*) *op cit*.
83. See for example, Kenny, *op cit*.
84. Prof B Waters, Professor of Child and Adolescent Psychiatry at the University of NSW, Head of the Department of Child and Adolescent Psychiatry at Prince of Wales Children's Hospital and Chairman of the Health Department's Advisory Committee on Child and Adolescent Mental Health Services. Oral evidence, Sydney 17.6.91, p20.
85. Kenny, *op cit*, p9.
86. See for example, submission by Lutton, *op cit*.
87. *ibid*, p1.
88. Andrews, *The Tolkien Report*, *op cit*, p24.
89. Weir, *op cit*, p57.
90. *ibid*, p55.
91. *ibid*, p51.

92. See Chapter 8 — Inpatient Care and Treatment, and Chapter 9 — Community Care and Treatment, for evidence from consumers.
93. A Newham, Executive Director, Alliance for the Mentally Ill — Australia, NSW. Submission, pp2-3.
94. Residents of the Fintry Bank Supported Accommodation Project, Victoria. Submission, pp3-4.
95. Lutton, *op cit*, p2.
96. Dr S Byrne, Hon. Secretary, RANZCP, Western Australian Branch. Submission, pp2-3.
97. Dr J Ellard, NSW. Submission, 'Chelmsford and After', *Modern Medicine of Australia* Aug 1990. p90.
98. Lutton, *op cit*, p2.
99. Kenny, *op cit*, p9.
100. Lutton, *op cit*, p1.
101. Weir, *op cit*, p52.
102. See Chapter 8 — Inpatient Care and Treatment.
103. See for example, Lutton, *op cit*.
104. *ibid*, p1.
105. Notably Chapter 8 — Inpatient Care and Treatment.
106. McGuinness and Wadsworth, *op cit*, p16.
107. A Davis, Executive Officer, Association of Relatives and Friends of the Mentally Ill (ARAFMI) NSW. Oral evidence, Sydney 18.6.91, p156.
108. Prof H Brodaty, State and Federal President, Alzheimers Association. Oral evidence, Sydney 19.6.91, p263.
109. Andrews, *The Tolkien Report*, *op cit*, pp20-21.
110. Prof J Snowdon, School of Community Medicine, University of NSW. Oral evidence, Sydney 20.6.91, p510.
111. N Rowlands, Australian Psychological Association. Oral evidence, Orange 12.7.91, p946.
112. 'Health Care For All Australians: 1992-93 Reforms', *Budget Related Paper No.8*, AGPS, Canberra 1992, p27.
113. *ibid*, p32.
114. The Federal Government made available \$17 million in the 1992-93 budget to encourage general practitioners to broaden their role beyond the level of individual patient care, to improve access to after hours services and allied health services and to support the establishment of local networks or 'divisions' of general practice.
115. Prof J Webster, Professor of Community Medicine, University of NSW and President, NSW Association for Mental Health. Oral evidence, Sydney 20.6.91, p458.
116. P Fanning, Chief Executive Officer, Orange Health Service and Director of Psychiatric Services, Central Western Health Region. Oral evidence, Orange 12.7.91, p884.
117. See, for example, Chapter 17 — Elderly People.
118. Australian Health Ministers' Conference, *National Mental Health Policy*, AGPS, Canberra 1992, pp26-27.
119. Australian Nursing Federation Policy Statement on Nurse Education — Comprehensive Curriculum, adopted by the Federal Council, 1989, p2.
120. *ibid*, p2.



121. S Delacour and G Curry, 'From the "Deep Minoan Regions": Marginalisation of Psychiatric Mental Health Nursing in Tertiary Curricula', *Proceedings of ACMHN Inc 17th Convention*, 1991, p151.
122. G Curry, Senior Lecturer, School of Nursing, University of Technology, NSW. Submission, p4.
123. id.
124. *ibid*, p5.
125. Vidovich, *op cit*, p2.
126. Cox, *op cit*, p23.
127. Vidovich, *op cit*, p7.
128. *ibid*, p2.
129. D Jones, Secretary, Queensland Nurses Union. Submission, pp10-13.
130. Andrews, *op cit* (oral evidence), p47.
131. The Institute was established in 1964 and is, through its Board, directly responsible to the NSW Minister for Health. The Board is comprised of nominees from a number of universities, the NSW Department of Health and the RANZCP. It is a statutory body, independent of any individual university or teaching institution.
132. Dr T Williams, Director of the NSW Institute of Psychiatry. Oral evidence, Sydney 18.6.91, p188.
133. *ibid*, p190.
134. Kenny, *op cit*, pp3-4.
135. E Nimri, Executive Officer, Mental Health Coordinating Council, NSW. Submission, p7.
136. Commissioned by the Office on Disability of the NSW Premier's Department, 1990.
137. W Weir, *Report on Project Commissioned by the Disability Services Coordination Unit of the Premier's Department of NSW for the Ministerial Committee on Disability*, 1990.
138. *ibid*, pp4-5.
139. *ibid*, p5.
140. See Chapter 8 — Inpatient Care and Treatment, for evidence regarding police and ambulance officers.
141. Senior Constable H Adams, Community Policing Squad — Victorian Police Department, in oral evidence (Victoria 9.4.91 pp188-199) outlined the role of police officers in dealing with children and adolescents affected by mental illness. Senior Constable Adams told the Inquiry that Victorian police are often called to a situation in times of crisis — and usually as a last resort when other avenues have proved inadequate or fruitless. In these instances, children and adolescents affected by mental illness who display violent or suicidal tendencies are often forcibly removed. While several juvenile psychiatric facilities exist in Melbourne, these facilities have limited bed capacities. As a result, many are placed inappropriately in juvenile detention facilities. (See also Chapter 20 — Children and Adolescents.)
142. S Madex, South Australia. Submission, p1.
143. R Hearne, *Locked Up, Locked Out: The Denial and Criminalisation of Young People's Mental Health Crisis*, Young People, Mental Health and Criminal Justice System Project, Victorian Community Managed Mental Health Services Inc, 1993.
144. See Chapter 13 — Education and Training.
145. C Flynn, Policy/Administration Director, Mental Health Coordinating Council, NSW. Submission, p16.

146. J Said, Executive Director, After Care Association, Chairperson of the Mental Health Coordinating Council. Oral evidence, Sydney 17.6.91, p34.
147. J Clarke, Central Queensland Multidisciplinary Psychiatric Team, Division of Psychiatric Services, Queensland. Submission, p3.
148. A Davis, Executive Officer, Association of Relatives and Friends of the Mentally Ill (ARAFMI). Oral evidence, Sydney 18.6.91, p158.
149. The Australian Youth Foundation was previously known as the Bicentennial Youth Foundation.
150. Davis, op cit, pp158-159.
151. In addition to their schools education program, ARAFMI also wish to incorporate a core mental health education program into every first-year university course — so that future doctors, nurses, lawyers, teachers, police officers, social workers, politicians and public servants will have a greater awareness of mental illness.
152. Dr R D Jamieson, Faculty of Health Sciences, Bendigo College of Advance Education, Victoria. Submission, p1.
153. Davis, op cit, p157.
154. P Martyn, Regional Coordinator Mental Health Services, NSW Health Department, North Coast Region, NSW. Submission, pp5-6.
155. Association of Relatives and Friends of the Emotionally and Mentally Ill (ARAFEMI) Victoria. Submission, p6.
156. Kenny, op cit, pp3-4.
157. J Gee, Mental Health Legal Centre, Victoria. Submission, p13.
158. Residents of the Fintry Bank Supported Accommodation Project, Victoria, op cit, p2.
159. P Carberry, Association of Relatives and Friends of the Mentally Ill (ARAFMI), Western Australia. Submission, p3.
160. ARAFEMI Victoria, op cit, pp6-8.
161. M Harries, Australian Association of Social Workers, WA. Submission, p4.
162. Flynn, op cit, p19.
163. ARAFEMI, op cit, p8.
164. This is a key element of the ARAFMI schools program funded by the Australian Youth Foundation and referred to earlier in this chapter.
165. Martyn, op cit, p6.
166. M Long, consumer, NSW. Submission, p2.

# Chapter 7

## DEVELOPMENTS SINCE THE INQUIRY BEGAN

A number of significant developments have occurred at both the Federal level and in individual States and Territories since the Human Rights Commissioner formally announced the Inquiry in June 1990. The most significant of those which the Inquiry has been able to identify are tabulated in this chapter.<sup>1</sup>

Many of these developments, incidentally or coincidentally, were closely related to evidence of serious deficiencies in legislation, policies and programs for the mentally ill presented to the Inquiry.

### Federal

#### Policy

- June 1990 • The Commonwealth and State Social Welfare Ministers establish a Working Party to develop a national framework for funding and operation of disability services.
- Oct 1990 • A Special Premiers' Conference endorses the proposed national framework for disability services.
  - Publication of a draft *Charter of Consumer Outcomes* — Report of the Mental Health Task Force to the Australian Health Ministers' Advisory Council (AHMAC).
- March 1991 • AHMAC adopts the *Charter of Consumer Outcomes* as the Mental Health Statement of *Rights and Responsibilities*.
  - The Commonwealth relaxes its discriminatory policy of denying patients who had been in a State psychiatric facility for more than twelve months access to Federally funded nursing homes.

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<sup>1</sup> This chapter covers developments in the period from 1 June 1990 to 1 April 1993.

- July 1991 • Heads of Government sign the Commonwealth-State Disability Services Agreement at a Special Premiers' Conference.
- Aug 1991 • The Mental Health Task Force reporting to the Overarching Committee on Health And Aged Care and to AHMAC produces an initial report.
- Oct 1991 • Mental Health Policy Section established in the Department of Health, Housing and Community Services.
- Nov 1991 • Commencement of the Disability Reform Package. (Amendments to the *Social Security Act 1990*.)
- Dec 1991 -  
Jan 1992 • National consultations held concerning the development of a National Mental Health Policy.
- April 1992 • AHMAC adopts the National Mental Health Policy.
- May 1992 • The National Mental Health Policy launched by the Federal Minister for Health, Housing and Community Services and the Victorian Health Minister.
- Aug 1992 • Establishment of a National Consumer Advisory Group. (The title is subsequently amended, in 1993, to the National Community Advisory Group.)
- Feb 1993 • Release of the Mental Health Workforce Committee's discussion paper on Mental Health Workforce Issues.
- March 1993 • Reorganisation of the Health and Community Services portfolios. The Deputy Prime Minister and Minister for Housing, Local Government and Community Services retains responsibility for psychiatric disability and mental health issues. The Department of Health, Housing, Local Government and Community Services is created.

## **Legislation**

- Dec 1991 • Passage and part commencement of the *Health and Community Services Legislation Amendment Act*, affecting the approval of hostels and their funding.

April 1992 • Commencement of the rest of the *Health and Community Services Legislation Amendment Act*, amending the *National Health Act 1953* and *Aged and Disabled Persons Homes Act 1954*.

Oct 1992 • Passage of the *Federal Disability Discrimination Act* (covering psychiatric disability).

### **Services**

Sept 1990 • Launch of the *Statement of Rights and Responsibilities* for the Home and Community Care (HACC) Program.

March 1991 • Guidelines for approval of admission to nursing homes relaxed to cover people who have been residents of psychiatric institutions in certain circumstances.

Oct 1991 • Commencement of Vocational Rehabilitation Units for People with Psychiatric Disabilities within the Commonwealth Rehabilitation Service.

Dec 1991 • Launch of national service standards for HACC funded programs, developed by the Commonwealth in consultation with the States and Territories.

April 1992 • Introduction of a three-tiered hostel subsidy scheme involving higher subsidies for accommodating residents with dementia and the phasing out of the Dementia Grants Program.

### **Funding**

May 1992 • Announcement of \$52 million (over five years) from the Better Cities Program to upgrade mental health facilities in Victoria by providing new beds for psychiatric patients, primarily in general hospitals, and improved community services.

Aug 1992 Budget announcements -

- Inclusion of the National Mental Health Program funding arrangements in the new Medicare Agreements.

- \$135.2 million to be provided over six years to implement the National Mental Health Plan. The funding initiatives include:
  - a) \$106 million to be paid directly to States and Territories to allow the introduction of additional services and facilitate the transfer of patients from institutional to community-based care;
  - b) The balance of Program funds to be used to support a program of structural reform at the national level; mental health workforce training and redistribution; the development of a national mental health data collection strategy; innovation in service delivery; national service standards; education and promotion; evaluation; and research (including the establishment of a National Network of Brain Research). \$17 million to be provided for projects of national significance in priority areas.
- An increase in the Domiciliary Nursing Care Benefit from \$21 to \$26 per week.
- Allocation of \$150 million over three years (1992-1993 to 1994-1995) for a new community housing program.
- Allocation of \$31 million over five years for the implementation of a National Action Plan for Dementia Care.
- Allocation of \$17 million to encourage general practitioners to broaden their role beyond individual patient care, to improve access to after hours services and allied health services and to support the establishment of local networks or 'divisions' of general practice.

## **New South Wales**

### **Legislation**

- Sept 1990 • Commencement of the *Mental Health Act 1990*.
- Aug 1992 • The Committee appointed to monitor the implementation of the *Mental Health Act 1990* reports to the Minister for Health.

## Services

- Sept 1990 • A Mental Health Act training program commissioned through the Institute of Psychiatry for professionals and other interested groups, including consumers.
  
- Oct 1990 • Funds provided to establish or enhance Community Mental Health Services in Eastern Sydney, Southern Sydney, Wentworth, Western Sydney Area and North Coast Region, South Coast Region and New England Region.
  - Funds provided to extend Community Child and Adult Mental Health Services in the Western Sydney Area.
  - Funds provided to extend Psychogeriatric Outreach Services to the North Coast, New England, Orana and Far West Regions.
  
- Dec 1990 • Release of the final Report of the Royal Commission of Inquiry into Deep Sleep Therapy. (The Chelmsford Hospital Inquiry.)
  - Ward 21 at Morisset Hospital (a ward for forensic patients) is closed and some patients transferred to the new Long Bay Prison Hospital.
  
- April 1991 • Funds provided to acquire additional supported accommodation for the mentally ill in Southern Sydney, South Western Sydney, Western Sydney, South West Region, North Coast Region and Wentworth.
  - A 30 bed acute psychiatric admission unit opened at Nepean Hospital.
  
- May 1991 • The Department of Health releases a report on Aboriginal mental health in NSW.
  
- June 1991 • Special purpose units for the confused and disturbed elderly (CADE) opened at Wingham and Goulburn.
  
- July 1991 • A psychiatric suite opened at Broken Hill Hospital.
  
- Aug 1991 • A psychiatric suite opened at Dubbo Base Hospital.

- *Guidelines for the Integration of Hospitals and Community Mental Health Services* published by the Department of Health.
- Sept 1991 • *Standards of Care for Area Integrated Mental Health Services* published by the Department of Health.
- Nov 1991 • A new domestic cottage development (20 units) opened at Cumberland Hospital for the rehabilitation of patients back into the community.
- Dec 1991 • The Western Sydney Regional Information and Research Service releases a report indicating a particular lack of mental health services in the western region of Sydney.
- Feb 1992 • A 20-bed psychiatric rehabilitation unit opened at Shellharbour Hospital.
- The first Clinical Professor of Forensic Psychiatry appointed.
- April 1992 • Opening of a 30-bed acute psychiatric admission unit at Manly Hospital.
- Opening of two psychiatric rehabilitation units at Kenmore Hospital.
  - A new 20 bed hostel and acute admission unit opened at Macquarie Hospital.
  - A new 40 bed acute psychiatric admission unit opened at Blacktown Hospital.
  - CADE units opened at Mt Druitt Hospital and Lottie Stewart Hospital, Dundas.
  - Release of the NSW Mental Health Strategic Plan for the development of services in the next two decades.
- May 1992 • A CADE unit opened at Wagga Wagga.
- July 1992 • Five cottages opened at Rozelle Hospital for the rehabilitation of patients back into the community.



- Sept 1992 • Amalgamation of Gladesville and Macquarie Hospitals under one administration.
- Release of a revised version of the computerised psychiatric client register (CRISP), incorporating an inpatient component.
- Oct 1992 • Release of *A Double Jeopardy* — a report on dementia in clients of non-English speaking backgrounds.
- Dec 1992 • Closure of two wards (72 beds) at Gladesville Macquarie Hospital.

### **Funding**

- Aug 1991 • Removal of the specially guaranteed allocation of funding to mental health.
- June 1992 • Recommendation by the Northern Sydney Area Health Service that \$2 million be cut from the budgets of Macquarie and Gladesville Hospitals, necessitating the closure of three wards at Gladesville and one ward and administration functions at Macquarie.

## **Victoria**

### **Legislation**

- April 1990: • Commencement of the *Community Protection Act 1990*, giving the Victorian Supreme Court power to order the preventive detention of Mr Garry David.
- Oct 1990 • The Victorian Law Reform Commission releases its report on *Mental Malfunction and Criminal Responsibility*.
- Jan 1991 • Commencement of amendments to the *Mental Health Act 1986* under the *Mental Health (General Amendment) Act*.
- April 1992 • Commencement of the *Sentencing Act 1991*, providing for hospital security orders for those convicted of crimes and in need of psychiatric treatment.

## Services

- Oct 1990 • The Department of Health establishes a Board of Inquiry to investigate circumstances surrounding the death of a patient at Lakeside Psychiatric Hospital.
- Jan 1991 • Closure of the inpatient ward at Parkville Adolescent Psychiatric Unit.
- April 1991 • Report of the Inquiry into the Administration of Lakeside Psychiatric Hospital.
  - The Minister for Health announces a Statewide audit of psychiatric services in Victorian psychiatric hospitals.
- May 1991 • Establishment of a special Task Force in the Department of Health to investigate services and specific allegations of staff misconduct at Aradale Psychiatric Hospital.
- Nov 1991 • The Office of Psychiatric Services commences a review of its child, adolescent and family programs.
  - The special Task Force in the Department of Health reveals widespread abuses and neglect at Aradale Psychiatric Hospital.
- Dec 1991 • Announcement by the Government of its intention to close Aradale Psychiatric Hospital by July 1993.
- Jan 1992 • Release of a report on *Policy and Strategic Directions for Psychiatric Services in Victoria*.
- Feb 1992 • Commencement of the Mental Health Patients' Advocacy Scheme.
- Aug 1992 • Opening of the Early Psychosis Research Centre at the Parkville Centre (a psychiatric outpatient clinic).
- Feb 1993 • *New Directions for Juvenile Justice* implemented.
  - *Discharge Planning Guidelines for Psychiatric Services in Victoria* released.

## **Funding**

- May 1992 • Receipt of \$52 million (to be spent over five years) from the Better Cities Program for capital works to upgrade mental health services in Victoria.

## **Queensland**

### **Legislation**

- Aug 1991 • Review of the State's mental health legislation commences.
- Sept 1991 • Passage and commencement of the *Mental Health Amendment Act*, allowing Patients' Review Tribunals to be chaired by persons other than currently serving District Court judges.
- Dec 1991 • Passage of the State anti-discrimination legislation, covering psychiatric disability and mental illness.
- Completion of negotiations with the Human Rights and Equal Opportunity Commission to administer the State anti-discrimination legislation.
  - Passage of the *Health Rights Commission Act*.
- June 1992 • Commencement of the operation of the State *Anti-Discrimination Act 1991*.
- Dec 1992 • The Minister for Health announces new mental health legislation is expected to go before Parliament early in 1993 (following the release of the Human Rights and Equal Opportunity Commission's Background Paper on *Mental Health Legislation and Human Rights*).

### **Services**

- Feb 1991 • Release of the report of the Commission of Inquiry into the Care and Treatment of Patients in the Psychiatric Unit (Ward 10B) of Townsville General Hospital.
- July 1991 • Announcement of regionalisation of administration of health care in Queensland.

- Nov 1991 • Seminar for Official Visitors conducted as part of the review and restructuring of the Official Visitors program.
- April 1992 • Publication of an information kit for Regional Quality Assurance Coordinators (Mental Health).
- June 1992 • Publication of draft Minimum Service Standards for Mental Health Services in Queensland.
- Oct 1992 • Appointment of a psychiatrist to implement programs to improve mental health in remote North Queensland, particularly among Aboriginal and Torres Strait Islander people.

### **Funding**

- Dec 1992 • The Minister for Health announces the Queensland Government has committed \$22 million to a capital works program to build psychiatric facilities in regional centres.

## **South Australia**

### **Legislation**

- Oct 1991 • The SA Law Reform Commission recommends that the *Equal Opportunity Commission Act 1984* be extended to cover discrimination on the ground of mental illness.
- May 1992 • Introduction into Parliament of the Mental Health Bill 1992 and the Guardianship and Administration (Mental Capacity) Bill 1992.

### **Services**

- April 1991 • Announcement that Hillcrest Psychiatric Hospital will be closed down. (No firm commitment that all funds saved will be expended in the mental health area.)
- Aug 1991 • The South Australian Mental Health Service (SAMHS) established as a separate statutory authority responsible for the administration of mental health services.

- March 1992 • Opening of the Child and Adolescent Forensic Psychiatry Unit at the Adelaide Children's Hospital.
- May 1992 • Relocation of first 30 beds from Hillcrest Hospital and transfer of patients to Glenside Hospital.
- Dec 1992 • The Minister for Health dissolves the Board of the South Australian Mental Health Service and appoints a temporary administrator (following the death of a psychiatrist at the hands of a patient).

## Western Australia

### Legislation

- Sept 1990 • Passage of the *Guardianship and Administration Act*.
- Nov 1990 • Publication of a Discussion Paper by the WA Mental Health Act Review Working Party.
- July 1991 • Release of the WA Law Reform Commission Report on the *Criminal Process and Persons Suffering from Mental Disorder*.
- June 1992 • Introduction into Parliament of health complaints legislation.
- July 1992 • Implementation (but only partially) of the *Guardianship and Administration Act 1990*
- Dec 1992 • Draft Mental Health Bill 1992 released for comment.

### Services

- Aug 1990 • A Working Party, established by the Minister for Health, reports on the *Care of Patients in Psychiatric Hospitals*.
- Feb 1991 • A Working Party, established by the Minister for Health, reports on a *Review of Multicultural Psychiatric Services in WA*.
- Nov 1991 • Report of the Rehabilitation Advisory Group on Community Based Rehabilitation and Support Services.

March 1992 • A Task Force to review child and adolescent services in WA is established by the Minister for Health.

Feb 1993 • Revised *Aftercare Policy* released.

## **Funding**

Dec 1991 • The Minister for Health announces that the 1991-92 budget for mental health services is to be quarantined from reductions and that a total of \$4.3 million is to be spent over the next 18 months on several new initiatives designed to upgrade psychiatric services in WA.

July

Sept 1992 • The Minister for Health announces an extension of the mental health budget quarantine and funding for

a) community mental health services (including mobile teams) in rural areas;

b) community rehabilitation and support services in the metropolitan area;

c) child and adolescent services;

d) a Chair of Child and Adolescent Psychiatry at the University of Western Australia.

## **Tasmania**

### **Legislation**

March 1991 • The Department of Health releases a discussion paper on *A Health Consumers' Complaints Mechanism for Tasmania*.

April 1992 • The Department of Health releases a discussion paper on *A Review of Mental Health Legislation*.

Dec 1992 • The Minister for Health announces that Cabinet will consider new mental health legislation early in 1993 (following the release of the Human Rights and Equal Opportunity Commission's Background Paper on Mental Health Legislation).

## **Services**

- July 1991 • Closure of the Devon Clinic, a psychiatric inpatient facility in Devonport.
- Responsibility for the administration of mental health services transferred from the Division of Psychiatric Services in the Department of Health to Regional Boards (Southern, Northern and North-Western).
- Nov 1991 • Announcement that a Select Committee of the Legislative Council is to inquire into health services, including psychiatric services, in the North West and West Coast of the State.
- Dec 1991 • The Premier announces a special inquiry by Prof Joseph Correy into the circumstances surrounding the death of Mr Kenneth Wootton.
- June 1992 • Prof Ross Kalucy appointed to review psychiatric services in the North West.

## **Northern Territory**

### **Services**

- Oct 1991 • Restructuring of the administration of the Department of Health — from four regions to seven health districts.
- The Department of Health approves the Northern Territory Mental Health Care Standards — prepared by the Mental Health Service Quality Assurance Committee.
- Aug 1992 • The NT Government announces (following hearings conducted by the Inquiry in July) that the design of new mental health facilities being built at Royal Darwin Hospital will be modified to ensure that facilities for forensic patients and sex offenders are separate from those for other psychiatric patients.
- March 1993 • Reports on the Reviews of the Mental Health Services of the Darwin Urban District, the Alice Springs Rural and Urban Districts and the Barkly Region are released.

# Australian Capital Territory

## Legislation

- Nov 1990 • The Mental Health Review Committee releases its report, *Balancing Rights*.
- Oct 1991 • Passage of the *Guardianship and Management of Property Act 1991* and the *Community Advocate Act 1991*.
- Dec 1991 • Passage of the *ACT Discrimination Act 1991* (covering psychiatric disability).
  - Completion of negotiations with the Human Rights and Equal Opportunity Commission to administer the discrimination legislation.
- Jan 1992 • Commencement of the *Community Advocate Act 1991* and the *Guardianship and Management of Property Act 1991*, replacing the guardianship provisions of the *Lunacy Act 1898* (NSW).
  - Commencement of the *Discrimination Act 1991*.
- Feb 1993 • The Minister for Health responds to the *Balancing Rights* report, announcing that the Government will implement most of its recommendations.

## Services

- Dec 1990 • An After Hours Mental Health Crisis Team begins operation in the ACT.
- Sept 1991 • Opening of the psychiatric ward (Ward 15) at Woden Valley Hospital.
- Jan 1992 • The Guardianship and Management of Property Tribunal and the Community Advocate commence operation.
- Oct 1992 • The Minister for Health announces the establishment of a Mental Health Review Tribunal; a Case Management Scheme and a new Mental Health Advisory Council comprising



representatives of mental health consumers, carers and community groups.

## **Funding**

- Sept 1992
- Funding is announced for the Mental Health Review Tribunal and Case Management Scheme and for the establishment of a Forensic Service; an Intensive Care Team for the Seriously Mentally Ill; and an Outreach Service for Adolescents with Mental Health Problems.

## **Part II**

# **Living with Mental Illness**

## Chapter 8

# INPATIENT CARE AND TREATMENT

You go inside, they lock the door, the windows are barred. You're questioned and questioned, you wait and wait, you are cold and hungry, but no one offers you a meal. You hear people screaming. You are told to undress and are given a hospital nightgown and slippers and your possessions are taken away. You are given injections, not knowing why or what they will do to you.<sup>1</sup>

There was no privacy or dignity whatsoever for the patients, and very disturbed people were crowded together in a locked ward with untrained staff. The psychiatrist in charge subsequently admitted that there was no healing for anyone in there.<sup>2</sup>

## Pre-Admission and Admission

### Crisis Arrangements

My daughter's first admission involved so many horrific experiences that it was almost worse than the schizophrenia.<sup>3</sup>

The recurring nature of some mental illnesses means that emergencies requiring professional intervention will inevitably occur. In all States and Territories the Inquiry received extensive evidence from consumers and family members concerning their experiences during these episodes and the problems and procedures they confronted in obtaining assistance.

Apart from the confusion, fear and pain associated with such psychiatric crises, the Inquiry frequently heard accounts of suffering compounded by inappropriate or inadequate responses from a range of professionals and institutions in trying to deal with these emergencies. There was also evidence about people receiving helpful and appropriate assistance.

Most of the evidence submitted to the Inquiry about psychiatric emergencies and hospital admissions related to situations in which individuals did not want to go to hospital and were detained against their will. (The legal issues relating to involuntary detention in different States and Territories are addressed in Chapters 3, 4, and 29.)

Relatively few urban areas in Australia are serviced by mental health crisis teams<sup>4</sup> — and a number of the emergency teams which do exist are not available outside regular hours. Outside major metropolitan centres, however, there are very few specialised emergency mental health teams at all.

The Inquiry repeatedly heard evidence of people experiencing psychiatric emergencies out of hours — at weekends or at night. Several accounts were presented by those who had been ill themselves, but most came from relatives, support organisations and health professionals.

We would certainly stress the need for a 24-hour service. It is essential — many crises occur for the mentally ill at night time. The gulf between things happening in the home and people getting help and knowing where to turn is outstandingly wide. I understand that 24-hour services are written into the legislation, but they don't exist yet, except in one or two places.<sup>5</sup>

Crisis teams play an important part in the prevention of hasty hospitalisation...the mentally ill deserve a chance to [use] this service, no matter what time of the day or night their crisis occurs... Due to lack of funding, some crisis teams are available till only 5 pm, others finish at 10 or 11. Only a few at this stage cover the full 24 hour period. I have never yet met a mentally ill person who can [be relied on] to have his crisis during business hours.<sup>6</sup>

Evidence presented indicated that in places where there are no mental health community crisis workers it is very difficult to obtain inpatient treatment for someone who appears to be gravely disordered and who does not, or is not able to, seek treatment. One submission to the Inquiry, from the daughter of a 74-year-old woman who needed urgent treatment, stated:

I visited the GP...when the situation rapidly became worse. His response was that, unless she walked into the surgery and asked for treatment herself, there was nothing he could do... I did manage to get my mother in the car and drive to hospital — about half an hour's drive. I do not believe it was a safe thing to do because, apart from her agitated condition, I was extremely stressed myself and had not slept for two days. Once she was admitted, the care she received was excellent and the people responsible for her care were wonderful. The problem lay in trying to get badly needed medical attention... I can truthfully say I was appalled, shocked and angry... [I had] no previous experience of the system [and] did not know the ropes. I do not believe that what happened is in any sense acceptable.<sup>7</sup>

The need for an experienced mental health professional to assist individuals in crisis in a humane and professional way was raised repeatedly by carers of people with mental illness (usually close family members). Many witnesses expressed deep concern about the lack of assistance available, and the necessity to involve police. The following account is typical of many presented.

I suffered a severe depressive episode which was badly mismanaged. In the course of it, I was forcibly committed to a mental hospital, with police dragging me from my home, punitive custodial staff mocking at me and physically hurting me... The process itself of being forcibly detained is distressing, but to [show you are] upset by it or to exhibit anger or despair or agitation is to 'prove' oneself 'ill' or 'disturbed'. There must be better ways of responding to people's need for care and treatment which protect dignity, self respect,

privacy and self-determination, even — and especially — when they seem not to have the wit to function. Funding agencies such as community provision of crisis help in practical, comforting and healing ways, such as some of the crisis teams now do, must become a priority. But of course, there are far too few of them, and some have very short hours.<sup>8</sup>

The former clinical director of the Psychiatric Emergency Team in Perth told the Inquiry that:

[In order to get help in a crisis before the Psychiatric Emergency Team was established], what was required was usually some form of disruptive or dangerous behaviour by the person, which would then mobilise the authorities — police, medical practitioners — to go through the appropriate channels under the Mental Health Act to get people into hospital. These delays led to immense (and largely unnecessary) suffering on the part of the individual... I used to think 'What if this person could have been brought to hospital three weeks ago'... I think, without any doubt, the Psychiatric Emergency Team has been the most innovative measure taken by the Health Department in psychiatry in the last twenty years... People who are seriously ill frequently take active measures to avoid treatment. Unless the Health Department provides a flexible, community-based service which will go out to that person wherever he or she may be, make a sound assessment and appropriate intervention, a person who is psychotically ill with no insight will get no treatment or else delayed treatment... A service that does not go to the patient in [that] sort of circumstance — that is tantamount to neglect, gross neglect.<sup>9</sup>

Some of the most disturbing issues emerging from the evidence concerned the vexed social, emotional, legal and practical issues surrounding admission — and failure to obtain admission — to a psychiatric hospital or ward. Evidence presented covered difficulties with both voluntary and involuntary admissions.

### **Difficulty In Gaining Voluntary Admission**

In all States and Territories the Inquiry heard evidence concerning problems experienced in gaining admission — both in cases where treatment was actively sought as well as where it was resisted. A number of witnesses had been unable to gain voluntary admission to a psychiatric facility when they felt they badly needed it. In some cases this denial of assistance had tragic results.<sup>10</sup>

In a number of cases cited to the Inquiry these 'tragic results' (sometimes involving the death of the individual) followed almost immediately on failure to gain admission to, or discharge from, a hospital or psychiatric institution. While it is impossible to definitively establish a causal connection, the evidence is particularly disturbing:

I currently have to look after an area of Melbourne...with fewer beds than downtown Trieste in Italy where they have actually outlawed psychiatric hospitals by government decree. As a result my patients' rights for adequate treatment of their illnesses are denied to them.

It is very difficult in Melbourne today to find a bed in a psychiatric hospital. Occupancy rates hover around 100 percent despite decreases in length of stay. The last thing that you, trying to get your 17-year-old ill daughter into hospital, want in a time of such dreadful crisis is to have to search around Melbourne for beds, to argue with admitting officers who are contesting your need for admission as they defend the last bed they have in case of some even greater crisis.

Further, this is not consistent with safe standards of care. The daily preoccupation of staff in hospitals is to discharge people to make room for more urgent crises rather than concentrating on the patient's treatment needs or their discharge planning needs.<sup>11</sup>

The Mental Health Foundation in the Australian Capital Territory, having described the substantial difficulties faced by consumers seeking voluntary admission to inpatient psychiatric facilities in some detail, concluded:

Persons suffering from mental illness experience great difficulty in being accepted for treatment...on their own assessment of their mental situation. Chronic sufferers know the signs of impending crisis, but are unable to persuade those in control of admissions that they are unwell enough to be admitted and they are turned away. Frequently, the sufferer is admitted a week later in a severe crisis, requiring longer term stay and [being given] heavier doses of medication than they...would have if admitted when they themselves first noticed the symptoms.<sup>12</sup>

This summary also accurately characterised a great deal of evidence in other jurisdictions.

### **Involuntary Detention**

Involuntary detention — for any reason and under any circumstances — is an extremely serious matter involving curtailment of several fundamental rights, the most important of which is the right to liberty. The Inquiry received extensive evidence on this subject, particularly from consumers.<sup>13</sup>

The ways in which involuntary detention and other circumstances associated with admission seriously — and frequently deleteriously — affected people's lives were frequently raised in all jurisdictions.

### **Difficulty In Gaining Involuntary Admission**

Families and other carers are faced with a dilemma when the person for whom they are responsible has lost touch with reality and has insufficient insight into his or her condition to accept the need for treatment. Many witnesses recounted the difficulties they experienced in attempting to gain hospital admission for someone experiencing an acute episode of schizophrenia — and the reluctance of health professionals to take account of relatives' information about the situation.

## **A parent whose son has schizophrenia told the Inquiry:**

He was highly functioning when the illness first struck...that all deteriorated. By this time he had withdrawn from the University, he had withdrawn from the family, spent most of the time in his own room and needed prompting for basic skills like showering, cleaning his teeth... Things were deteriorating rapidly... It took 6 months to get into the public system because he would not voluntarily go... We were heading for a little volcano explosion... We had to [reach] a situation where the police would come and take him to hospital.<sup>14</sup>

**A Schizophrenia Fellowship member highlighted another issue which recurred frequently in evidence from carers — the capacity of some ill individuals to present well at a psychiatric assessment interview, in spite of the fact that their behaviour at home is out of control.**

The admitting doctor at the hospital might, after a brief examination of the young person, who's putting on a great act of being absolutely normal, refuse to admit him for treatment. For very good legal reasons, he will not admit the young person, because he is showing no signs of psychosis, despite the evidence from the family.<sup>15</sup>

**The Inquiry repeatedly heard evidence from family members about their frustration and impotence:**

Carers often know weeks in advance that their loved one needs help, but help is not forthcoming... The rules say the patient must be a danger to himself or others before any action can be taken... The threat of suicide does not seem to be taken as a threat to himself... These patients need to be treated immediately, honestly and with dignity, the same as someone suffering from a physical illness.<sup>16</sup>

Families can often highlight the early warning signs, which are usually rather individual to the person and can be easily recognised within the family. Carers feel they have the right to expect credibility in this area... Good liaison at this point can prevent tremendous disruption to the life of the sufferer and the relatives... But health workers are afraid they might be seen to be invading rights... It is damaging to the welfare of the sufferer, who need not have been allowed to deteriorate so badly... Mental health workers appear to be reluctant to take the responsibility for early intervention and to admit people to hospital if necessary.<sup>17</sup>

**This evidence was supported in submissions from people outside the immediate families — neighbours, health workers, students and lawyers. One Victorian health worker remarked on the inflexibility of admission criteria:**

Cases have occurred where a worker has observed a build-up of disturbed behaviour over a period of time, but finds these observations are ignored when seeking specialist intervention. The nature of the admission criteria appears to be based [only] on the presenting behaviour, ignoring what has occurred in the immediate past. A similar criticism has been made [to the agency] by carers, who...have come to recognise the

imminent onset of a crisis...[but] this knowledge has not been given any credibility by OPS<sup>18</sup> staff. They feel that the illness has to reach a crisis point before they can gain access to service and treatment.<sup>19</sup>

One novel — and outrageous — approach to the problem of ensuring that a person experiencing an acute episode gains admission to an inpatient facility was addressed in a consumer's submission discussing the difficulties faced by rural people in gaining access to a city psychiatric facility:

In the mid-North of this State the mentally ill are transported to hospital in the Metropolitan area, 220km away... They are not allowed to be given any form of tranquilliser to calm them [during the journey], because they have to be kicking and screaming when they get assessed at [the hospital], in order to be admitted.<sup>20</sup>

Overall, the evidence established that the most appropriate response to this problem lies not so much in the relaxation of admission criteria as in the provision of adequate facilities, including community mental health services — so that they can provide an appropriate range of intensive treatment and support services — including before a crisis arises. Clearly there will always be a need for some people to be treated in hospital, at least for a short period, and in some cases, over a much longer period of time.<sup>21</sup> This reality is recognised by the families affected.

### **Transport To Hospital**

Traditionally, persons warranting involuntary admission to a psychiatric hospital have been transported by police, invariably in the rear of a divisional van...<sup>22</sup>

Some of the most traumatic experiences reported to the Inquiry concerned forcible transportation to hospital. Evidence from consumers and carers highlighted the anguish and humiliation experienced by those involved. Their distress was often aggravated by the involvement of the police:

- He just sat there and they physically had to pick him up. Now, why should he be degraded like this? Us, four police cars outside, five police officers into the home, him screaming, 'Mum, Help me! Dad! Help me!' Now, why should they be degraded and we be degraded like that, really? That's what it comes to here. And I am only one person. This happens to everyone here, because that person is allowed to deteriorate to such an extent that this has got to happen. It has happened a dozen times to me, and it is really bad — absolutely — it is disgusting.<sup>23</sup>

- At this point, the police arrived. Without exchanging a single word, they threw me in the back of a van, where I had to crouch (no headroom)... The trip was dangerous and uncomfortable as I could not sit up, was not secured, but thrown around in the rear of the vehicle. There was no seat, only a dirty floor... As a result of this, I am now being



victimised by the neighbours and am now also fearful of the police... I spotted two police in the street while shopping recently and suffered an anxiety/paranoia attack.<sup>24</sup>

- People who need stabilisation or hospitalisation in the country are transported in the back of a paddy wagon, regardless of the time of year, regardless of the temperature... In the first week of February from out near Coober Pedy where the temperature outside is 42 degrees in the shade... if they're hot, they're just told to strip off... In terms of human dignity and what it does for the relationship of that person to the rest of the community in which they have to live [afterwards] they have a mental health issue, but suddenly also, there's this whole issue of being carted off by the police.<sup>25</sup>

Even in situations where carers complimented police for handling a difficult situation with kindness and restraint, their involvement was still considered to be inappropriate:

Finally we were forced to call the police. They were wonderful, sensitive, gentle. They gave him time to gather himself and his things. However, the mere fact that he had to be with the police is most distressing — he is not a criminal... He blames us for betraying him by calling them.<sup>26</sup>

Community organisations and welfare agencies generally expressed the view that the presence of a police officer in a situation where a person is neither suspected of, nor accused of, any crime constitutes an infringement of that person's human rights.<sup>27</sup> The frequent association between mental illness and the police was condemned by Dr David Wells, Victoria's Director of the Office of Forensic Medicine, in his evidence to the Inquiry:

Transport of a mentally ill person by police reinforces to the police and to the general public that mental illness is a criminal problem. They've been taken away by police, they've been put in divisional vans and then [sometimes] put in cells, so that even the best efforts of an enlightened group who are saying that mental illness is a health problem are being destroyed by that action.<sup>28</sup>

Witnesses called for greater use of psychiatric emergency teams<sup>29</sup>, the introduction of a nationally consistent policy on the use of ambulance services<sup>30</sup>, and specialist training to equip police to deal more appropriately with involuntary detention should they be required to do so.<sup>31</sup>

### **Admission Procedures**

The Inquiry was told that hospital admission procedures need to be 'dramatically overhauled'<sup>32</sup> to reduce delays and minimise patient distress, particularly when a psychiatric emergency is being handled by the casualty department of a general hospital.

It can take hours, even if you're taken in order of arrival. Quite often, the psychiatric patient is put to the end of the queue...and you have to wait till the others go through first. If there is no psychiatrist on duty at a weekend, you can be told to come back on Monday!<sup>33</sup>

Eight hours have been known to be endured [in casualty], with patients getting out of control and very distressed, much to the amusement of some staff members. I have actually been laughed at in casualty departments... When you are in that kind of state, it is not at all funny for [your] husband and son to see their loved one just being dismissed as an idiot. It would be a very simple matter to just call the psychiatric registrar, particularly when the patient...is known to the psychiatric team in that hospital.<sup>34</sup>

Evidence presented to the Inquiry indicated that staff in accident and emergency departments are simply not trained to recognise, assess or appropriately assist people with mental illnesses.<sup>35</sup> This lack of expertise among the staff of casualty units can have serious consequences. (One example of this problem was the case, reported in Alice Springs, where a patient with a psychiatric history was admitted, solely on that basis, to the hospital's psychiatric ward — even though she was actually suffering from a chronic physical condition which required urgent medical attention.)<sup>36</sup>

This problem is not confined to general hospitals. Although psychiatric hospitals have generally now developed proper guidelines for dealing with acute admissions, witnesses to the Inquiry reported that 'The reality is often very, very different... The guidelines are there, but they're not always used in the ways they were intended.'<sup>37</sup>

Very rarely is a consumer given the chance to participate in decisions relating to assessment and admission.

At present the admission procedure for a client does not allow the client to make an informed choice of where they should receive their treatment. The NSW *Mental Health Act* encourages use of the 'least restrictive' treatment model, but does not address the structures that should be put in place to achieve this goal... It is usually the admitting doctor who decides whether or not the client should be admitted... When a client presents for admission, a dual assessment should be undertaken...which should include the doctor (hospital-based), the community mental health team, and the client... [With] this system, the client is offered options... At present, a client can be admitted to hospital, which is a major life event, and the community team know nothing about this until they visit the admission unit.<sup>38</sup>

Evidence from psychiatrists also highlighted the inconsistencies in admission policies and procedures in different States.

A patient who is admitted as an emergency should, no matter what time of day, or of the week, be promptly assessed, including a physical examination, and...no medication should

be provided until an initial assessment has been completed... The purpose of emergency provisions in any Mental Health Act should be to take control of the situation so that a person can be adequately and promptly examined... In South Australia, for example, it is necessary for an individual admitted on a compulsory order to be examined...within 24 hours. No such provision exists in Tasmania. In Tasmania, indeed, there is no guarantee that the staff in the receiving unit would even know what rights that individual might have.<sup>39</sup>

Another psychiatrist, who had worked in both the emergency department of a psychiatric hospital and a community crisis team, emphasised the importance of utilising a range of specialist expertise to expedite the assessment process.

We assessed [the emergency patients] very quickly and very intensely, using nursing staff, psychologists and social workers, as well as medical staff, to readily assess their problems.<sup>40</sup>

It is clearly unacceptable that so many of the people giving evidence to the Inquiry had experienced long periods of distress (amounting in some cases to post-traumatic stress disorder<sup>41</sup>) as a result of their 'treatment' in hospital during this critical stage of their illness.

### **Procedures Related To Involuntary Detention**

In the case of people with a serious mental illness who do not wish to be admitted to or detained in a psychiatric facility, a hearing before a Tribunal, Magistrate or Board is required in some jurisdictions — either to approve the detention or to review it after a specified period. Many consumers and family members told the Inquiry they found the hearing bewildering and upsetting, due to lack of information and to the attitudes and actions of solicitors appointed to represent the mentally ill person. This consumer's account is typical:

The lack of simple, basic information was annoying and distressing. On my first day in hospital, I asked what my legal rights were. I was never given an answer. I went to the admission hearing without legal advice from the hospital, or from the solicitor representing me. The roles of the people at the hearing were not explained to me. The solicitor did not speak to me at the hearing — he did not say anything to anyone.<sup>42</sup>

The mother of a 19-year-old young woman suffering schizophrenia, who subsequently committed suicide, told the Inquiry in Sydney:

[In relation to] the Magistrate's hearing, I found the public solicitor appalling... The solicitor spoke cheerily to me, my husband and others outside the court, then approached my daughter, with no greeting, and said: 'Are you expecting to get out of this? You haven't got a hope in the world'... I found the inquiry appalling, with a room full of authoritarian people and one little sick girl... Whatever did she do, to deserve this? I have never felt so sorry for anyone on earth in all my life.<sup>43</sup>

Most people involuntarily detained in hospital told the Inquiry how much they resented their detention. Any error made in the decision to hospitalise someone against their will takes time to remedy. The Mental Health Legal Centre in Victoria, addressing unsatisfactory avenues of appeal against a Magistrate's order in that State, told the Inquiry:

One of the most frequent requests we receive...is for us to put into place legal mechanisms they believe will prevent them from being admitted involuntarily into a psychiatric hospital. When their rights of appeal under the *Mental Health Act* are explained, they react with incredulity... There is no immediate avenue to either prevent certification or to discontinue their stay once [involuntary] admission is confirmed... They have a 'right' to appeal at any time, and whilst such an appeal must be heard 'without delay', it is unlikely, for administrative reasons, that it will take place for seven days after lodgement — [longer] in smaller and country hospitals [where] the Board only sits fortnightly — [so] if an admission is found to be wrong on the facts, it can only be remedied by the Review Board [retrospectively]...when the patient may have been in hospital for four to six weeks.<sup>44</sup>

The legal aspects of these issues are dealt with comprehensively in other chapters.

## Clinical Treatment and General Care

While recognising that people who have had positive experiences as psychiatric inpatients may be less likely to give evidence to an Inquiry examining the human rights of people with mental illness, the fact remains that the very large body of evidence received concerning inpatient treatment was overwhelmingly negative.

A great deal of that evidence came from consumers themselves. Notwithstanding the sometimes considerable difficulties for individuals affected by mental illness speaking about their experiences,<sup>45</sup> the Inquiry received over 200 submissions from consumers<sup>46</sup> and consulted with many more at informal mental health issues forums conducted in a number of States. Almost all of these people had experienced inpatient treatment at some time during their illness.

We spent the day in the lounge room, while the staff spent their day in the adjoining room with a large one-way mirror. I felt like an animal in a cage. I was conscious that every move I made was possibly being watched and interpreted for signs of insanity.<sup>47</sup>

I felt a desperate need that the outside world should know what was happening to me — surely someone would rescue me?... There was not anything available to occupy the mind, but I was consistently refused pen and paper.<sup>48</sup>

While the Inquiry received evidence of harassment, intimidation and physical abuse (see later sections of this chapter), the most frequently reiterated concerns related to the way psychiatric patients are devalued, dehumanised and their views ignored. The evidence presented by a community support worker in Tasmania was typical:

[One of our members] was in a ward... [She] is a professional counsellor and has a very serious mental illness.. Her word was the last to be taken as reliable — even ordinary facts about her life history...her food allergies...unless they were independently corroborated, were not taken to be believable... Incorrect [matters] were documented about her, while she herself was not approached to give her own view.<sup>49</sup>

A large number of submissions, both from consumers and carers, indicated that the **physical wellbeing** of people in psychiatric hospitals is frequently neglected. The Inquiry was told of cases where quite obvious medical conditions were not treated and consumers' requests for medical attention were ignored.

I had to endure severe pain due to an injury... Surely, if a person is being detained involuntarily at a hospital, one might expect treatment of medical conditions. It was terrifying for me to be an involuntarily detained individual and yet be denied medical treatment... Is it too much to expect that one's health be protected, when one is in a psychiatric hospital?<sup>50</sup>

In addition to recounting specific experiences and incidents, a number of consumers, members of support groups, academics and clinicians commented adversely on the overall standard of care in psychiatric facilities.

There is a vast range of standards of care, ranging from very, very low quality indeed to very good care in Australia. Unfortunately, in my experience, a lot of it ranges toward the low quality care. I think that has to be addressed and I think consumers need to be asked about that...asked: 'What was useful for you, and was not useful for you'?<sup>51</sup>

A care facility which is physically and psychologically abusive to its clients is not a healing environment.<sup>52</sup>

Leading psychiatrists who gave evidence to the Inquiry in Melbourne and Sydney were scathing in their criticisms of the existing psychiatric hospital system:

I have a 'gold standard' for any psychiatric service... It should be a place where you can take your nearest and dearest and most vulnerable relative — for example your 17-year-old daughter, with her first psychotic breakdown — and be confident that she'll be treated effectively in a safe, congenial, pleasant environment by people who care, who have good professional training and skills... She should not be upset by her experiences in treatment... It's a matter of great heartache to me...that this is not the situation in most parts of Victoria... I have the highest regard for the skills...and the caring attitudes of the

majority of doctors, nurses and other mental health professionals, [who] have an extraordinarily difficult job... [But] in my opinion, the psychiatric hospital system is not at this stage able to deliver an effective, even a safe, level of treatment... The right of these people to first-rate treatment...is denied to them. I believe it is a disgrace which no caring community should tolerate.<sup>53</sup>

What comes through all the time from consumers is that...they didn't get the right treatment and...they were handled in ways that made it doubly, trebly difficult for them to survive when they were acutely ill. All those things are eminently fixable.<sup>54</sup>

In summary, the extensive evidence submitted by consumers, clinicians and carers who have experienced inpatient hospital 'treatment' clearly indicates that insufficient planning and seriously inadequate resources have been devoted to providing appropriate care. The loss of dignity and respect suffered by consumers represents a clear denial of their fundamental human rights.

## Medication

Psychotropic drugs have — and are intended to have — a significant impact on the way people think, feel and behave; that is, they are not only powerful and potentially therapeutic substances, but also intrusive and open to gross misuse... Their impact on personal and social functioning is typically severe...and, not infrequently, more disruptive to life than the original complaint.<sup>55</sup>

The use of psychotropic (mind-affecting and mood-altering) medication and reactions to drug treatment elicited the most intensely expressed and controversial material presented by consumers in evidence to the Inquiry. Medication is clearly an issue of major significance to people in psychiatric hospitals and other forms of institutional care. While clinical practice over decades has established the effectiveness of anti-psychotic and anti-depressant drugs in alleviating the symptoms of a significant proportion of sufferers of major mental illnesses such as schizophrenia, major depressive illness and manic depressive disorder, the quality of life of those affected has received little attention. Evidence indicated that clinicians, although aware of the influence of the drugs' primary effects and side effects on the outward behaviour and appearance of people taking them, may not always appreciate the extent to which their patients are affected in other ways.

The issues associated with the use of medication are complex, as demonstrated by the range of concerns raised in submissions — not only from consumers, but also from family members, carers, nurses and clinicians.

These complexities include the vexed area of subjective versus objective criteria in determining the degree of the person's disorder, both before and after the

administration of psychotropic drugs. In some submissions, witnesses affected by illnesses which deprive the individual, even if only temporarily, of the capacity for objective insight, or produce delusions or hallucinations, reported adverse responses to the medication given, but gave few details about their situation prior to the administration of the medication. In these circumstances, it is difficult to reach any useful conclusions concerning the effectiveness or otherwise of the medication in ameliorating their symptoms.

On the other hand, many consumers did provide detailed evidence of the circumstances preceding the administration of psychotropic medication and the effect this had had on their lives.

The Inquiry has not drawn any conclusions about the appropriateness or otherwise of medication administered in any particular case. However, the allegations concerning violations of people's rights are addressed in the following sections.

### **Information About Medication**

While several witnesses told the Inquiry they had received written information on admission to hospital about various commonly used medications and their possible side effects, the majority complained about the lack of information provided. Many said that as inpatients they had been given no information at all about the drugs prescribed — what effects were hoped for, what side effects might be expected, what dosage was being administered, what the names of the drugs were, or whether there was any choice in medication.

Most of the people there don't know what medication they are on, or care. No professional has ever given me direct answers to questions about levels and types of medication, or how long to stay on medication.<sup>56</sup>

The first psychiatrist I saw for eight years was quite unusual, in that he would tell me what the side effects were...but I know that many people with mental illness complain bitterly that they are not taught about the side effects... I think consumers and families need to be told very clearly what they are.<sup>57</sup>

It is a matter of serious concern that many individuals believed medication was used as a control mechanism, rather than as a therapeutic tool, and that no choice in the selection of appropriate medications was ever offered to them. There is an urgent need to ensure more openness and the frank exchange of information about the effects of drug treatment and the way it affects the person to whom it is being administered.

## Consultation

In the case of a mental patient, it's often difficult to get anyone to hear that you have side effects, or that you want treatment to be altered or modified.<sup>58</sup>

Even when people told the Inquiry they had been informed about the medication they were being given and its purpose, not one consumer who gave evidence reported having been given any choice in the matter, or having been asked for their views on it by the prescribing psychiatrist.<sup>59</sup>

In one recent Australian study of people's rights in respect of psychotropic medication, the authors found a 'virtual absence of collaborative decision-making' between doctor and patient concerning drug treatment.<sup>60</sup>

From evidence provided to the Inquiry, it also appeared that many consumers are reluctant to discuss their medication with their psychiatrists, sometimes because they fear this will lead to an increased dosage.

I must admit that I never actually explicitly stated how I felt on Serenace to the psychiatrists. This was mainly due to excess paranoia, which everyone in hospital seemed to possess. Any sign of 'aberrance' only gained the response of an increase in medication!<sup>61</sup>

Consumers frequently felt either that they were not listened to, or that the nature of the doctor-patient 'relationship' prevented them from discussing medication issues.

In evidence concerning the need for consultation on drug treatment, one prominent lobbyist for the rights of people with mental illness was emphatic:

If they say they are suffering side effects from treatment, if they say they are suffering pain or harm, they must be believed. We can't have that ignored.<sup>62</sup>

The Inquiry heard from many consumers with a history of multiple hospitalisations who knew from previous experience which drugs suited them, which they were allergic to, and which had the most pronounced primary effects and side effects. However, their views were generally not sought.

While clinicians obviously have training and experience in the range and efficacy of drug treatments available, there is no reason they should not explain the treatment (as often happens in the case of doctors treating patients with a physical disease) and offer choices to the large majority of consumers who are not too disordered to discuss the matter. The simple process of explaining effects and offering options would allow individuals to feel they were being treated with some respect and courtesy.



Clearly, there are situations in which this approach would be inappropriate or impracticable. But, equally clearly, that is not true of most cases. It would certainly help to break down the sense of powerlessness and loss of dignity, of being controlled and treated like a child — which was a constant theme in evidence from witnesses in every State and Territory.

### **Precise Application of Drugs**

Many people reported side effects from virtually all classes of psychotropic and anti-depressant medications. However, a number also referred to the lack of precision in the primary effects of the drugs administered to treat the symptoms of their illness.

The drugs are non-specific. They're non-specific to the illness. They're non-specific to the particular individual... We can look at different medications. We can see a person who responds incredibly well to a drug and the next person, who looks the same, responds very badly to it.<sup>63</sup>

Witnesses often described what they saw as the 'hit-and-miss' nature of medications prescribed during inpatient treatment, or reiterated the view that individuals respond quite differently to the same medication.

A lot of the drugs are very crude... We need better drugs. It's a brain chemistry disorder.<sup>64</sup>

Research into new medications with more precise or predictable primary effects — and fewer adverse side effects — requires much more substantial funding than it is currently receiving, although continuing psychopharmacological research in Switzerland, Sweden, Belgium and the US has resulted in the development, trialling and limited release in the past two years of two of the three new drugs to treat schizophrenia<sup>65</sup> and two new drugs to treat depressive and manic depressive illness.<sup>66</sup> (Two of these drugs are claimed by the manufacturer to have some adverse side effects, but in a smaller percentage of people than the more commonly used drugs.<sup>67</sup>)

### **Side Effects**

She has experienced horrific side effects, which have usually been treated by prescribing further drugs... Some instances of these side effects include becoming totally expressionless, heavily sedated and almost immobile; enormous and sudden weight gain; hallucinations; constant walking, compulsively, all day; hideous rashes; sleeplessness; constant sleeping; memory loss; tremors.<sup>68</sup>

The side effects of psychotropic medication are well documented by drug manufacturers, researchers and clinicians<sup>69</sup> and are listed in authoritative sources such as the *Monthly Index of Medical Specialties (MIMS)*.<sup>70</sup> Evidence to the Inquiry indicated that side effects are also generally well recognised by mental health nurses, who usually have close day-to-day contact with people on medication.

Side effects were repeatedly referred to in the course of the Inquiry by relatives and individual consumers. Among the most common of these side effects — or just simply ‘effects’, as some consumers insist they be called — are dizziness, blurred vision, nausea, constipation, weight gain, sleeplessness, drowsiness, a generalised sedative effect (‘heaviness’), decreased sexual function, eyes rolling back in their sockets, dribbling, shuffling, and twitching of feet or other parts of the body. While some of these effects are short-lived and minor, others are more serious and prolonged. Some are reversible by lowering dosages, changing medication, or giving another drug to counter the side effects of the primary medication.<sup>71</sup>

Despite the effectiveness of medication in controlling the symptoms of a range of psychiatric disorders<sup>72</sup>, the unpleasantness of the side effects was mentioned by the majority of consumers.

One consumer, relating to the Inquiry in Sydney the side effects of nine different psychotropic drugs she had received during four separate hospitalisations, said in relation to one of these drugs:

Largactil would knock out a horse — I became a vegetable on it within 24 hours... All my muscles went into spasm. I dribbled constantly, couldn't talk and my tongue hung out of my mouth all the time... It took me months to get over the experience. It really haunted me.<sup>73</sup>

A South Australian witness described the side effects of medication administered during treatment for an episode of a schizophrenic illness in these terms:

A lot of the drugs...have awful side effects, really horrific side effects which make you socially unacceptable. When your eyes roll up and you show the whites of your eyes or your tongue hangs out, or your legs become restless, you find that people don't relate to you as well as when you're sitting here just as I am today.<sup>74</sup>

As noted by this witness, the adverse responses of others to these embarrassing side effects — based on discomfort or fear of people who look and behave differently from the established ‘norms’ of society — compound the distress of mental illness. At a time when people are most vulnerable and in need of

comfort, care and support, these embarrassing reactions sometimes cause even those nearest to them to turn away.

### **Long-Term Effects**

Evidence presented to the Inquiry by people who have experienced long-term effects of psychotropic medication fell into two distinct categories — the lasting physical effects on some people from continued use of certain drugs; and the psychological and emotional effects which persist for long periods after medication has ceased.<sup>75</sup> One particularly distressing long-term effect mentioned by several witnesses as a concern and a potential risk, is the condition known as tardive dyskinesia. Tardive dyskinesia, which typically produces constant uncontrollable mouth and tongue movements, is a possible side effect of some drugs routinely prescribed to treat schizophrenia and other psychoses. It may persist permanently, even after discontinuance of the medication.<sup>76</sup>

### **Over-Prescription of Psychotropic Medication**

Caught on a cycle of drug treatment [she] has been unable to escape, she has continued to be drugged and over-drugged for 25 years. The 'cure' has been far more destructive and devastating than the so-called disease.<sup>77</sup>

Numerous allegations concerning over-prescription of drugs in psychiatric hospitals were made to the Inquiry. Commonly, the evidence was of a subjective and non-clinical nature. The individuals concerned were intensely aware of major changes in their mental and physical functioning, which they frequently described as alarming.

My first night in hospital, I was given a drug — I don't know what it was. I woke the next morning feeling as if I had been hit by a piece of '4 by 2' and I went into a foetal position... I asked to see the doctor. I asked him if he could lower the dose and gradually build it up if necessary. This was outrightly denied me... I locked myself in the toilet and cried... [Later,] I told my psychiatrist how I felt... He apologised and doubled my medication. This is where I started seeing things crawling up the wall... I can't make sense of the emotional scars I'm left with.<sup>78</sup>

[We know of] a doctor who prescribes, as an initial dose, 150mg of Modecate... The drug company which manufactures the medication itself says in MIMS that the maximum dose should be 100mg and that there should be an incremental increase in the medication up to that level... These different approaches are seen as medical prerogative... It is possible for a doctor to experiment with medication and then fall back on the argument of medical discretion in the treatment.<sup>79</sup>

The Inquiry is fully aware of the consensus of mental health specialists, both in Australia and overseas, that the greatest advances this century in the treatment of people with mental illness have been made possible by the development of psychotropic drugs. It is also aware of the fact that, since the late 1950s, the use of these powerful substances has enabled many people who would previously have been confined for life in a psychiatric institution to live (subject to the availability of appropriate community services and facilities) much freer and more productive lives outside hospitals than they could have in the past.

However, the fact that some people are so adversely affected by high doses of psychotropic medication that the effects appear to be worse than the illness for which the drugs were administered, raises serious issues about the rights of the individuals concerned.

### **Evaluation and Monitoring of Medication**

A large number of submissions from consumers and carers referred to the apparent lack of clinical or social-function evaluation of drug types, drug levels or the combined effects of drugs. The following account from a young woman in NSW was typical of many.

I had a very adverse reaction to Serenace, a fact that, over two long-term periods of treatment, only one psychiatric nurse ever realised. [Prior to my second admission, a community mental health] nurse...gave me 10mg of Serenace without Cogentin<sup>80</sup> to allay the side effects. Within half an hour, I had fallen into a nameless void. My mind was climbing the walls trying to hang onto some type of reality amidst nothingness... I had to wait, whimpering, for him to come back with some Cogentin... The [side effects] did not subside for two weeks, so even on only 10mg, it was obvious that I was allergic to Haloperidol [the generic name of the drug]. And at [the hospital], they had me on 60mg a day! I felt as if every moment of existence was unendurable. Every morning over that nine-month period, I woke up wishing I was dead... I think it has scarred me permanently. Haloperidol has probably helped a lot of mentally ill people — I am only objecting to its use for those whom it doesn't suit — I think it is a drug which requires careful administration and those who have a sensitivity to it should never receive it.<sup>81</sup>

With regular — and skilled — clinical evaluation, this kind of experience would be less likely to occur (although it is acknowledged that the action of many psychotropic drugs is relatively imprecise and varies considerably from one individual to another). It is for precisely this reason that regular evaluations should be undertaken, and that both nurses and doctors should be more aware of and responsive to these effects.

Appropriate evaluation of the effects of drug treatment should also be complemented by regular monitoring of medication. Many witnesses suggested this

often does not occur. One witness who suffers from manic depressive disorder gave evidence that some doctors are unable to perform the tests necessary to determine the levels of lithium carbonate (the medication usually prescribed to treat the symptoms of manic depression) in her bloodstream. Lithium is toxic in high doses.

I find it amazing that, in the country where we actually discovered lithium... we still have doctors who cannot do a lithium level test. I think that is a severe indictment on the level of research and the quality of care that we actually have in terms of specific disorders here.<sup>82</sup>

Conversely, the Inquiry was provided with evidence (in the form of a statistical survey of long-term schizophrenia sufferers),<sup>83</sup> indicating that, with very careful monitoring and evaluation of levels of medication for schizophrenia, many people manage extremely well and continue to take the medication at much lower levels than are often prescribed as 'maintenance' dosages.<sup>84</sup>

Several witnesses also stressed the necessity to appropriately supervise and monitor people taking addictive drugs, citing examples of consumers who had been prescribed drugs like Valium (now known to be highly addictive) to deal with anxiety problems—and who had become addicted to them.<sup>85</sup> A number of consumers informed the Inquiry of the difficulty they had had in 'getting off' addictive anti-anxiety drugs prescribed in hospital. In most cases they had not been warned about the possibility of dependence and had not received adequate advice or supervision regarding the slow 'weaning off' process required to avoid distressing withdrawal symptoms.

### **Drug Use as a Mechanism for Control – The 'Chemical Straitjacket'**

The view that medication in psychiatric hospitals is commonly used to keep people quiet or to control them — rather than for sound therapeutic reasons — was expressed by many consumers who made submissions to the Inquiry. One of these, a man who had been an inpatient in the Northern Territory, alleged:

Most situations where a person receives involuntary medication arise from their non-compliance, not from violent psychotic behaviour. It is quite obvious to the writer that the majority of psychiatric staff use involuntary medication as a method of ward management and control.<sup>86</sup>

Evidence was given by an experienced psychogeriatrician that, in some inpatient facilities for the elderly, patients are routinely sedated as a management technique — rather than for therapeutic purposes.<sup>87</sup> (This evidence is discussed in more detail in Chapter 17 — Elderly People.) Another submission — typical of a number regarding alleged misuse of medication — was provided

by someone whose elderly relative had undergone many hospitalisations for a chronic mental illness. The writer had grave reservations about medication being used to keep the relative quiet:

*Failure to comply with drug treatment, or questioning of...treatment is inevitably punished by...involuntary sedation.<sup>88</sup>*

It was not possible for the Inquiry to substantiate beyond doubt the details of individual accounts of misuse of medication as a control mechanism. However, the allegations made on this subject were extremely widespread and are particularly disturbing.

The origins of these unacceptable practices are understandable in so-called 'acute wards' where staff are under great stress, under-resourced, inadequately supported professionally, or simply people with inappropriate temperaments and skills to take on the challenging profession of caring for deeply disturbed and sometimes aggressive people. However, the fact that the origins of such practices are understandable does not mean the practices themselves can be tolerated. To accept them would mean that the rights of consumers can be dismissed as inconsequential and set aside in favour of easier management techniques by the elimination of a 'nuisance' factor in wards or other institutional settings.

### **Administration of Medication by Threat, Coercion or Force**

Another commonly alleged occurrence was the forcible administration of medication, either orally or by injection.

*I was told that if I didn't take my medicine voluntarily, then the nurse would call five burly wardsmen to give me an injection in the bum.<sup>89</sup>*

Other consumers described various incidents of harassment or intimidation:

*While in hospital, being stood over...while I took my medication...has stripped me of any dignity. The contrast between a psychiatric ward and a general medical ward has made me feel punished and fearful towards a profession that appears hell-bent on control.<sup>90</sup>*

The Inquiry also received evidence from many consumers who alleged they had been assaulted by nurses and forcibly injected with medication. Witnesses described being held in headlocks, being sat on, having both arms and legs held down, being punched, pushed, pulled, held up against walls, and wrestled to the floor during these incidents.

There is no act more dehumanising, degrading and painful than three or four psychiatric nurses physically restraining a human and injecting him/her with a mind/nerve-altering tranquilliser... The writer has witnessed at least four occasions where psychiatric nurses forcibly administered medication on patients. These violations were such brutal sights and sounds that they will stain the writer's memory for the rest of his life.<sup>91</sup>

The Inquiry heard evidence (some of which is dealt with later in this section) about the challenges facing psychiatric nursing staff, especially in dealing with people whose mental illness has rendered them gravely disordered, disruptive and sometimes aggressive. This evidence indicated that, in many cases, these are the very people who most strongly resist taking medication which might calm them. However, the evidence provided concerning forcible administration of medication raises fundamental human rights issues — specifically whether, and in what circumstances, people should ever have to be treated in this way; and whether a culture of acceptance has developed in some hospital and ward environments, so that staff become insensitive to the extreme dehumanisation implicit in such 'treatment'.

### **The Availability and Cost of Specific Drugs**

Evidence was presented concerning drugs which a number of witnesses either knew of or had used overseas, but which have not yet been approved by Australian authorities. Some of this evidence related to drugs reported to be more precise in their control of symptoms, more effective, or with fewer side effects. Other evidence related to drugs which are available in this country, but are not listed on the Pharmaceutical Benefits Scheme list. Many witnesses (including psychiatrists, consumers, family members and members of support groups) expressed frustration that, although there are as yet no problem-free drugs for dealing with the symptoms of mental illness, certain drugs which may be better suited to some people are either unavailable or unaffordable.

The parent of a young man with schizophrenia told the Inquiry that:

There are other medications available in both the United Kingdom and Europe, but they are not yet available in Australia. So I would suggest that there is perhaps too stringent a process of evaluation to bring new drugs into Australia... While I appreciate that there needs to be an evaluation process...where there's clear evidence — as there is in the case of this drug — Australia seems to be placing incredibly stringent controls on bringing them in... He is disadvantaged, because this is the drug of choice and the hospital would give it, were it available.<sup>92</sup>

One psychiatrist presented evidence that Australia has the smallest range of medication for mental illness of any Western country.<sup>93</sup> A witness who had experienced psychiatric illness and hospitalisation in England 15 years ago, and more recently in Australia, told the Inquiry about taking medication in England

that is still not available here, although she said it has just been brought in and is now undergoing clinical trials, prior to Australian approval (or otherwise).<sup>94</sup>

On the question of benefit subsidies, a representative of the NSW Schizophrenia Fellowship told the Inquiry that:

There are drugs that have been available overseas for 25 to 30 years that are still not available here on the Pharmaceutical Benefits Scheme. One...example is Orap, available in England since the 1960s. It is not a miracle drug, but for some people it allows them to [continue on] medication with minimal side effects. For others, it will be terrible. [But] if it is prescribed as an appropriate drug by a person's psychiatrist, the responsibility for payment for it is theirs or their family's... Recently, we had a young woman...of 19 who had been tried on a couple of medications... Orap [had] no side effects and she was very happy with it. But out of every Social Security cheque, it was costing her \$50 to buy the drug — [so] she was not eating! To deal with her mental health, her physical health was suffering...[which] may well [trigger] another psychiatric episode.<sup>95</sup>

Given the extremely debilitating effects of many mental illnesses and the comparative availability of drugs for physical maladies there are, again, fundamental human rights considerations concerning non-discrimination in government policies and equality of treatment which must be addressed.

### **The Dangers of Misuse of Drugs**

Throughout the Inquiry, references were frequently made by consumers and relatives to unsatisfactory practices in prescribing and supervising the administration of psychotropic medication. Several consumers told the Inquiry about three, four or more changes or combinations of medication and asserted they had found it relatively easy to appear to take pills handed out by staff, but instead to conceal them, sometimes over lengthy periods, either to avoid taking them because they disliked their effects, to hoard them for later use if they became very depressed or desperate, or to trade to others who might want them.

One thing that concerns me greatly is the number of suicides that happen in a hospital situation by taking prescribed drugs. My question is: Where do they get the drugs from? Often, they are cached and not taken at the time... This is not taking enough care of people who are known to be suicidal.<sup>96</sup>

Such evidence indicates a need for greater control in the dispensation of some medication in some institutions. (This problem is, however, more serious in boarding houses and other 'extra-institutional' settings addressed in later chapters.)



## Electro Convulsive Therapy (ECT)

Evidence presented to the Inquiry illustrated a range of attitudes to electro convulsive therapy administered during treatment in hospital. Consumers' views ranged from acceptance to outright rejection and abhorrence. A number of clinicians gave evidence that ECT is effective in certain depressive illnesses — while conceding it is still not understood how the treatment works.

The use of ECT appears to have declined in recent years. The most common complaints in consumers' evidence concerned the intrusive nature of ECT and the short term memory loss following its administration, which some witnesses found disorienting and distressing.

One consumer told the Inquiry she had felt compelled to resist treatment with ECT while she was a voluntary patient.

I know that ECT is a reasonable suggestion to be made in a case such as my own, when I had seemingly failed to respond to drug therapy and had side effects from it... I had seen a great deal of ECT...in the 1950s when...prior to and in the early days of drug treatment, [it was] greatly used...and...generally agreed [to have been] over-used. Whatever the medical benefits may or may not be, the process of ECT remains totally repugnant to me. While I respect the right of others to agree to it, I realise the improvement in techniques over the years and the greater restraint with which it is used, I could never agree to have it myself. Involuntary ECT is an invasion of man's last barrier of freedom — his mind, and hence of greater moment than invasion of his body. The medical aspect of a problem is one aspect only...sometimes, the patient would rather suffer through the illness than accept a particular line of treatment. I doubt [whether] I could have psychologically survived a course of ECT and continued to regard myself...as ever again being authentically myself. Whether this is logical or not, it is the way I feel [and] I believe these feelings of repugnance and great anxiety regarding ECT would have militated against any useful outcome of the treatment.<sup>97</sup>

One experienced psychiatrist identified important benefits in administering ECT to older people with depressive illnesses. His views on the use, appropriateness and efficacy of ECT — and its poor estimation by the general public and consumers — paralleled those of a number of other expert witnesses:

Roughly speaking, there are two types of depression... [There] is reactive depression to bad circumstances; and the other thing is the chemical change inside you which creates a depression where you lose your ability to reason correctly... It is mental agony. [To illustrate this] awful agony, I had a patient who suffered from...one of the most painful [physical] conditions known to man. He also had recurrent...depressive episodes. He said: 'Given a choice, please give me the [physical condition]. The other one is so agonising mentally that it is unbearable and you have to kill yourself'... Elderly people who get this quickly starve themselves to death in mental agony. They do not take psychotropic medication (ie anti-depressants) easily — they all have a bad effect on (elderly people's) hearts, if they get a dose sufficient to sort out the heavy depressions. If other age groups

get depression...we have the choice of ECT or anti-depressants, and most of us will go for anti-depressants... And in heavy doses...the most severe depression is usually cleared. In the elderly, there is no choice — they cannot take the...drugs to get the depression clear. ECT is not only lifesaving, but it is curative.

We [psychiatrists] are in an embarrassing position, because we do not know how [it] works...and it is so difficult to defend our position with ECT; but it is so safe that anybody who can take an anaesthetic for two minutes can have ECT — and anaesthetics for two minutes are very, very safe. The side effects are almost nil now. The problem is we have got a bad press and we are in a situation where we can't defend ourselves.<sup>98</sup>

In certain cases therefore (particularly endogenous depression in some elderly people) expert evidence indicated that ECT may be the only effective treatment available.<sup>99</sup>

The substantial discrepancy between the attitudes to ECT expressed by consumers and the clinical view of most health service providers typifies the ignorance and mystery which still surround mental illness. Most consumers expressed a deep personal fear and rejection of ECT — even when it had been administered as a last resort and when it was accepted by them as an effective treatment. Most psychiatrists who mentioned it viewed it simply as a 'treatment option' or an 'appropriate next step' in a limited number of cases. The evidence suggests that the depth of consumers' negative feelings about ECT is often discounted, overridden, or misunderstood by their treating doctors. In some States, the legislation relating to information on the use of ECT has been, or is in the process of being, extensively amended to protect the consumer from involuntary administration of ECT — except in certain specified circumstances. (See Chapter 4.)

## Alternative Therapies

Many witnesses expressed a need to be seen and understood as individuals — rather than 'a manic depressive', 'a schizophrenic' or 'a disorder' — which is how so many said they had been made to feel in hospital. A spokesman for the Victorian Mental Illness Awareness Council told the Inquiry:

Services that our members say they would prefer are...much more of a holistic nature, [services] that actually look at them as a whole person and not as a diagnostic label. Ten people with schizophrenia are ten people — they're not 'ten schizophrenics' as they would often be labelled in the medical model.<sup>100</sup>

## Consumers' Views

Many consumers gave evidence that their psychiatrists concentrated on the symptoms of their illness and simply discounted other experiences which they considered relevant. This particularly emerged in evidence from people with long-term illnesses:

Many times, when I bring up something very important to me, I have heard my psychiatrist say: 'What has this got to do with your schizophrenia?' ... I have found that **all** my concerns, experiences and worries relate to my schizophrenia — they are intertwined, intermingled. Dealing with them helps me deal with life, myself and other people, and therefore helps me deal better with my schizophrenia.<sup>101</sup>

Some consumers advocated a balance between chemical intervention and a wider range of therapeutic activities in hospital:

The balance I'd like to get is one where psychiatric [clinicians] can see medication as a temporary measure, so that you can go on seeing a psychiatrist without using the drugs. But for this, psychotherapy is very important — it takes a lot more than just being able to use drugs... I'd like to see shock therapy banned and a return to traditional occupational therapies — craft activities, painting, sewing — to allow the client to express their emotions and to utilise their minds industriously. If I could offer solutions to the hospital problem, I would say that at least an hour or two hours a day be spent working with the patient, using role plays and patients talking about their relationships, working at ways to resolve differences and problems. Group therapy, sharing anxieties, chanting, meditation... Expression is an excellent tool for finding out who you are.<sup>102</sup>

Other consumers emphasised the need for attention to diet and nutrition, exercise and alternative physical methods of treatment and health promotion.

Since the mid-50s, the 'chemical strait-jacket' has been the mainstay of treatment and the traditional professionals have discounted such things as use of other drugs, amount of sleep and exercise, diet and nutrition... [We] note that there are some doctors, notably those who have had a rounded training... who are prescribing other than psychotropic drugs as treatment.

There is a place for psychotropic drugs as an initial stabiliser, like aspirin for a headache — thereafter, a thorough investigation to find a cause is a must... There are many rights that institutions catering for the mentally ill regard as privileges... [Rights to]: pure clean water; low-sugar, tasty meals; therapeutic activities (eg gardening; sport; trips; having pets — the therapeutic effect of dogs on people is now well-known); the right to receive harmless supplements to the diet when needed.<sup>103</sup>

Consumers generally shared an intense sense of frustration that their needs were not understood, far less catered for, in the day-to-day life of psychiatric wards.

Many consumers gave detailed evidence about the types of treatments and activities they believed would have helped them to deal with their illness and assist in their recovery. Most asserted their rights to take part in a range of therapeutic activities, not less than other people because they were mentally ill, but **more** than other people because they were mentally ill. They spoke passionately about the basic human rights to spiritual and creative expression, optimum physical health, recreation and education – insofar as the illness itself allows.

Common themes raised in evidence to the Inquiry also included the benefits of rest and quiet during hospital stays; the value of fresh air, gardening<sup>104</sup> and exercise; and access to the services of a dietitian.<sup>105</sup>

Because someone has a mental illness doesn't mean they are stupid... The six steps to mental fitness are: to think positively; to like yourself; to set yourself realistic goals; to be assertive; to talk about your problems; and to balance work and play. It would be nice if patients could be more encouraged in these fields.<sup>106</sup>

Suggestions to the Inquiry as to therapies which I have found most helpful for my own management [include] a holistic approach to healing, incorporating physical, mental and spiritual methods.<sup>107</sup>

## **Views of Community Groups**

The NSW Mental Health Coordinating Council, an umbrella organisation for State consumer groups, recommended that alternative treatments such as relaxation therapy, guided visualisation, biological approaches, and counselling should be discussed with consumers and made available wherever possible.<sup>108</sup> A Queensland representative of the Schizophrenia Fellowship recounted members' frustration that too little attention was paid by conventional psychiatry to possible benefits from physical alternatives to psychotropic medication:

We feel that a more holistic approach to treatment is required. Psychiatrists tend to deal only with the behavioural, emotional and cognitive problems of the patient and tend to feel that if patients present with a physical problem, it is likely to be psychosomatic... It's a matter of concern that treatments such as [orthomolecular medicine]<sup>109</sup> which could benefit some psychiatric patients, are not more widely investigated and used... When no one has the definitive answers to the problems of mental illness, it does seem reasonable to suggest that people who need psychiatric treatment should have access to all forms of treatment.<sup>110</sup>

Other witnesses expressed frustration concerning the lack of investigation of underlying physical factors which may be relevant:

Nobody really goes into a long and detailed investigation of their physical state of health, as a consulting physician would... We know that the schizophrenics have their roots in

incorrect biochemistry, yet we don't investigate...to see what could be causing or exacerbating the condition... I am not against psychiatry per se, but I think the way it is practised is incomplete.<sup>111</sup>

Several witnesses also gave evidence about psychiatrists discouraging consumers from pursuing alternative therapies.<sup>112</sup>

### **Health Professionals' Views**

Among health professionals who provided submissions to the Inquiry or presented evidence at public hearings, a number were intensely aware of the gap between the way many professionals view treatment for mentally ill people and the way those people themselves would like to be treated; put simply, the symptomatic approach versus the whole-person approach.

I believe people suffering from mental illness ought to have the right to treatment by practitioners of natural medicine, such as osteopathy and iridology... It has long been accepted that mind and body are interdependent... I can personally testify to the touch of the healing hand — a feeling of being cared for can be the most important ingredient missing from a person's life.<sup>113</sup>

People cannot be separated into discrete parts — the relationships between the parts need to be constantly taken into account. To look from more than one perspective is to enrich and enliven our appreciation of...what it is to be human.<sup>114</sup>

A plea was made by one psychiatrist for an adequate assessment of alternative approaches to traditional treatment by medication:

*It's been very difficult to prove the specific value of psychotherapy... What I'm asking is that, if some kind of therapy — non-pharmacological therapy — is provided, for heaven's sake let's have it evaluated and monitored... Let us have a single assessment unit, a mental health unit, which takes priority over all others in a community service, to assess whether people should have psychotherapy or not, and what type of treatments they should receive... Counselling is basically supporting people. Psychotherapy is about changing people.<sup>115</sup>*

A number of psychiatrists who gave evidence acknowledged that there is a great deal more to treating people with mental illness than the 'specifics' of treatment. One expert witness emphasised this point:

I think half the race is run on specifics of treatment and half the race is run on non-specifics of treatment; and the real problem with health professionals — when they do get trained — is that they think specifics of treatment are all.<sup>116</sup>

Others provided compelling evidence concerning the benefits of alternative approaches to health — including mental health. Dr Joan Ridley, psychiatrist

in charge of mental health services for the Northern Territory, told the Inquiry that in November 1991 she had been informed she had cancer and had only a short time to live:

I sorted out my clothes...arranged support people for my family when I died... It was a depressing and despairing five weeks... All my energies were for preparing to die.

Then...[a colleague] suggested a book for me. From the day I read the book everything changed for me. I became in control of my life again, knew that I did not have to accept the doctor's prognostication and that I could put my energy into becoming healthy instead of into dying. The last six months have been a truly wonderful voyage of discovery... Among the resources I have discovered is a...man who conducts Chi Kung classes... He is a truly caring person dedicated to helping others help themselves... There are many more people in the community, people involved in meditation, Yoga, Tai Chi, Reiki, and so on.<sup>117</sup>

Dr Ridley offered the Inquiry some of her insights as a doctor about the implications of conventional medical training and the need to involve **all health professionals** in prevention, health promotion and healing:

Over the last six months, I have had...time to think about what we expect of doctors, because at first I was angry with [my] doctor...apart from the way he told me... But then I thought of the way we are trained and...said [to myself]: 'Well, what are we really expecting of doctors?' We have either got to change the whole training, or we have got to say, 'Look, doctors are doing fine at what they do, but let us just leave them doing what they are doing.' Let us look to these other groups of people who actually — I mean, nurses in their training look at holistic health and they look at mental, physical and spiritual health... The first time I realised that, I thought, 'What on earth are they talking about, spiritual health — I mean, what has that got to do with it?' And certainly, when I was a medical student, nobody ever talked to me about spiritual health. So these other professions are more open to it, I think, than medicine is...

Now, there are some doctors who actually are interested and who do well because that is a special interest of theirs; but I just wonder whether we should be trying to make all doctors good at it, because they are very expensive anyway. You know, why do not we keep them for the special things that they do and use other people who are not so expensive... Maybe we have to look at it from a different direction.<sup>118</sup>

This is a particularly important suggestion, in light of the numbers of community support groups and health professionals<sup>119</sup> who emphasised that, no matter how valuable their services might be to those affected by mental illness, the problem is that many people are precluded from attending clinical psychologists and allied health professionals — because of the costs involved.

We are very concerned that Medicare does not cover services such as private psychology, psychotherapy, hypnotherapy and social work services [which include counselling]...[that] means that some people will not be able to get certain therapeutic services they need, because they can't afford to pay for them.<sup>120</sup>

(This and other aspects of the role of allied health professionals are dealt with in more detail in Chapter 6.)

## **Relationship Between Psychiatrists and Inpatients**

### **Access and Continuity of Care**

Whilst one recognises the...resource constraints hospital staff are under, a fairly common complaint we hear is that medical staff seldom visit patients and when they do, rarely explain the nature of their treatment or other matters of concern to that patient... numerous complaints of this kind tend to indicate systemic problems.<sup>121</sup>

One frequently recurring issue in evidence presented by those who had been hospitalised with a mental illness was serious dissatisfaction with the access they had to psychiatrists — particularly to a psychiatrist to whom they were becoming accustomed and who they thought understood their symptoms and progress. Most said they felt it would have assisted in their recovery to have had consistent, constructive contact with a single clinician. Many witnesses also told the Inquiry they had seen psychiatrists in hospital infrequently — and only for short periods — and that none was available when requested.

A submission from one woman, whose son has a chronic schizophrenic illness, was typical of many:

At most State hospitals, patients are treated by registrars... [Over] the four years after my son's [first admission], he was seen by four different registrars, never by one of the qualified psychiatrists... Are these patients the guinea pigs of the learning process?... The frequent transfer of the patient from doctor to doctor means that [he or she] has to form new affiliations every few months. Patients suffering from mental illness find this extremely difficult. In March 1988, my son was [scheduled again]... His medication was changed and he was 'going through hell', as he termed it.<sup>122</sup>

One experienced psychiatrist summarised the problems associated with frequent changes of psychiatric registrars in hospitals:

The current system...involves six months' attachment of trainee psychiatrists to a clinical unit. This is administratively convenient, and is partly dictated by the training requirements of the Royal College of Psychiatrists. Trainee psychiatrists are required to move from one unit to another in order to obtain accredited training experiences in a variety of settings. This entails treating a cohort of patients for about six months, then dropping the lot and leaving that cohort behind to take up another at another location. This process is severely disruptive to continuity of care. Patients and families complain bitterly about changes of their doctors... The sense of abandonment by the doctor is associated with distress and a sense of futility in having to go through the whole business of getting acquainted yet again with a new doctor. Patients may learn to deal with this repeated loss of their doctors

by...failing to develop a therapeutic alliance. Such repeated disruptions...work against quality of care.<sup>123</sup>

**The rotation system would appear to have few benefits for patients or trainee registrars:**

A new doctor taking over a patient's care can't quickly obtain a detailed knowledge and understanding of a patient with a complex and severe disorder, especially if he or she is a junior doctor and is consequently more likely to deal with emerging problems by inappropriately prescribing an excessive reliance on anti-psychotropic medication... The sickest patients are treated by the least experienced doctors... The defence of this practice often put forward is that the continuity is provided by 'the team'... Now, I believe that's a flawed argument — patients bond to persons, not to teams... A way needs to be found...of providing personal continuity of care over a much longer period than currently takes place in most services.<sup>124</sup>

**Clearly, serious consideration must be given to changing this 'system'.**

### **Attitudes of Psychiatrists**

My public psychiatrists have been very supportive...although, in 15 years, the focus of service seems to have been replaced by a less caring attitude and an almost 'statistical' idea of care, complete with a dominance of administration.<sup>125</sup>

**Consumers consistently called for more effective communication with their psychiatrists in hospital:**

I find it is difficult to get doctors to communicate. They do not listen and they do not give feedback. I was very disappointed that none of my doctors suggested any treatment...other than medication and half-hour consultations two months apart... Doctors have failed to provide me with [any] counselling.<sup>126</sup>

**Consumers and their families indicated that psychiatrists often appeared to take no personal interest in the people they were treating:**

He does not like going to [that] clinic, he hates it there. He says that the doctor will not talk to him. [The other doctor] would talk to him and listen to [his] problems and spend time with [him] and make [him] feel [his] worth. Now, he says [he] just gets a couple of minutes with the regular doctor and he will not listen to [him] or listen to any of [his] concerns. [My son] feels they are not really interested.<sup>127</sup>

**Consumers also frequently alleged insensitive behaviour by psychiatrists, particularly during acute episodes of mental illness:**

Another psychiatrist...gave me a terrible time last year when I was admitted. I was admitting myself as a voluntary patient...and he forbade me to have the door open. I felt terribly claustrophobic, having been locked up many, many times in small cells in [that



hospital], and I was very, very claustrophobic and very frightened. He would not allow me to have the door open at all — he was very dogmatic about it... Some professional attitudes that we [consumers] have to deal with are very institutional and they certainly do not promote mental health.<sup>128</sup>

## **Clinical Issues**

The most common criticism expressed by consumers and families about psychiatrists' clinical approach to mentally ill people in hospital was their narrow focus on the 'medical model' — medication first and last:

The doctors are rarely interested in anything except your medication... The doctor is not interested in you, your aims, anything you want to be... Uniformly, doctors just want you to act like an assembly line mental health product and to respond to the drugs... If you ever see a psychiatrist in hospital, just tell them the drugs are great...you're not hearing voices, your thoughts are ordered now, you won't do it again. This will please your doctor and you should get out of hospital soon.<sup>129</sup>

Several psychiatrists emphasised the importance of recognising that an individual with mental illness has a range of dimensions:

If we come to look at attitudes to the mentally ill in our own time...the dominant view, [which] I think works against the welfare of the mentally ill, is that of dualism. The split between the mind and the body dominates professional thinking in relation to mental illness... In my view, contemporary practice has not yet fully caught up with the notion of an integrated bio-psychosocial model of mental illness that was first promulgated some 20 years ago in the United States by George Engel.<sup>130</sup>

One emphasised the importance of input and feedback from consumers:

I would like to pay tribute to...the consumers who have been actively speaking up... because we in Western Sydney really appreciate that, and we are attempting to take notice of the things that the clients of our services really need and we are trying to devise systems that meet those needs.<sup>131</sup>

A witness for the Schizophrenia Fellowship recounted the frustration of many members concerning a perceived lack of co-operation among clinicians in relation to the diagnosis and treatment of schizophrenia:

[We ask for] an end to this polarisation...on forms of diagnosis and treatment of schizophrenia... Psychiatrists...have seven models of assessment and treatment...on which they cannot agree. If you add to these vitamin therapies, diet therapies, herbal therapies, naturopathic therapies, orthomolecular therapies and other treatments, we finish with a real mish-mash of ideas, none of which has found a cause [of schizophrenia] and none of which has found a cure... it's time all of these antagonists got together in a collaborative rather than an adversarial manner.<sup>132</sup>

Clearly, this frustration could be addressed, at least to some extent, by better communication between clinicians and consumers and carers — and a frank admission by the specialists that there is a great deal they do not know.

## **Issues Concerning the Power of Psychiatrists**

The Inquiry received numerous submissions about the power relationship between psychiatrists and consumers.

Remedial action is imperative, and well overdue, to restore the profession [of psychiatry] to a valuable and unassailable position in our society as a caring and altruistic professional practice, which I am sure its members intend it to be. The extent of the power of psychiatrists in relation to mentally ill patients should be seriously examined... The comprehensiveness...of the multiple forms of power needs to be questioned... Unprecedented power in the hands of the psychiatric profession should be examined in relation to its disabling and disempowering effect on persons who suffer episodes of mental illness... [Disempowerment] is inherent in the relationship, especially so in...involuntary treatment, [which is in itself] inherently degrading... I do not believe there are adequate checks to this power and...I do not believe enough emphasis is put on informed consent in treating people, because it is too easy to resort to legal powers.<sup>133</sup>

Several psychiatrists also conceded the legitimacy of some of the frustrations and complaints conveyed by consumers. As one experienced practitioner put it:

Psychiatry and psychiatrists...view patients...too exclusively within a medical model, seeing any level of symptoms or disturbed behaviour as reflecting some sort of underlying pathological process, and then putting them on medication perhaps too precipitately. [Many psychiatrists ignore] environmental or life stresses that may have, in fact, precipitated the problems the patient presents with, hence inadvertently increasing the patient's dependency, lowering their self esteem and lowering their sense of empowerment as they increasingly...identify themselves as a patient.<sup>134</sup>

Clearly, and justifiably, consumers expect to be treated as individuals in the illness and recovery processes, not just as 'a pathology'.

## **Relationship Between Nurses and Inpatients**

In my experience, the nurses hold the key. I mean, the nurses themselves are the people in power. When you're in a locked ward — anyone who's been in a locked ward knows this — it's worse than being in jail, because you are totally dependent on that person. If you rock the boat, you're done as far as any privilege goes, like being allowed outside, or having supper, or something like that. And these things take on monumental proportions when you're in hospital. Your cup of tea, your right to sit with others, is paramount... Within the hospitals there are many marvellous staff — a lot of us wouldn't be here today without these marvellous staff. You can't speak too highly of them. They work under dreadful conditions with the most atrocious people, including myself, and they have a

terrific spirit and camaraderie that has to be recognised. It's only the few who abuse the status they have.<sup>135</sup>

The majority of consumers who gave evidence to the Inquiry made it clear they did not want their evidence to be attributed to them by name — in case they had to return to hospital at some point in the future. It was disturbingly common for witnesses to say that they feared repercussions, should they be readmitted, for having spoken out about nurses or doctors.

It is important to note that people presenting evidence to the Inquiry — either oral or written — were not asked specifically about their experiences with nurses. Yet nearly all of those who spoke about being hospitalised had a great deal to say about this aspect of their inpatient experiences.

A typical account came from six residents of a group home in Victoria:

The qualities of compassion, empathy and understanding, which we have found to be of great therapeutic value, are certainly present in some of the best staff. However, these staff members are often overshadowed by staff who are extremely limited in their ability to relate to patients and who are at times cruel and sadistic. Among our group are people who have seen another patient kicked in the head as a form of discipline. The staff member who did this proceeded to inform other patients that if they complained, they would receive similar treatment... There seems to be a fear of spontaneity [with] the patients and a rigid adherence to routine... We have the distinct impression that these routines are more for the benefit of staff than of the patients.<sup>136</sup>

A senior lecturer in nursing at a Sydney tertiary college<sup>137</sup> quoted a key passage from the 1897 'Rules for Attendants, Nurses, Servants, and others at Kenmore Hospital for the Insane' in his submission to the Inquiry:

The essential qualities in an attendant or nurse are patience, gentleness, and firmness, with constant perseverance in all efforts to induce the patients to work, to join in recreation, to take the food and medicine considered necessary and to [undertake properly] the duties of everyday life. It is absolutely necessary that attendants and nurses should observe the...character and take a personal...interest in the patients under their care, since it is only by becoming acquainted with their habits, tendencies and delusions that they can manage them properly.<sup>138</sup>

The evidence leaves no doubt that in the case of many patients affected by mental illness this salutary injunction from almost a century ago has frequently been honoured in the breach.

## Incidents

A number of consumers related incidents involving nursing staff which had left a lasting impression — especially incidents which occurred immediately after admission, when they were most vulnerable.

Parents, too, told the Inquiry they were strongly affected by nurses' mistreatment of family members:

My son was lying on his bed in a very anxious state and was asked to come to the dining room for his meal. He said he couldn't eat and one of the male psychiatric nurses came into his cubicle and dragged him by the collar of his shirt right up to the dining room.<sup>139</sup>

Submissions to the Inquiry about rough and insensitive treatment by nurses were frequently accompanied by comments about the kind of response consumers expected to receive when in crisis.

When I was admitted for acute care, I supposedly struck a staff member... I have no recollection of striking the nurse. I was suddenly rushed by three nurses and forced backwards down a hall into a seclusion room... I was forced to a mattress on the floor. Not one word was spoken of comfort or explanation. My clothes were ripped off and I was dressed in a nightdress. In the process, a heavy male nurse kneeled with all his weight on my arm. My hand went blue and I requested to see a doctor; the request was denied. I was left alone to cry. The only way to communicate with staff was to kick on the door. Later in the night, I was [given]...an injection. In the morning, I was released. I found this episode very traumatic and I have discussed it with various professionals since... I am told there are more humane nursing procedures that should have been used, where I would have been led forwards [not backwards], with staff talking and comforting me... The new *Mental Health Act* offers some improvements, but would not alter nursing procedures. There is a need for kindness and consideration and minimum force.<sup>140</sup>

It was common, however, for those recounting insensitivity or mistreatment by some nurses to qualify these criticisms with positive experiences they had had with other nursing staff:

I approached staff to inquire about access to a priest... They laughed at me and said: 'Lady, you have no rights in here at all'. I replied: 'Excuse me, but I do have rights, it's written there in black and white.' A group of patients had gathered around and...refused [nurses' requests] to return to their beds... [The nurses] put me into isolation for 'inciting the patients to rebellion.' One of the staff [did arrange to get me a priest the next day]. I feel so grateful to the person who got this help for me — it gave me the strength to hold my mind together. Since then, I have resumed my life and taken on a responsible place in society.<sup>141</sup>

Evidence to the Inquiry clearly indicated that the intense fear and anxiety experienced by many inpatients are identifiable symptoms of their mental

illness.<sup>142</sup> Some people told the Inquiry that, without positive reassurance from nursing staff, they were afraid of what nurses **might** do to them — even when nothing had occurred:

I felt extremely vulnerable... The nursing staff were cold and distant... [Their] main job was to enforce the taking of medication and I did not receive what I would consider therapeutic nursing. I was very frightened of being taken away to some room away from other patients where anything dreadful they might like to do could happen to me... Doctors are sort of more remote figures — it's the nurses who you're dealing with day to day.<sup>143</sup>

Those who had been inpatients for more than a short time, or who had been admitted on several different occasions, quickly learned which of the nurses were approachable:

With a few exceptions, nursing staff tend to minimise their interaction with patients, so that they are in a position of control rather than care — the 'them and us' mentality. I found this to be counterproductive with regard to improvement in one's condition. I am of the view that carers can be co-therapists. On the whole, nursing care was adequate to satisfactory and in some cases, exceptional. At times, however, it was not only unsatisfactory, but reprehensible and would have been better suited to the [nearby] jail. For example...I was able to predict whether or not I would be granted day leave just by knowing who was on duty.<sup>144</sup>

It is true that within a ward, section or hospital, a patient may receive the best, kindest or most benevolent treatment from staff. Yet this often seems to be because of the individual attitudes of staff, rather than the way the system operates — a system which is based on the premise that a patient who receives even minimally decent treatment would think themselves lucky, rather than inherently deserving.<sup>145</sup>

Evidence such as this indicates serious shortcomings — both in the system of monitoring standards of nursing care and in implementing the ethical codes of conduct of the professional nursing associations.

The Inquiry also frequently received evidence about nurses reading novels and doing crosswords in the office while patients wandered around the ward needing attention or assistance.<sup>146</sup> In other cases, nurses were overheard by distressed family members joking about patients in the ward.<sup>147</sup>

## **Conditions for Nurses**

As a practising nurse, I'm intimately aware of the ethical dilemmas and the subjective experience of patients and staff: of the collision of mental illness and human rights... I've chosen to work within the psychiatric specialisation because, for me, it represents the essence of nursing — the use of oneself as a therapeutic tool.<sup>148</sup>

Most representatives of the professional nursing organisations presenting evidence to the Inquiry were intensely aware of the personal and professional difficulties faced by mental health nurses and the enormous strains which limited resources create for those working in psychiatric hospitals and units. Several of these witnesses referred to the difficulty of recruiting people in sufficient numbers and with the appropriate qualities, commitment and skill to work in the area. Psychiatric nursing does not enjoy a high status, although evidence from consumers and other witnesses confirmed that many dedicated and talented individuals continue to work in the profession.

A representative of the Queensland Nurses Union informed the Inquiry of an arrangement for employing psychiatric nursing staff which is unfair to existing staff, unsatisfactory for the new recruits, and completely unacceptable in terms of expert patient care:

[The hospital] earlier this year was unable to recruit qualified psychiatric nurses and employed instead totally unqualified persons. Psychiatric nurses were then expected to provide a six-week course for these people to enable them to provide adequate care. This is a totally unacceptable practice and returns mental health care to the level of custodial care. It also places heavy burdens on the qualified staff.<sup>149</sup>

Another witness in Victoria presented evidence concerning shift arrangements and roster changes which placed severe strains on nursing staff and prevented reasonable continuity of care for patients in the ward:

In admissions units, the stress levels can get very high. A nurse, in particular, has to have a lot of patience and energy to cope with the demands placed on them by the ill and disturbed patients. In this setting, asking nurses to work a 13-hour day is asking for a drop in the standards of care... In psychiatric nursing, it is essential that the nurse develop a close therapeutic rapport with the patient. If this does not happen, very little can be achieved. The 'two [days] on, two [days] off' roster is renowned for the inability of staff to provide continuity of care. It is difficult to find a nurse who was here yesterday and even more difficult to find one who will be here tomorrow.<sup>150</sup>

A representative of the Australian Nursing Federation emphasised that the skills needed to work effectively in a therapeutic relationship do not have to be hospital-based — they are equally relevant and useful in the community, in people's homes, and in day clinics.<sup>151</sup> With the move towards community-based care and shorter periods of hospitalisation in every State and Territory, the latter point is particularly significant. Hospital-based mental health professionals, particularly nurses, who are the cornerstone of daily care, may need additional training and professional support in order to make the necessary transition. (This subject is addressed in greater detail in Chapter 6 — The Role and Training of Health Professionals and Others.)

# Access To Information

## Consumers' Access To Information

Many consumers told the Inquiry that the fear and confusion they felt before and during admission was exacerbated by not knowing what was going to happen to them.

I am currently a patient in an acute unit... When a patient is first exposed to a psychiatric environment, it is most frightening, especially if they are in a confused state. Staff should be made aware that the patients need to know exactly where they are being taken, and to have procedures explained to them.<sup>152</sup>

Witnesses emphasised the importance of receiving adequate information about staffing arrangements and the daily routine of the ward. (As already indicated, consumers also frequently complained about lack of information about medication and its effects.)

The Executive Director of the Queensland Association for Mental Health summarised salient points in the Association's submission to the Inquiry:

There is a need for mandatory improvement of the information given to sufferers, particularly on first admission. Such information should include: what treating personnel believe is happening to them; what treatments and medications are being used; and what are the expected effects of these. After remission of the acute state, full and open discussion of the diagnosis, prognosis, treatments to be used and side effects of medications should be standard practice.<sup>153</sup>

Many consumers spoke about misunderstanding the roles of various staff members, and their embarrassment about approaching the 'wrong' person.

I realised after many days that there were different 'ranks' of staff. People of higher 'rank' resented doing lesser jobs. It would have helped considerably if they had explained to us which particular people we were to go to with our needs. Once I had realised all the numerous and confusing rules, I began to get along better... I realised that, as a patient, my complaints carried little weight.<sup>154</sup>

There was a great deal of evidence from consumers in all jurisdictions that no one had made any attempt to explain even the most basic facts about hospital life to them.

When one is ill, one needs information, but it must be offered. The sick person cannot press for information. In my experience, [the only source of] information has been family and friends. The doctors and the hospital, who would be the logical information providers, have given me nothing... In hospital, almost nothing was explained to me. I was told the

meal times and when to take my medication. Who was who, and what their roles were, was not explained to me. I knew who the doctors were — they were the men who wore ties. No one told me there were occupational therapists available. No one told me how the hospital worked, or what the basics of hospital life were. I learned everything about menus, leave policy, categories of patients, smoking policy, etc, from my own observation or from asking other patients. I have asked my psychiatrist about his notes about me and he has refused, without explanation. The way we are treated, suffering from a mental illness is a terrible experience. And it is made worse, in that people are not respected as human beings.<sup>155</sup>

Many consumers questioned the apparently prevalent assumption that most individuals are not in a state to comprehend information provided to them on admission.

Many patients are not given much information at the early stage of treatment — presumably because it is felt they would not be able to comprehend. Special attention needs to be given to this issue... Patients should be given information — repeatedly if necessary — about their medication and side effects. In particular, they need to be given a time frame, to encourage them to continue treatment.<sup>156</sup>

Another important issue frequently raised concerned the manner in which information about a person's diagnosis is imparted to inpatients. While the complaints on this subject varied widely, the gravamen was that psychiatrists were frequently insensitive and unnecessarily reticent to provide an explanation of the illness.

### **False Information**

Several witnesses alleged they had deliberately been given inaccurate or false information in hospital. This may have been a pragmatic way of handling a person who may object to or resist the truth; but deliberate deception generally constitutes a violation of one's right to be treated with dignity and respect.

It was also alleged that in some hospitals there is a practice of deceiving consumers about their medication:

There are many other aspects of practice that I feel transgress and compromise the rights of the mentally ill... [Eg] the practice of giving a Modecate injection to a patient and telling him it was a vitamin injection... The allied practice of giving the patients as little information as possible about their medications...is more common.<sup>157</sup>

In another case, a submission was provided to the Inquiry on behalf of a woman suffering from depression who was a voluntary patient in a private hospital and wanted to go home. It was alleged she had been told a number of



half-truths about what would happen if she left the hospital and had been threatened with involuntary committal if she did not stay:

She was held against her will, but by deception and bluff, rather than by reasonable and understanding persuasion, to which a sensitive person is entitled.<sup>158</sup>

The fact that the Inquiry could not substantiate these particular allegations should not mean the issues involved are ignored.

### **Informal Information Networks**

An informal network has developed which provides consumers with information about psychiatric hospitals and similar facilities. People who have been in and out of a number of psychiatric institutions told the Inquiry they had become active in consumer support groups and were often used by other consumers as a source of information.

People ring me...any active consumer would have the same thing — they run a sort of clandestine information service where you find out... You're relatively well informed, so that you can help the people who may one day have to help you.<sup>159</sup>

While such a 'network' has positive elements, it is an indictment of our system's ability to provide information to vulnerable individuals in a timely and appropriate fashion.

### **Relatives' Access to Information**

The majority of relatives and carers who gave evidence to the Inquiry said they had been frustrated by the lack of information provided about their relatives' condition, treatment, and prognosis. Some witnesses had attempted to find the appropriate person to ask about their relative's progress, but said they had not been sure whether to approach the consultant psychiatrist, the registrar, the social worker, the charge nurse, or someone else.

When information is available — and there is quite a lot of information available — either it doesn't get to the family, or the family don't assimilate it, because of the state they are in at the time... There needs to be some formal contact person when you are dealing with a system that is enormous. [There are] a number of doctors, nurses, social workers, occupational therapists — you are not aware of the functions of all these people. [Relatives] do not know what questions to ask of whom... I often hear [families] saying they are not informed about diagnosis, about medication, about side effects, about what treatment is being applied... Now, we recognise that the person — the patient — has a right to [ask that] no information be given out. But where a person is to be cared for in a family situation, the rights of that family also come into contest.<sup>160</sup>

The Inquiry found that both carers and mental health professionals were unsure of their respective rights and obligations regarding information about the progress of mentally ill people in hospital. This is a matter which is also of concern to consumers — both those who wish their families to be kept informed, and those who want details of their illness and treatment kept from their relatives. This general uncertainty was summarised in a submission from a group of parents and citizens in Queensland:

An issue of concern is the precise nature of the patient/practitioner relationship and what obligation (if any) the practitioner has to keep third parties informed. It is our view that information concerning the patient's wellbeing should be provided — on an ongoing basis — to parents/guardians.<sup>161</sup>

Even where consumers had clearly indicated they wanted relatives kept informed of their progress in hospital, clinicians and nurses were alleged to have withheld relevant information from relatives on the grounds of confidentiality or, in the case of people over 18, because doctors took the view that parents and spouses have no right to expect regular reporting of an adult patient's progress. A number of carers compared this situation with the approach taken when someone's relative has had a physical illness or accident, and the treating doctor has spoken to them freely about diagnosis, treatment and prospects for recovery.

When a family member is hospitalised, the next of kin needs to be informed as to progress and plans of treatment: information, for example, as to when the person will be discharged...is sometimes not given... I know of one man whose wife had made a suicide attempt and was admitted to intensive care. He only found out — 12 hours later — quite by accident. He was outraged that he was not informed of that.<sup>162</sup>

A witness representing the Queensland Association for Mental Health suggested that relevant information should be provided in both oral and written form:

Discussion of the diagnosis, prognosis, treatments to be used and side effects of medications should be...made available to families and carers of sufferers, subject to the consent of the sufferer. In all cases, written as well as verbal information is important to ensure accuracy and consistency and to provide the opportunity for thoughtful consideration, away from the pressure of the acute episode and the treatment centre. And we would note that the Australian Council on Healthcare Standards now has a specific section to deal with standards for psychiatric services, which includes the kind of information to be given.<sup>163</sup>

Clearly this approach has much to commend it — not only from the perspective of carers, but to ensure proper protection of the rights of the person who is ill.

## **Information from Carers to Hospital Staff**

Many parents and carers expressed anger and frustration that their knowledge and experience, although potentially a valuable resource to the treating team, was neither sought nor accepted by psychiatrists and nursing staff caring for people with mental illness:

The family has the right to be heard... They have the right to give the benefit of their knowledge to the 'team'.<sup>164</sup>

Evidence presented to the Inquiry clearly established that the right of people with mental illness to appropriate and timely information is not, in many cases, being respected. It is equally clear that people close to consumers — who will often be responsible for their care on discharge — frequently do not receive the information they need about their relative's condition, progress and treatment needs.

## **Privacy**

One of the basic human rights frequently neglected in any institutional setting is the right to privacy. On the basis of evidence presented to the Inquiry it is one of the rights frequently denied those in psychiatric facilities.

I have been in the nursing profession since 1956 and have worked in many public hospitals, but I was appalled when I saw the conditions for both patients and nursing staff at [two psychiatric hospitals in NSW]... These people all sleep, shower and eat in the same ward. During the day...if they need a sleep or are physically sick, they have no access to a bed and have no privacy at all. The showers are communal, interviews are carried out in public [and can be overheard] in the lounge or in the gardens. Because people are mentally ill does not mean they don't have a right to privacy.<sup>165</sup>

A great deal of evidence was presented by consumers who had been inpatients in some of the largest and oldest psychiatric institutions in the country — hospitals which will probably be replaced by units attached to general hospitals as the policy of integration of mental health services with general health services gains momentum. However, the Inquiry also heard evidence from consumers about overcrowding and invasion of privacy by staff and other patients in a wide variety of hospital settings.

Many consumers told the Inquiry they felt stressed, tired, vulnerable, self-conscious and generally unable to cope with too many other people while they were ill. The fact that most inpatients feel a critical need for privacy, which is generally ignored, was repeatedly raised in evidence.

A typical example of institutional disregard for normal privacy—and the embarrassment it can cause — was given by one Victorian witness:

On my first day [in hospital], I was taken to have a bath against my will. Two males carried me to this bath and two women remained present while I bathed. I suggested to them that they at least turn around, but they said that was their rule and that they have to watch. I'm really appalled at this kind of procedure which seems to be pointless and unnecessary — I found it very demeaning... People are locked out of their rooms...in a very large ward with...very sick people... People are really crying out to just withdraw a bit and have a bit of privacy... And I think people, particularly when they have a schizophrenic condition, do need a bit of time away from a crowd of people, particularly distressed people... I think people do need a bit of a break... And there was only one toilet to be shared between men and women, and this was unlocked and you frequently had people bursting in on you.<sup>166</sup>

## Safety and Security

There is no doubt that it is difficult to care for some people with mental illness in an 'open' environment. It is also accepted that it is impossible to accurately predict which people will be a danger to themselves or others.<sup>167</sup> The pain of mental illness is so great that some people do not want to continue living.<sup>168</sup> If a person really wants to commit suicide, it is very difficult to prevent them from doing so.<sup>169</sup> The proposition that people be locked in and stood over night and day is not an acceptable option. However, evidence to the Inquiry indicated that reasonable precautions — such as knowing the whereabouts of patients at risk, caution in granting day leave, or checking on people at regular intervals — have frequently not been taken and tragedies have occurred.

The Inquiry considered submissions from many families and carers concerning safety and security for those in psychiatric hospitals. One witness spoke of the risks to which her son was exposed during his first acute episode. Fortunately, he survived. That did not minimise the degree of anxiety described by his parents, who felt that he was not safe in hospital:

He had just turned 17... The psychiatrist said he was very much out of control, that he did need help, and that they would schedule him. I visited him there the next day with a friend and we left in tears. He was in a ward with very elderly people and he was tied to a chair with his arms behind his back, although he wasn't in the acute area... The next afternoon at 4 o'clock, he arrived home [it was a three-hour drive]. He'd hitch-hiked with two trucks. When I phoned the hospital, they hadn't even missed him... What frightened me was what could have happened to him during the time he was hitch-hiking on the road.<sup>170</sup>

A number of witnesses believed the suicide of their loved ones could have been prevented if there had been more adequate supervision.<sup>171</sup>

Leigh was a 'regulated' patient under one of the sections of the Act, yet while he was in the open ward, he had little or no supervision. He was left to his own devices, which, in the end, proved fatal. To my knowledge, on that terrible morning, he was not sighted at breakfast, so must have wandered off soon after rising. [It] was such a big hospital, his escape was unnoticed and the tragedy was reported only hours later — he had hitched a ride to the station, walked along the rails... People reported that he lay on the rails waiting for a train to come along... No one will ever know the truth, but I know he obeyed those 'voices'.

If the hospital security had been proper, Leigh would never have been able to leave unnoticed, and would still be alive today. I do not wish to incriminate anyone involved in Leigh's case and would like to thank all the staff [of the hospital] for their dedicated time, care and attention given to him during his time [in hospital].<sup>172</sup>

**The Inquiry also heard evidence concerning failure to follow basic security procedures — such as conducting a search for a missing patient:**

She slipped away from staff after an aerobics class...and committed suicide on the hospital site [Graylands Psychiatric Hospital, Perth]... Her body was only found four days later... [We were told] by a member of staff that she had absconded from the hospital and no one contacted us at all during the four days it took to find her body. [We] feel not much of an effort was made to search for her after she absconded... After my daughter's death, our family received no word from the hospital until a letter came listing [her] belongings and asking us to collect them from the hospital... It appeared to our family that Graylands was an institution that did not care about our grief, or about the tragic death of our beloved daughter. Do people matter less because they suffer from a mental illness?<sup>173</sup>

**Other instances of the apparent failure of hospital personnel to follow prescribed procedures for ensuring the safety of people with mental illness while under escort were also cited:**

The daughter of one of our volunteers [who had] a long history of hospitalisation [with] schizophrenia [was in a psychiatric hospital and had to be taken] to a general hospital for some physical tests... The transport was by mini-bus. On the way back, the nurse escort and the driver both sat in the front seat, leaving the [young woman] alone in the back... [This was against] instructions for escort duty and transportation of patients, [a copy of which] was in the glove box, but it hadn't been read... She jumped out, and died in the process. The finding was that nobody was to blame.<sup>174</sup>

**These and many other examples indicated that inadequate resources and failure to follow prescribed procedures — rather than the absence of such procedures — had sometimes contributed to deaths which may have been prevented.**

## **Seclusion**

**Seclusion in psychiatric hospitals means the temporary isolation and detention of a person in a locked room if they are behaving in a way which is disruptive,**

violent, or potentially dangerous to themselves, other patients, or staff. To minimise risk to the person, the typical seclusion room has no fittings and resembles a prison cell, with a small reinforced viewing window.

In some States and Territories, there are limitations and conditions on the use of seclusion — but no prohibitions. The limitations generally refer to reasons for use and the length of time a person can appropriately be detained. Generally the limitations are observed. However, whether seclusion is over-used or appropriately used, or whether such factors as better ward conditions or more highly skilled nursing staff could sometimes provide a preferable alternative response is an important issue — given the nature of the experience for the individual involved.

This was the beginning of what now seems like a nightmare: I feel as if I will never be the same... I was ill, confused and very afraid. To my horror, after my parents left, I was ordered by the nurse to go inside a small cell-like room with no window, only a makeshift bed in one corner, and in the heavy wooden door, a tiny window made of thick glass for the nursing staff to look into the cell. What terrified me was that after I had gone in, the nurse slammed the door shut and audibly bolted it from the outside. I thought I was going to suffocate in there with no windows... Becoming desperately scared, I started pounding on the door, shouting for the nurse to come, as I needed to go to the toilet. My yells were ignored...no one came to see whether I needed something... I ended up having to suffer the utter humiliation of passing urine on the floor of that cell. It is very embarrassing for me to write this — I have to keep reminding myself that it was not my fault... Despite being locked up like a dangerous criminal, I did not commit any crime. [I feel] rage, disbelief and sheer bewilderment at having been treated like this...the feelings are as strong today [1992] as they were back in July 1990 — I still cannot comprehend how this treatment is supposed to benefit the 'mentally ill'.<sup>175</sup>

Another consumer from Victoria described waking in terror one night, convinced that men were climbing up to her window. She went to get help from the night nurse, who tried to drag her back to bed. Afraid of returning to the same bedroom, she resisted and screamed out. She was dragged off to seclusion and left there till morning. No one checked on her during that time. She, too, was forced by the lack of toilet facilities to relieve herself on the floor in a corner of the room — 'like an animal'. She described how 'utterly degraded' she felt. She also feared that she would be criticised or severely reprimanded by nursing staff for soiling the floor.<sup>176</sup>

The president of ARAFMI Queensland, addressing the Inquiry concerning seclusion on behalf of members of her organisation, said:

I was asked to [say at this hearing], if I had the opportunity, that when a person is in seclusion — if a person has a need, for any reason, to be kept in seclusion—that there be some dignified way in which a person may be enabled to [perform] the normal bodily function of elimination with some sort of dignity. That is not occurring at this time.<sup>177</sup>

Even most prison cells have toilets. The loss of dignity reported by consumers in this respect is clearly a humiliating breach of their human rights. It is outrageous that such treatment can occur precisely at the point when someone is suffering the most extreme effects of mental illness.

## **Assaults and Abuse**

### **Patient Assaults on Staff**

People with mental illness can be very challenging for nurses and other health professionals in psychiatric hospitals. Their illness makes some individuals behave aggressively and the Inquiry heard that resistance to requests by staff sometimes take the form of verbal or physical abuse.

I strongly support the rights of the mentally ill. However, 10 percent of psychiatric patients who are hospitalised can be dangerous... Most staff who have worked for a number of years in a psychiatric hospital have been assaulted at least once in their career. For years, I carried three vertical scratches down one arm because I was gouged by a man who wanted a cigarette and, not being a smoker, I was unable to oblige. So it is a factor, and while mental health rights for the individual are important, I believe staff rights must also be balanced [with those of consumers]... I visited seven United States hospitals and I was very concerned at the lack of staff rights — patient rights had superseded those of the staff.

I believe professionalism on the part of the nursing staff is very important. I believe counselling should be the top priority and trying to intervene earlier, prior to a situation becoming violent. Often, experienced staff can see things happening — for example, the patient becomes a bit restless and fidgety... Sometimes it is totally out of the blue, but I believe staff should be trained to recognise signs and intervene on a verbal level before things get out of hand and then staff have to resort to physical methods, like putting someone in ‘time-out’ [seclusion] and using chemical treatment to calm them down. But certainly, staff also...need to be trained to protect themselves and to work in numbers, rather than on their own. With staff shortages, sometimes it is very tempting to work on your own, because you just can’t get someone else.<sup>178</sup>

The importance of the caution conveyed in this submission was recently underlined by the tragic death of a female psychiatrist (apparently working with inadequate back-up support) in Adelaide.<sup>179</sup>

### **Staff Assaults on Patients**

Conversely, people with mental illness provided a considerable body of evidence relating to staff assaults and abuses. The evidence ranged from descriptions of minor incidents to serious assaults.

The following was typical of many incidents recounted by consumers:

A person I am familiar with...was being verbally abusive to staff and other patients... He had a headlock put on him in the psychiatric ward by a male staff member to the point where he was not able to breathe. He got out of that situation by sheer physical force. I submit it is not an appropriate action to put somebody in a head-lock so they can't actually breathe.<sup>180</sup>

The extent of evidence received by the Inquiry concerning sexual assaults in psychiatric institutions in all States was particularly disturbing.

Regarding the abuse of the consumer...the abuse I'm speaking about is abuse particularly by nursing staff. I know of many instances, innumerable instances of sexual abuse. I think this is enhanced by the state of powerlessness of the patient [who is] often heavily drugged. The person is not only heavily drugged, but if they have certain conditions, they're more likely to be provocative — to perhaps look as if they are 'asking for it'...and usually if these things happen to you when you are fairly heavily drugged (which is the norm if you've been very psychotic) then you have no real recourse, because at the time you have very little real power to resist, because this person is in a position of authority... They have the power to lock you away... You feel very intimidated and very vulnerable and often you have not a chance in the world about what happens to you.

They will often present you with very valid reasons for touching you and abusing you in other ways — reasons can be anything from... 'we've heard you've secreted your tablets somewhere on you', or 'You've stolen from the medications' — any of those who have been patients here could tell you the instances... Or they could lock you up and check you out for any other things they might think you have done... It has happened to me and it has happened to everyone that I know who's been a long-term chronic patient... It is not as prevalent...in the psych units of general hospitals, but I feel in the larger Schedule 5 institutions, it is still quite prevalent... I'm probably giving a wrong view here—sometimes the abuses come from other patients as well, but more frequently, to my knowledge, they come through the staff... [When a complaint has been made], usually the person has been sedated somewhat, so they are probably 'just deluding'. And the nurse claims something else, so the issue just passes... [In] my personal experience, none [of these sorts of abuses] ever reached the official complaint level...[because] you've been totally zonked out on medication and you're not entirely positive what he did... You're just a very unreliable witness.<sup>181</sup>

The Inquiry also heard evidence concerning sexual assaults on young people with mental illness — who are particularly vulnerable:

At 15, I was admitted to the Adolescent Unit because I had become very disturbed on account of my brother's continuing assaults at home... On one occasion in the unit, the male charge nurse drugged me heavily, took me out of the hospital grounds and raped me. He warned me no one would ever believe me if I tried to tell anyone. I broke down after it and told staff what had happened. I was requested to repeat the allegations in front of the charge nurse who raped me... I broke down again then, because I couldn't possibly face doing that. [My experiences during] this admission led to addiction to that medication [a benzodiazepine].<sup>182</sup>



Many of the consumers who gave evidence of sexual assaults in hospital emphasised that they had been unable to subsequently pursue the matter, because staff claimed they had been deluded or fantasising due to their mental illness.

Not all consumers' reports of rapes and sexual assaults in mental hospitals remain unresolved. In one recent case, a woman who had been an inpatient of a locked ward for three months pursued a criminal claim of multiple rape against a male psychiatric nurse. Although she was not believed by the jury at the trial, a later claim for compensation was decided in her favour by the Supreme Court.<sup>183</sup> The male nurse was subsequently de-registered. The Inquiry was also informed of a case in which a nurse had been de-registered on the grounds of professional misconduct for procuring. The Director of the NSW Complaints Unit, which investigated the complaint and prosecuted it before the relevant Tribunal, considered this to be a landmark case, because it was the first complaint, to her knowledge, where reliance had been placed on evidence given by a number of mentally ill people who were witnesses.<sup>184</sup>

Notwithstanding these recent developments it is clear that one of the major problems associated with large institutions is that they foster a custodial mentality — associated with a lack of accountability — ultimately reflected in a lack of respect for the individuals they are supposed to care for.

### **Patient Assaults on Patients**

The Inquiry heard numerous accounts of assaults among patients — usually in crowded wards.

Many witnesses who had been in a psychiatric hospital believed more staff resources and more adequate supervision and active intervention could substantially reduce assaults on patients by other patients. One witness, a former inpatient and Official Visitor appointed by the State Minister to visit psychiatric inpatients told the Inquiry:

*The most [notable] case I have come across was that of a young man who was attacking other patients. [In my capacity as an Official Visitor], we raised this a number of times. No action was taken — until he started attacking staff... More thought needs to be given to nursing practices and design of hospitals to protect people from other patients or staff while they are in treatment. Personally, when I have been in hospital, I have been absolutely terrified of other patients — and also of some staff. I find this very difficult to talk about...I was sexually assaulted while I was in hospital... Despite the complaints I made to staff at the time, despite the distress that I know I was exhibiting at the time, absolutely no mention was made of that assault in my hospital file.<sup>185</sup>*

## The psychiatrist in charge of one of the largest Victorian psychiatric hospitals told the Inquiry:

In a recent census at one hospital [where people were in the acute stage of a mental illness]...violence was [an occasional problem] in 40 percent, and a continuing problem in 25 percent of patients... Appropriate service development should take account of these problems... It is possible to provide some streaming to segregate the violent...from the non-violent...otherwise, assaults of patients upon patients are inevitable. Each area of any size in a psychiatric service, I would submit, should have a ward, a service available for handling people with severe psychiatric disorders in which violence is a problem.<sup>186</sup>

The risk of sexual assaults of female patients by males in adjacent wards, common areas, or the grounds of psychiatric hospitals figured prominently in evidence. A male nurse told the Inquiry he was extremely disturbed about the risks to female patients from male inpatients. He was equally disturbed about the staff's lack of care for the women involved and their repeated failure to deal with the situation. His submission included the following:

In February 1990, a young male patient assaulted a female patient in the courtyard... The assault took place in full view of nurses, ward cleaners and patients in the adjoining ward. The victim was so impaired that she could give no account of it. The male patient refused to [answer] any questions... No witnesses were prepared to come forward and make statements... The response of nursing and medical staff was to ensure that the matter was dealt with at ward level, specifically, to ensure that no one in the hospital administration discovered what had occurred... After making a brief note in the patient's file, the matter was apparently forgotten... The hospital apparently has no policy concerning...sexual assaults... [There is] a complete lack of guidance from senior nursing staff — there are no strategies offered to junior nurses to seek to prevent such occurrences or to respond to such problems appropriately when they occur. The emphasis has been to play down these incidents — the focus has been on potential damage to the hospital and nursing staff, rather than actual damage to patients.<sup>187</sup>

The coordinator of the consumer group MIND in Western Australia said:

I would like to raise some major points of distress for mental health consumers in Western Australia... One of the principal areas of total frustration — total denial — has been a lack of credibility when reporting incidents of abuse... At one stage, I was being sexually harassed by a male patient and...when I reported it, they said: 'Aren't you lucky, you have an admirer!'... I'm getting totally sick of being fobbed off like an idiot... I am a reasonably intelligent person and I am sick to death of being fobbed off with statements that my problems are purely to be dismissed!<sup>188</sup>

## Activities and Occupational Therapy

I have heard people say we should have quality activities whilst in hospital... I would have been happy to be given any activity... There were showers after we got up at 6, but nothing much to do all day long, except sit in the sunshine and smoke... We had an occasional group with the social worker and a rare game of cricket, but no occupational

therapy... After about three weeks of nothing to do, I told my psychiatrist if he didn't get me out of there, I really would go crazy.<sup>189</sup>

Evidence to the Inquiry established that many psychiatric hospitals failed to provide any substantial activities for inpatients with mental illness. These people are not, on the whole, physically incapacitated to any degree. The days in hospital were repeatedly described as interminably long and boring.

There was nothing to do on the ward. I was not allowed off the ward for the first four days... A workman was scraping a mural off the wall in the TV room. I asked if I could help him. This was not [recognised] as a sign that I was bored stiff and I was refused permission by the nurses.<sup>190</sup>

When programs are provided there is frequently little choice offered:

Life in hospital is deadly. If you're in Acute, or it's a weekend or a public holiday, there will be nothing to do at all. Because you can't concentrate [because of the effects of the drugs], you can't read. The television is very boring...and someone will come over at an inopportune moment and change it... When there is a program provided to occupy the patient in hospital, it's usually boring, full of tedious breaks... The spiritual being is thoroughly ignored in hospital... Recently, occupational therapy has been getting away from things like sewing and cooking and into things like assertiveness training, stress management, things like that — they are very good, because people are talking and reading and writing...but a lot of people are being shoved into occupational therapy groups, where they don't get to do craft activities, which they...want to do.<sup>191</sup>

A number of witnesses, both consumers and relatives, stressed the need for more programs — and more useful programs.

The time spent in [Royal Derwent Hospital] left many hours of spare time to sit and think and smoke... My husband felt that there should have been more activities to keep the patients busy and to help them regain the incentive to look after themselves... I recall visiting a centre in England where...people participated in a range of activities such as painting, crafts, knitting, metal work, woodwork, typing and gardening.<sup>192</sup>

More things like learning to type, getting references together for a resumé...should be introduced.<sup>193</sup>

Clearly, recent resource cuts in some States have had a detrimental effect on daily life in hospital for people with mental illness:

Funding and staff [at Larundel Hospital, Melbourne]...had been cut to such an extent that many of the facilities stood idle. A fine art complex, little more than ten years old, was virtually [abandoned]; a fully-equipped gymnasium was unused... I had been in there once before, in 1980 there were far more staff psychologists who came to the ward several times a week and took patients in groups and individually, nurses took many sessions, and

there were special art sessions in the art complex. There was hardly a spare minute during the day and the activities were worthwhile, not pointless time-fillers.<sup>194</sup>

[At Wolston Park Hospital, Brisbane] it appears that...recreational and occupational facilities cannot be used satisfactorily because of staffing problems and regulations. It is easier to let many patients 'vegetate' rather than be motivated into activity.<sup>195</sup>

A Northern Territory occupational therapist working with inpatients and in the community<sup>196</sup> emphasised that programs depend on the particular skills of staff (and whether they in fact have staff). He, too, referred to budgetary restrictions affecting the range of occupational therapies available, but noted that therapists specialising in creative activities, such as music and drama, could be employed on an occasional basis to complement more conventional occupational therapies such as craft-based activities.

While daily occupation, recreation or exercise are not the principal focus of hospital care, long, empty days of stifling boredom clearly do not constitute an environment conducive to the recovery of people with mental illness.

## Environment and Facilities

You visit a psychiatric institution... Where are the visitors? Where are the flowers? Where are the cards? That's the external [impression]. But more importantly, where is the lifting of the person's spirit? Where is the nurturing of that person? It isn't there.<sup>197</sup>

The Inquiry visited many psychiatric facilities — including forensic wards, child and adolescent therapy services and psychiatric clinics, facilities for elderly people with mental illness and major psychiatric hospitals. (A list of institutions inspected is at Appendix 3.)

While standards varied, some facilities were grossly inadequate. At Rosemount Hospital in Brisbane, for example, the buildings were in need of urgent repair and the atmosphere was one of shabby neglect, with peeling paint and ancient linoleum in open dormitories dating back to 1919. The hospital has no air-conditioning or central heating and no segregated shower facilities for men and women. The fact that buildings which are 'too run-down to be used for any medical purpose'<sup>198</sup> are expected to house acute psychiatric patients clearly demonstrates the priority given to the mentally ill in this country.

Rosemount, it should be noted, is one of the main 'Teaching Hospitals' in Queensland.

## Environment

There [is] a lack of old-fashioned 'asylum'. I believe that there is a significant number of people who do require asylum — somewhere quiet, somewhere to be, where it is recognised that...they are not going to suddenly emerge as some well-adjusted, fully-functioning person.<sup>199</sup>

Health professionals giving evidence to the Inquiry highlighted the importance of the hospital environment. One of the consumers addressing the issue spoke of hospitals as alienating — even hostile — environments:

The cards and the flowers don't come, because the facility is hostile, even to visitors... [There is a] disconnection from the community, from the family, from friends, which is engendered in every way possible by a mental health facility.<sup>200</sup>

Many of the newer psychiatric units are cramped and poorly designed:

[Being] put into an environment with other people who are distressed and agitated... This has major implications for the design of locked units in general hospitals and particularly, the importance of providing adequate space... Often psychiatric units get put in the last available space on the ninth floor of [a general hospital] and I think people need freedom. There are many things wrong with [the old] mental hospitals; but the one thing they do provide is unusual facilities in terms of open space.<sup>201</sup>

A representative of the RANZCP told the Inquiry that the poor quality of facilities has detrimental effects not only on patients but also on the recruitment of appropriate professional and other staff.

We recognise that we work in an imperfect system... The mentally ill have a right to dignified, safe, modern facilities... Facilities need to inspire confidence on the part of those who are being admitted to them, particularly if they are being admitted involuntarily... It's very hard to give the persona of a dignified, quality service when everything about the milieu and the architecture of the place symbolises the fact that our society doesn't give it a high priority — that it's got a downgraded appearance — that facilities are minimal to non-existent... Whilst I'm specifically talking about Queensland, I've worked in other States and the same issues apply... There are basic aspects that should be part of any psychiatric establishment and these include adequate privacy, adequate sound-proofing, adequate ability for staff to observe patients... Poor, run-down, or inadequate facilities have a very detrimental effect on the recruiting of adequate or appropriate staff.<sup>202</sup>

The Chief Executive of the Hunter Area Mental Health Service acknowledged the effects of the surrounding environment on patients — particularly long stay patients:

[Psychiatric hospitals] are essential as part of a range of mental health services. There are people who will need at times to be hospitalised. There are people who will need to spend fairly long periods in hospital. And there are perhaps a few who may need to spend most of their adult lives in a hospital setting. It's essential they live in decent and high standard accommodation. And I believe that, until the [NSW] Mental Health Capital Works Program, none of the psychiatric hospitals would have met those criteria.<sup>203</sup>

A number of the hospitals he referred to are still being used.

## Facilities

I think it is very, very important to underscore the fact that there is discrimination against people with the severest illnesses who have to go into public hospitals because they are treated in a system which is under-manned, under-populated, under-resourced.<sup>204</sup>

In every State and Territory the Inquiry received disturbing evidence about seriously inadequate and often antiquated facilities in public psychiatric hospitals and units.

An examination of government expenditure generally revealed that this was not the result of a lack of money — but the fact that facilities for the mentally ill receive low or no priority. One experienced psychiatrist, deeply frustrated — as so many in the public health system are — told the Inquiry:

I empathise strongly with the despair, helplessness and hopelessness frequently expressed by the mentally ill and their families. Their feelings arise from the processes of illness [and its consequences]...my feelings arise from a profound sense of failure to be an effective advocate on behalf of my patients within the health care system... To illustrate...patients on the psychiatric unit at Fremantle Hospital do not have wardrobes for their clothes — the issue of wardrobes has been raised repeatedly with the hospital administration. The present [unsatisfactory] interview rooms are 'made do with', because change would require substantial funding. New furniture in the day centre was only obtained after a patient took photos of the old, dilapidated furniture... [The fact] that the hospital, supported by the State Government, was able to find substantial funding recently to construct a new cardiac catheter laboratory, and to renovate its Intensive Care unit and its Cardiac Care unit simply rubs salt in the wound.<sup>205</sup>

Unacceptable standards in both service and facilities were constantly raised in evidence from carers and consumers.

[Osler House in Brisbane] is in need of heating facilities...the building is draughty and cold. Patients...do not currently appear to have any systematic access to telephone facilities. Psychiatric patients should be entitled to at least the same telephone 'privileges'

as inmates in the care of the Queensland Department of Justice and Corrective Services. The diet is inappropriate for people in institutional care... Provision of heavily-sugared, stodgy food and milk drinks is outdated and inconsistent with...accepted ideas of the relationship between diet and health. Mealtimes appear better suited to the convenience of the staff... Visiting hours appear to be in a constant state of flux — they have no relation to the stated hours posted on the front of the building... Staff appear to...extend or curtail visits at their discretion.<sup>206</sup>

I would say [Rosemount Hospital] is the worst I've seen run down, dingy, cold — it was a very depressive atmosphere... They did have heaters, but there was a great shortage of blankets during the winter — one blanket per bed. Not proper male facilities — no male bath at all. That meant that disabled men had to be bathed in the female bathroom, which led to no privacy at all, really, for anyone.<sup>207</sup>

Restricted access to telephones is more important than may first appear. As many consumers pointed out, communication with the 'outside' is a lifeline for inpatients cut off from family and friends by their illness. Yet effective access to a phone is not available in a number of institutions.<sup>208</sup>

The mother of a young woman confined in one of the old psychiatric hospitals in Sydney told the Inquiry:

Whilst...emphasising the kindness and good care she had [in hospital], I did not like the showering arrangements with everyone having to shower at a certain time in the morning and evening... And toilet doors with locks broken with a two-foot space at the bottom... If my child chooses to live as she pleases, that is her choice. But when it is forced on her — and I know she was most distressed by this... There is absolutely no dignity.<sup>209</sup>

Other consumers complained that even where there were facilities for their personal belongings, institutional practices effectively deprived them of a reasonable degree of control:

Arrangements for security of patients' belongings are unacceptable. Wardrobes are lockable, but are not kept locked by nursing staff. Patients are not issued with keys. A leaflet states that patients' possessions are secure, but this is not so. During both my hospital stays last year, items were stolen. This was reported to nursing staff, but nothing was done and the items were not recovered.<sup>210</sup>

The Caring Committee for the Mentally Ill in Queensland held a public meeting in Rockhampton to gather consumers' views about how the system of psychiatric treatment could be changed. Subsequently, the Committee forwarded to the Inquiry a summary of the meeting's 'wish list' of facilities for inpatients:

An environment more conducive to relaxed recovery [should include]:

- \* a free-standing building, surrounded by gardens;
- \* birds in large cages;
- \* a library;
- \* a piano;
- \* an activities room; and
- \* a pleasant environment in the special confinement room [seclusion room].<sup>211</sup>

The list fosters an image of a civilised, restful environment — suitable for people recovering from the severe stresses often occasioned by mental illness. It is a sad, but accurate, reflection on the priority our society accords to the human rights of people affected by psychiatric disability that this image is so far removed from the facilities described by so many witnesses.

## **Education in Hospital**

Many witnesses told the Inquiry they were adolescent or just reaching adulthood when first institutionalised. Many longer-term psychiatric consumers have been educationally deprived and have not had the opportunity to develop social skills since the onset of their illness. In addition, many people with a good education and highly developed social skills need to regain confidence by learning and studying during or after an episode of mental illness.

The previous section addressed the sheer boredom of hospital life. After leaving hospital, many consumers with chronic illnesses depend on benefits and pensions, and have little money to spend on leisure pursuits. Encouraging literacy and fostering an interest in reading among inpatients is clearly one of the most practical ways of promoting learning, enjoyment and access to a range of necessary information.

One submission to the Inquiry was based on a study conducted in the occupational therapy area of Plenty Psychiatric Hospital in Melbourne.<sup>212</sup> Literacy teachers involved in the program recognised that participants often had problems with blurred vision, due to the effects of medication; suffered from restlessness and lack of concentration; and some had trouble with short or long term memory loss or mood swings. The submission demonstrated that patients were successfully motivated to learn to read — with patience, understanding and sensitivity to their anxieties.

It is significant that little other evidence was provided to the Inquiry regarding the educational needs of adult psychiatric inpatients, although this was a key issue in evidence relating to children and adolescents with mental illness (see Chapter 20) and was also discussed in the context of community care (see Chapter 9). The inference could be drawn that while great attention is now



accorded to adult education, those who are mentally ill have largely been forgotten — or simply assumed to be incapable.

## Discharge Planning

It is rarely recognised that the main group providing community care comprises the relatives... Regrettably, many psychiatrists and staff still do not consider it their duty to offer explanation, support, advice and guidance to relatives to help them in their anguish; worse, some do not talk to relatives at all. If a relative of any one of us suffers an illness, either physical or mental, then we would want to know about that illness in order to understand it, to be able to help...to know [the] danger signs, and to know how to deal with problems [that] may arise. When relatives are offered such help, they become effective allies of the staff.<sup>213</sup>

Evidence to the Inquiry established that effective discharge planning depends on three factors: careful preparation of the plan well before the person leaves hospital; involvement of post-discharge caregivers (both agencies and families) in constructing the plan; and sufficient resources and expertise to successfully implement the plan. However, the evidence also indicated that implementation is particularly problematic, since resources in most areas in Australia are grossly inadequate to meet the range of needs of consumers discharged to community care (particularly accommodation needs — see Chapter 10).

## Continuity of Care

Before discharging someone from hospital, priority should be given to ensuring that proper arrangements have been made for accommodation, general welfare and assistance with living skills.

Witnesses to the Inquiry repeatedly expressed dismay concerning the inadequacy of discharge planning for individuals leaving hospital after treatment for an acute episode of mental illness. One carer told the Inquiry that her son had been hospitalised 14 times, but had never received any follow-up after discharge. The spokesperson for a North Queensland support group told the Inquiry that ‘the desperately necessary ongoing support...ends once people are discharged from acute care hospitals’.

The Inquiry received a great deal of evidence about lack of continuity of care from representatives of shelters, refuges and other facilities for the homeless (see also Chapter 18). A typically disturbing account was given by a witness from a large crisis accommodation centre in Melbourne:

Psychiatric hospitals refer people directly to us on discharge... It's an inappropriate referral and raises serious concerns about why housing options for people being discharged

from hospital aren't considered before they leave hospital... They are not getting follow-up... I can't think of one example when we have received a phone call from anyone at the hospital to offer any suggestions about how we might manage that person, given that...there [would have been] some expertise developed with that person during their stay in hospital.<sup>214</sup>

Lack of transitional support and after-care following discharge from institutions was also raised in evidence presented by the Health Services Commissioner of Victoria, who commented that 'the gravest problem we encounter is the number of complaints from individuals, families and group members who are suffering because of the lack of adequate support...after discharge from a psychiatric hospital.'<sup>215</sup>

### **Involvement of Families**

If consumers are to return home after leaving hospital, as evidence suggests the majority of people do,<sup>216</sup> it is obvious that carers must have adequate knowledge about the symptoms of the illness, the medication required, and also a general understanding of what is involved in caring for a person with mental illness — particularly if it has been the first episode.<sup>217</sup> (These issues are dealt with more fully in Chapter 15; however they form a significant part of discharge planning and were frequently mentioned in this context in evidence.)

Many witnesses expressed concern about people being discharged precipitately and returning to families who were not ready to deal with the situation:

Early discharge is causing unnecessary family suffering. Families need time to recover, too, especially if they are to remain carers. Families cannot be expected to cope continuously.<sup>218</sup>

Consumers, carers and support groups gave numerous examples of inadequate pre-discharge preparation and post-discharge support for families. One Melbourne consumer told the Inquiry:

It is unfortunate that psychiatric hospitals don't provide any information for parents and caregivers, and they don't do any discharge planning with these families to prepare them for the kind of problems that could arise after the patient is released.<sup>219</sup>

A Western Australian couple made a submission concerning their daughter, who was suicidal when she was discharged. At no time was the family consulted about her subsequent welfare:

I was not informed when she was discharged of [her] spoken intention to commit suicide... The staff at the hospital did not inform us of...resources available in the community or at the hospital to enable us to cope with our daughter's illness... It was only after her death

that we learned there was a social worker at the hospital who could talk to us about [her] welfare.<sup>220</sup>

Evidence to the Inquiry indicated that similar situations occur frequently, often unnecessarily, and affect many people. The evidence also indicated that a combination of factors is responsible: inadequate resources; lack of coordination between health professionals and between different agencies; professional reluctance to share necessary information with 'lay people'; and an astonishing lack of understanding, or indifference, about the consequences of 'dumping' vulnerable people without making adequate arrangements for their future care.

### **Inter-Agency Coordination**

The majority of people who experience serious or chronic mental illnesses need time to recover after leaving hospital and are not immediately able to resume domestic, financial and social responsibilities. They therefore need access to a number of community, State and Commonwealth services after discharge.

However, witnesses recounted experiences involving lack of coordination between Commonwealth agencies handling sickness and pension entitlements and sections responsible for rehabilitation, training and employment services; State departments of housing and health; and local community services and facilities (see Chapter 5). Witnesses stressed the necessity for the involvement — before the person is discharged from hospital — of multidisciplinary teams to facilitate access to these services and to ensure that consumers' needs for continuing care in the community are met.

A [critical] issue is the problem of discharge planning... Service providers are very clear that the difficulties of discharge planning are often associated with pressures of work, with disagreements between service providers and with the difficulty of marrying where people should go... A lot of effort needs to go into the dynamics of organisations... Between service delivery units, there seem to be a lot of difficulties — between the hospitals and the clinics — and with referrals from hospitals to clinics... We have been talking about continuity of care for 25 years — continuity of care is vital to the maintenance of human rights. If the hospitals service one area and the clinics service another area, the people fall in between.<sup>221</sup>

### **Case Management**

The Inquiry heard repeatedly that a case manager should be allocated to each person on or before discharge from hospital. A case manager's role is complex,<sup>222</sup> but should include coordination of a multidisciplinary team of health and welfare professionals; oversight of referrals for clinical consultations; assessment and adjustment of medication; and assisting with accessing appropriate housing, living skills and rehabilitation programs.

Many mental illnesses are cyclical and require periodic readmissions. For this reason, case management systems providing access to both hospital and community services were seen as essential by many witnesses:

Linkages...between hospital and community are paramount — continuity of care and follow-up systems are very important. It appears that where a case management system is linking a hospital and a community service, this works very well in having one specified person responsible for monitoring how that person is getting on.<sup>223</sup>

[On discharge from hospital], treatment and other rehabilitation needs are very much intertwined... The illness fluctuates, medication needs fluctuate [and] stress measurement is required. We would certainly recommend flexibility of movement between hospital and community.<sup>224</sup>

Different people need different levels of case management on discharge. An experienced director of a Sydney community mental health service summarised the range of responses required:

Some just need help with adjusting their medication and [with] how things are going in their life...all the way to intensive case management teams, which work on a seven-day basis with small case loads in order to support people who are most vulnerable... You need a range of services and...the hospital is an important part of that. We are not talking about hospital versus community here, we are talking about integrated services which include both hospital and community.<sup>225</sup>

The Inquiry also received recommendations concerning the types of agencies which could provide effective case management.

There should be better consultation prior to the person leaving hospital. A case manager should be appointed for that individual... The case manager could be any agency within the community who links people into various services. The case management model [currently] proposed is that the case worker be a health worker. In that case, they would need to have consultation with the accommodation services, the living skills centre... All the different components should be brought to the hospital and an outcome agreed before the person leaves hospital. It's very difficult for individuals to have to re-negotiate each time they want to make contact with a service [after leaving hospital].<sup>226</sup>

The same witness identified potential problems of access to the community crisis team (part of the health system) if the case manager were from a community agency:

There would have to be absolute agreement on access to these services for that to work properly, whereas if the case manager is the health worker, right of access is automatically there. That would have to be debated.<sup>227</sup>

This evidence raises issues requiring clear decisions at a policy level to establish workable case management systems. As this witness pointed out, if the

case manager were a community agency worker, access to hospital, public psychiatrists, social workers and crisis teams would need to be negotiated. If, as occurs now in some States, the case manager is a member of the community mental health team, the range of health services should be readily available,<sup>228</sup> but access to housing (unless special accommodation services are attached to the mental health service), training, and community services would have to be arranged through different channels.

One community-based psychiatrist told the Inquiry that the title in his area had been changed from 'case manager' to 'service coordinator':

because consumers don't like to be cases and they don't like to be managed... 'Case managers' is the phrase used in the international literature...but [what] is required is **good services!**<sup>229</sup>

Because these issues are of central importance in delivering effective responses they are also considered in the context of Chapter 9 — Community Care and Treatment.

### **Transfer of Patient Information**

The Inquiry received a number of submissions concerning difficulties associated with making patients' hospital records available to the community treatment centre responsible for their supervision after discharge from hospital. One difficulty commonly referred to by both carers and community mental health workers was the failure by hospitals to transfer any information to the new treatment team, or to pass on only a discharge summary.<sup>230</sup>

While health professionals need to be familiar with the history of consumers in their care, they also need to be able to reassure clients that information is treated in confidence and that access to records is appropriately controlled.

There is an issue regarding government and non-government services — numbers of members [of the Australian Association of Social Workers] have raised the concern they have had...in non-Government organisations about their rights to information about clients and about their families. If people are discharged from [hospital], they have a right for that information to remain at [the hospital]. [If, however,] they are turning up at a non-Government sector organisation — they may or may not be very ill or have some disturbance — what is the right of the person in that organisation to get information about them? They cannot function without information. But do they have any right to it?<sup>231</sup>

Given the reality that many people who have been patients because of mental illness are subsequently 'dumped' into the community and frequently turn to non-government organisations for assistance (see Chapter 18 — Homeless People) this issue must be urgently addressed.

The Inquiry also heard evidence concerning conflicts between carers' needs for information and consumers' desires for confidentiality.

If a recovering patient requests that a carer be given no information as to treatment or medication, that right is upheld. The carer is then in a position of being expected to look after the discharged patient without adequate information to properly do so.<sup>232</sup>

Clearly, sensible solutions must be found. (The central issue, one of balancing rights, is further analysed in Chapter 15 — Carers: The Experience of Family Members.)

### **Rehabilitation Planning**

Many witnesses contended that discharge planning is inadequately orientated to recovery and rehabilitation for independent living — where this is possible. Several witnesses expressed the view that not only discharge plans, but the entire course of inpatient care should be directed towards developing community living skills and eventual independence, rather than encouraging dependency while the consumer is hospitalised:

Discharge planning should commence on the day of admission. The community teams should be encouraged to visit the client every day whilst in hospital — they should be actively involved in inpatients' treatment. Greater effort should be made by hospital staff to access the client's community file, so that decisions can be made after gathering all of the relevant information. In an admission unit, nearly everything is done for the client, from money management and cooking to medication compliance. These people are then discharged and expected to function in the community, after being de-skilled in their living skills.<sup>233</sup>

People in hospital need to know before discharge that arrangements have been made for somewhere for them to live. Anxiety about future accommodation seriously affects consumers while they are still in hospital:

I don't like the thought of being discharged, because it's scary. I don't know where I'm going to live. I would like to go to a hostel somewhere.<sup>234</sup>

It is clear from evidence presented to the Inquiry that consumers cannot expect a smooth transition from hospital to community living. Bridging programs are urgently required to ensure that the welfare and the human rights of people with

mental illness are protected — as well as those of their families and the community.

## **Conclusion**

While no one would advocate a return to the Dickensian mental institutions of the nineteenth century, there is, and for the foreseeable future will be, a need for intensive, inpatient care for people experiencing acute episodes of mental illness and for the small minority of individuals with severe and chronically disabling mental illnesses who require long term institutional care. Given the evidence in every State and Territory from consumers, service providers, families and community support groups that people are frequently discharged from hospital with no accommodation to go to, urgent attention must be given to resolving the organisational and ethical questions which the substantial involvement of non-government organisations in community care of those people now present.

The evidence presented to the Inquiry concerning the alienation, indignity and frequent violence experienced by psychiatric inpatients indicates that we still lack a system of institutional care which adequately protects the rights of the mentally ill.

1. Name withheld. Submission No335, p1.
2. Dr Cris MacLeod, PALA, NSW. Oral evidence, Sydney 21.6.91, p617. (PALA, which means 'refuge' or 'asylum', is a consumer organisation which supports members and lobbies for non-coercive psychiatric treatment and for alternatives to what they see as the 'medical model' of treating mental illness.)
3. Name withheld, NSW. Submission No335, p4.
4. These teams are variously termed Psychiatric Emergency Teams (PET) in Western Australia; Crisis Assessment Teams (CAT) in Victoria; Crisis Teams in NSW; and Care and Assessment Teams (CAT) in the Northern Territory.
5. Marjorie Bull, Vice President, NSW Association for Mental Health. Oral evidence, Sydney 19.6.91, p297.
6. Anne Davis, Executive Officer, ARAFMI, NSW. Oral evidence, Sydney 18.6.91, p155.
7. Patricia Dasic, carer, Victoria. Submission, pp1,3.
8. Dr Cris MacLeod, op cit, pp616-18, 621.
9. Dr Malcolm Roberts, now in private practice, was formerly Director of the Psychiatric Emergency Team, Perth, WA. Oral evidence, Perth 12.2.92, pp330-33.
10. The Inquiry received confidential submissions from NSW and Queensland providing accounts by the relatives of people with major depressive illness who had voluntarily sought admission to psychiatric hospital, been refused admission, and, within hours or days, committed suicide.
11. Dr David Leonard, Director of Clinical Services, Royal Park Hospital. Oral evidence, Melbourne 14.4.91, pp343-44.
12. Brian I'Anson, President, Mental Health Foundation, ACT. Submission, p2.
13. In the majority of cases in which individuals related accounts of being detained against their will, there was no secondary evidence to provide information about the particular circumstances at the time.
14. Name withheld, Adelaide. Oral evidence, Adelaide 23.10.91, pp372-3.
15. Name withheld. Submission No439, p5.
16. Names withheld. Oral evidence, Hobart 12.11.91, p250.
17. *ibid*, p248.
18. Office of Psychiatric Services. The Office has since been replaced by the Division of Psychiatric Services within the Victorian Department of Health and Community Services.
19. Lyn Light, Director, Ballarat Central Parish Mission Outreach Centre, Victoria. Submission, p19.
20. J Sherry, South Australia. Submission, p4.
21. See, for example, Margaret Herring, President, Schizophrenia Fellowship of North Queensland. Oral evidence, Townsville 12.8.91, p1251: 'The medium to long-term facility is one of a necessary range of facilities needed.'
22. Dr David Wells, Director of the Office of Forensic Medicine, Victoria. Submission, Appendix 1, p83.
23. Names withheld, op cit endnote 16, pp256-7.
24. Name withheld. Submission No302, p4.
25. Maria Heaton, Manager, Disability Complaints Unit, South Australia. Oral evidence, Adelaide 22.10.91, p184.



26. Unnamed member, Schizophrenia Fellowship of South Australia. Included in Fellowship's submission titled 'Draft Recommendations re Transportation to a Psychiatric Facility', p9.
27. See, for example, Rev Harry Herbert, General Secretary of the Board for Social Responsibility of the NSW Synod of the Uniting Church. Submission, p2.
28. Dr David Wells, Director, Office of Forensic Medicine, Victoria. Oral evidence, Ballarat 11.4.91, p603.
29. Roberts, *op cit*, pp337-8.
30. Heaton, *op cit*; and Wells, *op cit* (submission), p3.
31. Peter Swan, Schizophrenia Fellowship, Queensland. Oral evidence, Brisbane 14.8.91, p1493.
32. Laurie Maddison, Western Australia. Submission, p1.
33. Elaine Colbert, Member, ARAFMI, Cairns. Oral evidence, Cairns 9.8.91, p1095.
34. Patricia Vanderwal, MIND, Perth. Oral evidence, Perth 11.2.92, p215.
35. Tom Wade, convenor, Policy Committee of Queensland Association for Mental Health. Oral evidence, Brisbane 15.8.91, p1575.
36. Sue Jefford, Director of Psychiatric Nursing, Community Mental Health Services, Alice Springs Hospital. Oral evidence, Alice Springs 23.7.92, p220.
37. Janet Meagher, NSW. Oral evidence, Sydney 17.6.91, p128.
38. Michael Longhurst, team leader, Mobile Treatment Team, Ryde, NSW. Submission, p1.
39. Dr Ian Sale, Chairman, Tasmanian Branch of the Royal Australian and New Zealand College of Psychiatrists. Oral evidence, Hobart 12.11.91, pp183,186.
40. Dr Fiona Hawker, psychiatrist, Adelaide. Oral evidence, Adelaide 23.10.91, p342.
41. MacLeod, *op cit*, p617: 'I [needed help] to lessen the recurring nightmares and continuing depression that the treatment caused... Despite some months in a private clinic [with] caring staff...the nightmares of the [earlier] episode returned and had to be dealt with all over again repeatedly.' Also Prof Sandy McFarlane, Foundation Professor of Rehabilitation Psychiatry, Flinders University. Oral evidence, Adelaide 21.10.91, p106.
42. Name withheld. Submission No239, p4.
43. J Brown, NSW. Submission, p3 and oral evidence, Sydney 20.6.91, p493.
44. Jenny Gee, Mental Health Legal Centre, Victoria. Submission, pp3,4.
45. Eg name withheld, *op cit* endnote 42, p2: 'I think it is important that you have submissions directly from the people who are the focus of your Inquiry. I am sure that you will receive many submissions from professionals, institutions and organisations. I am equally sure that few people like myself will be able to write to you... I shall make some general points from my experience and then give you some specific instances... I could not write it without the help of a friend.'
46. Including 206 written submissions and evidence from 44 consumers at public hearings in all States and Territories.
47. Name withheld. Submission No88, p4.
48. *id*.
49. Cheryl Phillips, field worker for GROW, Launceston. Oral evidence, Devonport 14.11.91, p447.
50. Name withheld. Submission No302, p10.

51. Meg Smith, Manic Depression and Depression Association, Sydney. Oral evidence, Sydney 17.6.91, p88.
52. Noelene James. Oral evidence, Sydney 18.6.91, p164.
53. Leonard, op cit, pp341-343,346.
54. Professor Gavin Andrews, Director, Health Services Research Group, Clinical Research Unit for Anxiety Disorders, Sydney. Oral evidence, Sydney 17.6.91, pp47,53-4.
55. Bill Healy, senior lecturer, and Justine McNamara, student, Department of Social Work, LaTrobe University. Submission, p6. See also M D Oriol and R D Oriol, 'Involuntary Commitment and the Right to Refuse Medication', *Journal of Psychosocial Nursing* v24 No11, Nov 1986, p15: 'Psychotropic medications are not a cure for mental illness. While they have allowed clients to live and work in more meaningful social settings, this increased freedom is not without a price. Anti-psychotic medications are capable of affecting every organ in the body... Clients may have to make a choice between the symptoms of psychosis and the debilitating effects of psychotropic medication.'
56. Name withheld. Submission No239, p4.
57. Anne Greener, NSW. Oral evidence, Sydney 20.6.91, pp527,8.
58. MacLeod, op cit, p620.
59. K McIntyre, M Farrel, and A David, 'Inpatient Psychiatric Care: The Patient's View', *British Journal of Medical Psychology* v62, 1989, p249. The introduction to this report comments, in relation to health professionals in the UK, on 'the widespread assumption that the mentally ill are unable to give valid opinions.' There appears to be a similar assumption in Australia among some health professionals.
60. Healy and McNamara, op cit.
61. Name withheld. Submission No243, p2.
62. Jan Eastgate, Citizens' Committee on Human Rights. Oral evidence, Sydney 8.7.91, p632.
63. Robert Ramjam, Schizophrenia Fellowship of NSW. Oral evidence, Sydney 19.6.91, p321
64. Name withheld. Oral evidence, Adelaide 21.10.91, p154.
65. ♦ Clozapine (Clorazil). Claudia Wallis and James Willwerth, 'Schizophrenia: Awakenings; How a New Drug Brings Patients Back to Life', *Time* No97, 6 July 1992, pp68-73, describe the development of Clozapine by Sandoz and its approval by the US Federal Drug Authority in 1989 for treating people with schizophrenia for whom the common treatment with chlorpromazine type drugs was ineffective. Clozapine has been demonstrated to avoid most of the side effects of chlorpromazine. It can cause seizures in up to 6 percent of people but its major drawback is that treatment carries a 1-2 percent risk of the patient developing a potentially fatal blood-cell deficiency condition (agranulocytosis) which is reversible if Clozapine is discontinued immediately tests indicate the disease may be developing. Six Americans of 20,000 taking the drug died from this condition in the two years following its approval. Weekly blood tests are required to check for indications of the condition. The cost of the medication per patient is high (US \$4,100 per annum.) One State (Minnesota) has subsidised the cost for one quarter of its 4,300 eligible consumers, although it is estimated to save up to US \$30,000 per person per year (compared with those taking Chlorpromazine) in hospital and related costs of the illness. It is reported to have dramatically beneficial effects in 10 percent of schizophrenia sufferers. Clozapine was approved for release in Australia by the Australian Drug Evaluation Committee (ADEC) in March 1993 and is currently being provided to people with treatment-resistant schizophrenia in a number of inpatient psychiatric facilities.

- Remoxipride. Manufactured by Astra Pharmaceuticals, Sweden, Remoxipride may offer the advantage of fewer side effects than existing drugs used in the treatment of schizophrenia — improving quality of life and potentially overcoming the widespread reluctance to continue taking medication. Remoxipride was approved by ADEC in early 1993 and is being provided to people with schizophrenia in some inpatient facilities. Experts caution that, although there is reason for optimism about Remoxipride, longer-term appraisal of its effects is required before a full evaluation can be made.
  - Resperidone (Risperdal). Manufactured by Janssen-Cilag, Belgium, Resperidone is one of a new class of anti-psychotic drugs called SDAs — serotonin-dopamine antagonists — which, unlike the earlier anti-psychotics, include agents to combat the so-called 'negative' symptoms of schizophrenia (apathy, social withdrawal, lack of motivation) as well as the 'positive' symptoms (delusions, hallucinations, thought disorder and hearing voices). The manufacturer claims that Resperidone has significant clinical advantages in terms of negative, positive and affective (mood) symptoms and side effects. Resperidone has not been released in Australia and long-term assessment is necessary to evaluate its effectiveness.
66. • Prozac 20 (fluoxetine hydrochloride), an anti-depressant manufactured locally by Eli Lilly, Australia under licence from its American manufacturers, Lilly, is designed for the treatment of major depressive disorders. Some people find the drug has better effects and fewer side effects than other drugs. The manufacturer of Prozac lists a number of different side effects which affected between 1 percent and 20 percent of consumers during clinical trials. The worst of the potential adverse reactions to Prozac have been publicised recently and the Inquiry has received many telephone inquiries from concerned consumers. People have been advised to raise their concerns immediately with their doctor, or with hospital or mental health clinic staff, if they have any concerns about the drug, its risks, or its side effects.
- Aurorix (moclobemide), is an anti-depressant manufactured by Roche. Aurorix has been prescribed in Australia for some people with depressive illnesses since mid 1992. Unlike many anti-depressant drugs, Aurorix does not have a sedating effect and does not impair reaction times, but is claimed to increase sleeping time (insomnia is a common feature of major depression.) Studies indicate low toxicity and rapid elimination from the body. Unlike some medication, no restrictions on certain classes of food are necessary, and in those who have overdosed with Aurorix, there has been no significant cardiac or respiratory toxicity and no mortality. Aurorix does not have any adverse interactions with anti-hypertensive drugs — a significant breakthrough for the large number of depressed elderly people who also require anti-hypertensive medication. Aurorix is included in the Intensive Medicines Monitoring Program conducted by Roche in New Zealand.
67. Clorazil and Prozac.
68. Name withheld. Submission No556, p10.
69. E Fuller Torrey, *Surviving Schizophrenia: a Family Manual*. Harper & Row, New York, 1988, pp194-200.
70. MIMS is the former acronym for *Monthly Index of Medical Specialties*. Many years ago, its function changed, but the acronym remains and the publication is widely known as 'MIMS'. It is the approved pharmaceutical prescribing index and publishes information provided by the pharmaceutical manufacturing companies after clinical trials of the various pharmaceutical drugs listed.
71. Fuller Torrey, op cit.

72. Greener, op cit, p519.
73. Name withheld, Sydney. Oral evidence, Sydney 21.6.91, p584. As this witness was not able to supply information about the size of the dosage administered, the Inquiry is not aware whether the side effects were due to the substance itself or to over-prescription.
74. Name withheld. Oral evidence, Adelaide 21.10.91, p154.
75. McFarlane, op cit, p105.
76. *ibid*, p99: 'Much of the fear of using anti-psychotic drugs is linked to the fear of tardive dyskinesia...the condition usually develops in schizophrenics who are older and who have been on [these] drugs for many years... It usually begins while the patient is taking the drug, but rarely may begin shortly after the drug has been stopped. Occasionally it persists indefinitely. No effective treatment has been found to date... The frequency and seriousness of tardive dyskinesia are one of the most hotly debated topics in current psychiatry.'
77. Name withheld. Submission No556, p11.
78. Barbara Wainman, consumer, Queensland. Submission, p1.
79. Ramjam, op cit, p632.
80. Cogentin is an anti-parkinson agent which counters muscle spasm, rigidity and tremor.
81. Name withheld. Submission No243, p2.
82. Smith, op cit, p89.
83. Dr Christopher Alroe, a psychiatrist, gave evidence concerning this research. This is discussed in Chapter 9 — Community Care and Treatment.
84. While people with the two major mental illnesses — manic depressive disorder and schizophrenia — frequently have that condition for life, the symptoms can often be controlled, to a greater or lesser extent, by a low, continuous dosage of medication. If monitored carefully, this continuous 'maintenance dosage' can certainly moderate the individual's illness, although it is still common for psychotic episodes to occur — particularly as a response to personal stress.
85. Phillips, op cit, p446.
86. F Panaia, Secretary, NT Association for Mental Health. Submission, p1.
87. Dr Jacob Matthews, senior psychiatrist, Woodhouse Centre Psychogeriatric Service, Hobart. Oral evidence, Hobart 13.11.91, pp267-269.
88. Name withheld. Submission No556, p11.
89. Name withheld. Submission No671, p3.
90. Wainman, op cit, p1.
91. Panaia, op cit, p1.
92. Name withheld. Oral evidence, Adelaide 23.10.91, p373.
93. Dr Steve Robinson, psychiatrist, Community Assessment and Treatment Team, Newcastle. Submission, p2: 'This is largely due to legislation which unnecessarily demands pharmaceutical companies to repeat tests in Australia that have already been performed and accepted in America and Europe. Clozapine (see endnote 65) is one important drug for treatment-resistant cases of schizophrenia which is being withheld from Australian citizens.'
94. Name withheld. Oral evidence, Adelaide 21.10.91, p154.
95. Ramjam, op cit, p322.

96. Phillips, op cit, p445.
97. Name withheld. Submission No357, pp2,3.
98. Dr John Tooth, psychogeriatrician. Oral evidence, Hobart 11.11.91, pp64-5.
99. This was also the view, for example, of Dr Malcolm Roberts, who gave evidence to the Inquiry in Tasmania.
100. Terry Melbourne, Victorian Mental Illness Awareness Council. Oral evidence, Melbourne 9.4.91, p266.
101. Name withheld. Submission No334, p3.
102. Name withheld. Oral evidence, Sydney 21.6.91, p589.
103. Peter Bioletti, President, MINDS (Mental Illness and Nervous Disorders Society). Submission, pp1-3.
104. Arthur Nettleton, consumer, NSW. Submission, pp4-6.
105. id.
106. Name withheld. Submission No498, p4.
107. Name withheld. Submission No690, pp11-12.
108. Christine Flynn, Policy and Administration Director, Mental Health Coordinating Council, NSW. Submission, p10.
109. Orthomolecular medicine is a type of assessment and treatment utilising natural constituents such as vitamins, minerals, salts, hormones and nutritional regimes.
110. Judy Gray, Schizophrenia Fellowship of South Queensland. Oral evidence, Brisbane 15.8.91, p1622.
111. Jean Cant, Alliance for the Mentally Ill, Australia, (NSW branch). Submission, p1.
112. For example, see James, op cit, p165.
113. Joanne Short, NSW. Submission, p1.
114. Graeme Curry, Senior Lecturer, Faculty of Nursing, Kuring-Gai College of Advanced Education, Sydney. Submission, p2.
115. Dr Christopher Alroe, psychiatrist, Queensland. Oral evidence, Brisbane 15.8.91, p1640.
116. Andrews, op cit, p55.
117. Dr Joan Ridley, psychiatrist, Director of Mental Health Services, Northern Territory Department of Health. Oral evidence, Darwin 21.7.92, pp132-3. The book is I Gawler, *You Can Conquer Cancer: The Self-Help Guide to the Way Back to Health*. Thorson's Publishers, Rochester, Vermont 1987.
118. *ibid*, pp136-137.
119. See, for example, Evelyn Field, clinical psychologist, Australian Psychological Society, Victorian Branch. Oral evidence, Melbourne 10.4.91, pp379,381.
120. Liz Dalston, Executive Director, Mental Health Association Resource Centre, South Australia. Oral evidence, Adelaide 22.10.91, p163.
121. Jenny Gee, Mental Health Legal Centre Inc, Victoria. Submission, p8.
122. Name withheld. Submission No257, p1.
123. Prof Vaughan Carr, Professor of Psychiatry, Mater Hospital, Newcastle. Oral evidence, Newcastle 9.7.91, p751.
124. id.
125. Name withheld. Submission No4, p3.

126. Name withheld. Submission No239, p7.
127. Name withheld. Oral evidence, Devonport 14.11.91, p405.
128. Patricia Vanderwal, Coordinator, MIND (Mentally Ill Need Defending). Perth. Oral evidence, Perth 11.2.92, p214.
129. Name withheld. Oral evidence, Sydney 21.6.91, p586.
130. Carr, op cit, p746.
131. Dr Roger Gurr, Clinical Director of Psychiatry, Blacktown Community Health Centre. Oral evidence, Sydney 18.6.91, p222.
132. Orme Hodgson, past President, Schizophrenia Fellowship of South Queensland. Oral evidence, Brisbane 15.8.91, p1624.
133. Jeannette Sherrington, Breakthrough Support Group. Oral evidence, Hobart 12.11.91, p242.
134. Dr Fiona Hawker, psychiatrist. Oral evidence, Adelaide 23.10.91, p342.
135. Meagher, op cit, p132.
136. Residents of the Fintry Bank Supported Accommodation Project, names withheld, Victoria. Submission No50, p3.
137. Curry, op cit, p10.
138. Hospital for the Insane, Kenmore, 'Rules for the Attendants, Nurses, Servants and Others.' Sydney 1897, p5.
139. Name withheld. Submission No257, p3.
140. Name withheld. Submission No128, pp1-2.
141. Name withheld. Submission No462, pp1-2.
142. Bonnie Water, Australian Nursing Federation, South Australian Branch. Oral evidence, Port Lincoln 18.10.91, p88. Also McFarlane, op cit, p106.
143. Name withheld. Oral evidence, Sydney 9.7.91, p780-1.
144. Name withheld. Submission No302, pp16,18.
145. Gee, op cit, p10.
146. Name withheld. Submission No128, p3.
147. Phillips, op cit, p445.
148. Water, op cit, p76.
149. Denis Jones, Secretary, Queensland Nurses Union. Submission, p17.
150. Gerry Hoogenboom, Program Manager, Acute Psychiatry, Bendigo Psychiatric Centre, Victoria. Submission, p2.
151. Water, op cit.
152. Kate Lean, consumer, Queensland. Submission, p2.
153. Judy Magub, Executive Director, Queensland Association for Mental Health. Submission, p4.
154. Name withheld. Submission No397, p3.
155. Name withheld. Submission No243, pp5,6.
156. Libby Steeper, ACTCOSS, Australian Capital Territory. Submission, p3.
157. Name withheld. Submission No664, p15.

158. Name withheld. Submission No357, p1.
159. Meagher, op cit, p133.
160. Pat Carberry, Director, Association of Relatives and Friends of the Mentally Ill, Western Australia. Oral evidence, Perth 11.2.92, p249.
161. Names withheld. Submission No468, p7.
162. Phillips, op cit, p444
163. Tony Wade, Queensland Association for Mental Health. Oral evidence, Brisbane 15.8.91, p1573. (For further discussion on ACHS Standards for psychiatric services, see Chapter 28.)
164. Hodgson, op cit, p6.
165. Janet Noble, NSW. Submission, p1.
166. Leonie Walsh, consumer, Victoria. Oral evidence, Melbourne 8.4.91, p139.
167. J D Little, 'Inpatient and Outpatient Suicide: What Happened and What Do We Do?', *Australian and New Zealand Journal of Psychiatry* No26, June 1992, p163: '[Psychiatric] hospital suicide rates are at least five to ten times higher than the general population and over the past 75 years, the frequency of inpatient suicides has been remarkably constant, despite a wide range of therapeutic ideologies and methodologies.'
168. P Elmer-Dewitt, 'Depression: The Growing Role of Drug Therapies', *Time* 8 July 1992, p73: 'The condition once called melancholia, now better known as major depression — the crushing despondency that strikes more than 12 million Americans each year — accounts for at least half the nation's suicides.'
169. Little, op cit, 'There is an inevitability about suicide. A proportion of patients will commit suicide, regardless of preventive and treatment measures.'
170. Name withheld. Oral evidence, Newcastle 9.7.91, pp845,849.
171. Name withheld. Submission No805, pp1-2.
172. Mary Anne Broad, carer, Queensland. Submission, p2.
173. Marie Quinn, Western Australia. Submission, p1,4.
174. Ramjam, op cit, p320.
175. Name withheld. Submission No731, pp1-2.
176. Name withheld. Submission No15, p7.
177. Ailsa Whitehead, President, ARAFMI Queensland. Oral evidence, Brisbane 16.8.91, p1687.
178. Carol Kerr, occupational therapist, Queensland. Oral evidence, Brisbane 14.8.91, pp1420,1426.
179. Dr Nandadevi Chandraratnam was fatally assaulted by a patient at Hillcrest Hospital on 3 December, 1992.
180. Phillips, op cit, p444.
181. Name withheld. Oral evidence, Sydney 17.6.91, pp128-129,131.
182. Name withheld. Submission No727, p1.
183. A Darby, 'Patient Awarded \$12,000 for Rape by Nurse', *Sydney Morning Herald* 5 Sept 1992, p3.
184. Merrilyn Walton, Director, NSW Health Complaints Unit. Oral evidence, Sydney 19.6.91, pp332-33.

185. Smith, op cit, p87.
186. Leonard, op cit, pp342, 344, 345.
187. Name withheld. Submission No664, pp6-9.
188. Vanderwal, op cit, pp214-215.
189. Name withheld. Submission No334, p2.
190. Vicki Eyles, NSW. Submission, p8.
191. Name withheld. Oral evidence, Sydney 21.6.91, pp586,587,591.
192. Ruth Raward, ARAFMI, Tasmania. Submission, p1.
193. Broad, op cit, pp1346,49.
194. Name withheld. Submission No15, pp4-5.
195. Orme Hodgson, Schizophrenia Fellowship, Queensland. Submission, p12.
196. Paul Warren, occupational therapist, Mental Health Services, Alice Springs. Oral evidence Alice Springs 23.7.91, p214.
197. Meagher, op cit, p127.
198. Dr Warwick Middleton, Deputy Director of Psychiatry at Royal Brisbane Hospital, who also has responsibility for the day-to-day running of Rosemount, reported in *The Australian* 10 Sept 1991. The Chairman of the Queensland Branch of the RANZCP, Dr Jim Rodney, has also expressed concerns (*The Australian* 13 Sept 1991, p5) about patient safety at Rosemount, claiming the buildings, which are 'like something out of the old Bedlam days', constitute a fire hazard. Reports published since the Inquiry inspected this 'facility' (*Courier Mail* 7 Dec 1992, p12) have suggested that Rosemount is now top priority for replacement in the 1993-94 financial year.
199. Leonie Cox, clinical nurse specialist in mental health. Oral evidence, Sydney 8.7.91, p674.
200. James, op cit, p172.
201. MacFarlane, op cit, p109.
202. Dr Warwick Middleton, Psychiatrist, Royal Australian and New Zealand College of Psychiatrists, Queensland Branch. Oral evidence, Brisbane 14.8.91, p1351,53,54. Similar points were made by many other psychiatrists who gave evidence, including Dr David Copolov, Director, Mental Health Research Institute of Victoria. Oral evidence, Melbourne 8.4.91, p74.
203. Professor Rodney Morice, Chief Executive Officer, Hunter Area Mental Health Service. Oral evidence, Newcastle 9.7.91, p708.
204. Copolov, op cit, p75.
205. Dr David Lord, psychiatrist, Western Australia. Submission, p1.
206. Name withheld. Submission No468, p5.
207. Broad, op cit, p1342-43.
208. James, op cit.
209. Jan Brown, carer. Oral evidence, Sydney 20.6.91, p491.
210. Name withheld. Submission No302, p18.
211. Flora Pownall, Caring Committee for the Mentally Ill, Queensland. Submission, p2.



212. G Johnston, *You Don't Think I'm Going to Die in Here, Do You ? An Investigation into the Adult Literacy/Further Education Needs of Long-Term, Chronic Psychiatric Patients*. Northern Metropolitan College of TAFE, Victoria 1989.
213. J Houl, 'Community Psychiatry', in: P Beumont and R Hampshire, *Textbook of Psychiatry*, Blackwell, Sydney 1989, pp320-321.
214. Margaret Hamley, Crossroads, Melbourne. Oral evidence, Melbourne 8.4.91, pp99102.
215. Dr Ian Siggins, Victorian Health Services Commissioner. Oral evidence, Melbourne 8.4.91, p48.
216. Information provided to the Inquiry by Dr John Houl, Clinical Director of Psychiatry, Glebe Community Care, Sydney.
217. I Isaacs, Queensland. Submission, p2.
218. Pat Ingram, ARAFMI, Tasmania. Oral evidence, Hobart 12.11.91, p249.
219. Walsh, op cit, p142.
220. Name withheld. Submission No602, pp2-3.
221. Maria Harries, former President, Australian Association of Social Workers, Western Australian Branch. Oral evidence, Perth 11.2.92, p266.
222. M Baier, 'Case Management with the Chronic Mentally Ill', *Journal of Psychosocial Nursing* v25, No6, 1987, p17.
223. Pat Jones, Chairperson, NSW Association for Mental Health. Oral evidence, Sydney 19.6.91, p298.
224. Dr Roger Gurr, Clinical Director of Psychiatry, Blacktown Community Health Centre, NSW. Oral evidence, Sydney 18.6.91, p227.
225. Dr Alan Rosen, psychiatrist, Director, Northern Sydney Area Community Mental Health Service. Oral evidence, Sydney 19.6.91, pp373-4.
226. Joy Said, Executive Director, After Care Association of NSW. Oral evidence, Sydney 17.6.91, p37-39.
227. id.
228. Although recent funding cuts in several States make this uncertain.
229. Gurr, op cit, p226.
230. A discharge summary fulfils the function of a record of the hospital's assessment of the patient's status on discharge and of a referral note to any subsequent health service providers. It commonly contains the name of the discharging doctor, information about the person's diagnosis by the hospital, and current medication. It does not provide a full medical history and in most instances would not record medications rejected for unsuitability for the particular individual. It is commonly given to the patient at discharge.
231. Harries, op cit, p267.
232. Anne Davis, Executive Officer, ARAFMI, NSW. Oral evidence, Sydney 18.6.91, p153.
233. Michael Longhurst, team leader, Ryde-Hunter's Hill Mobile Treatment Team, NSW. Submission, pp2-3.
234. Name withheld, Victoria. Mentioned in Maggie McGuinness and Yoland Wadsworth, Victorian Mental Illness Awareness Council, Submission. *Understanding, Anytime: A Consumer Evaluation of an Acute Psychiatric Hospital*, Melbourne 1991, p20.

## Chapter 9

# COMMUNITY CARE AND TREATMENT

When psychiatric patients are discharged from hospital, there should be a definite plan for their management to ensure that appropriate treatment is provided, with a program of rehabilitation... To throw people onto the community who are not able to deal with everyday problems is hardly in keeping with a humane mental health policy.<sup>1</sup>

Hospitalisation takes a big chunk out of your life. You are locked up in this confined area, then you are practically kicked out the door and expected to stand on your own two feet!<sup>2</sup>

The term ‘community care’<sup>3</sup> encompasses many issues, broadly involving the care and treatment outside an institution of people who have (or who are recovering from) a mental illness.

‘Deinstitutionalisation’ has often been used to describe the policy of caring for people with mental illness ‘in the community’<sup>4</sup> instead of only (or mainly) in hospitals and psychiatric units. The word is becoming less commonly used, because the concept of community care includes arrangements for the care and support of families, as well as care and treatment for the significant proportion of people with mental illness who have never been admitted to a psychiatric facility and who may never need to be — if they are provided with appropriate care, support and treatment in their own environment.

Hospitals deal with less than 5 percent of people with mental illness. 95 percent of people [live in the community].<sup>5</sup>

Community care also includes issues affecting people who may need occasional inpatient care as well as community care, in that they may manage well in their usual environment for substantial periods of time, but may periodically require hospital admission for treatment and stabilisation when an acute episode occurs.

The vast majority of people with psychiatric illness can now be expected to be treated in outpatient clinics, or with only brief admissions to hospital — many will be able to pursue active and meaningful lives in the community.<sup>6</sup>

The old belief that when people develop a mental illness they must be confined in a psychiatric institution for long periods has been largely disproved by those working in community mental health in Australia and elsewhere. People with mental illness can generally be effectively and more humanely cared for in the community — provided there are adequate numbers of appropriate community support staff and other services.<sup>7</sup> This proviso is of paramount importance —

as is the necessity to acknowledge there are exceptions and appropriate arrangements must also be made for them. In general, however:

Even among the most disturbed patients, staff [in the community treatment team] found people who could exercise some power in their lives and learn to be responsible for their own medication, for seeking help early with symptomatic relapses, and for sticking at their [various] tasks.<sup>8</sup>

Many witnesses gave evidence concerning human rights abuses associated with inpatient psychiatric care, as recorded in the preceding chapter. But the Inquiry also heard evidence indicating major concerns about the policy of care and treatment in the community for people with mental illness.

There is a great deal of talk about 'community'; but for most people with schizophrenia, it is still a hollow concept, there being totally inadequate community resources.<sup>9</sup>

Health professionals and service providers repeatedly presented evidence concerning the abysmally inadequate resources which exist to assist people with mental illness to manage in the community.

The building blocks that are missing are things like community staff for (not only for the extended hours of work, but for assessments), rehabilitation in community settings, and the very capital structures. We just don't have the buildings -- we don't have the office space, we don't have the Living Skills Centres, we don't have the hostels, we don't have sufficient shared houses.<sup>10</sup>

Even in centres where there are comprehensive community mental health services, resources are poorly distributed and adjacent areas without adequate community care services tend to 'ship in' their own clients to gain access to services. As one Newcastle doctor put it:

Newcastle City Local Government Area has a range of community facilities including a 24 hour crisis team, living skills and activity centres, and residential and respite care facilities. This local government area constitutes only 30 percent of the Hunter Region population, so that 70 percent of the Region have no practical access to these facilities, unless they move into the Newcastle area. It is common for the Department of Housing and [other bodies] to move mentally ill persons into Newcastle in order to gain access to 24 hour community care. This 'warehousing' of people with mental illness is surely inhumane.<sup>11</sup>

## **Crisis Care**

Twenty-four hour crisis care is needed because of the episodic and sometimes unpredictable nature of several severe mental illnesses. With timely intervention, a crisis need not inevitably mean admission or readmission to hospital.

In terms of inter-agency coordination, the existence of psychiatric emergency (crisis) teams can also provide invaluable assistance to other types of community services and welfare agencies when their clients with mental illness need help, or when agency staff need information and back-up.<sup>12</sup> (Also see the description of crisis teams later in this chapter.) A recent Western Australian study of supported accommodation agencies reported that 'the Psychiatric Emergency Team was seen as making a significant difference to their capacity to deal with people with a psychiatric disability and to facilitate access to treatment for them.'<sup>13</sup>

Evidence to the Inquiry indicated that apart from relatively few metropolitan districts in several cities, the need for around-the-clock crisis teams is largely unmet. In most parts of Australia, therefore, families, mentally ill individuals and members of the general community are left to deal as best they can with psychiatric crises and all the pain and trauma such crises involve.

## **Continuity of Care**

The service should ensure that there is continuity of care while the person remains intermittently or continuously at risk. This should be an on-going, rather than a time-limited commitment to service users and caregivers.<sup>14</sup>

Continuity of care should mean that individuals with a mental illness are assured of appropriate care by trained people whenever necessary.<sup>15</sup> It is critically important that care does not cease on discharge from hospital, but continues in the community.

## **The Need for Discharge Plans**

The practice of discharging people from hospital and leaving them and their families (if any) to fend for themselves in whatever way they can — 'dumping' them back into the community — is widespread. Evidence to the Inquiry clearly demonstrated that discharging people from hospital without appropriate planning and connection to community-based services is still occurring in every State and Territory, and in major metropolitan centres as well as in rural and isolated areas. This can be a devastating experience, not only for the person with mental illness, but also for members of their family. (See Chapter 15 — Carers: The Experience of Family Members.)

People with a mental illness are being increasingly expected, on discharge from hospital, to establish a satisfactory living pattern for themselves in the community, with limited and diminishing support... [There is] far too little recognition given to the overwhelming social needs of people who have passed through the mental hospital process.<sup>16</sup>

Whether individuals return to live in their family home or any other form of accommodation (see also Chapter 10 — Accommodation), a suitable care plan developed prior to discharge is essential to ensure their future welfare. As indicated in the preceding chapter, discharge plans should represent realistic and workable arrangements to allow people to return to community living, with some dignity and assurance that their basic needs will be met and their rights respected.

The Inquiry repeatedly heard evidence about inappropriate arrangements for aftercare. In one case a Victorian housing service (which is not a psychiatric aftercare service) told the Inquiry that the local psychiatric centre deliberately directed people on discharge to go there, despite the fact that it does not and cannot accept them.

Such incidents are not isolated. For a patient's re-integration into the wider community to be successful, the hospital, the patient and community agencies need to be in agreement about optimal arrangements after discharge. It would appear that this kind of careful discharge planning does not take place at present.<sup>17</sup>

Even if there were a range of appropriate community support services available, they would be of little use without mechanisms in place to ensure that each individual's treatment plan is in fact linked to the necessary community services.<sup>18</sup>

Hospital staff need to be aware of services offered by the private, non-government and public sectors. It is critical that persons leaving hospital be given advice on where to find information on services they might need. Anecdotal evidence suggests that the necessary linkages are not in existence throughout NSW.<sup>19</sup>

Effective aftercare planning requires consultation with the consumer and the family and discussions with community agencies. But the Inquiry was repeatedly told by witnesses<sup>20</sup> that busy health professionals have rarely been able to spare the time to prepare their clients for life in the community.

Transition from the hospital ward to 'real' life is not easy for consumers. Apart from the demoralising after-effects of the mental illness and of medication, hospitalisation leaves many people traumatised and requiring guidance about the options available to them.

The step from hospital to the outside community is like going from one world to another. Leaving hospital shouldn't be just a matter of [staff] filling in the medical record and signing off. There should be a 'termination procedure', in which the person's situation is checked out, and options offered for the convalescent period. This should be done in a counselling context... There are a number of community services which offer drop-in facilities, day-time groups and courses, but I was never told about any of these, [nor

informed about] any assistance with getting work. My overall impression was that... as soon as I left hospital I wasn't their problem any more — nobody cared about me — who I was, what my situation was, or where I was heading.<sup>21</sup>

## **Integration of Hospital and Community Mental Health Services**

For as much as 25 years, we have been talking about continuity of care, but there appears to be little evidence that it happens. Both within service delivery units and between service delivery units, there seem to be a lot of difficulties — particularly between hospitals and clinics and with referrals from hospitals to community clinics. If psychiatric hospitals service one area, and community mental health clinics service another area, people fall in between. Continuity of care is vital to maintaining the human rights of mentally ill people so that they don't fall between services and so that they are not tossed from one unit to the other.<sup>22</sup>

According to current mental health policies, community care services for people with mental illness should be one component of comprehensive service provision in a particular area. Under this 'system', a given geographical area has administrative and clinical responsibility for all mental health services within its boundaries, including psychiatric hospitals or wards, community care and treatment, accommodation support and rehabilitation services.<sup>23</sup> In theory, this system of organising services should ensure effective integration of inpatient and community care functions.

In reality, community care can only function effectively if there is a very close association between community services and staff and hospital services and staff — so that people can go from one to the other easily, without substantial disruption to their treatment or to their personal stability.

It is essential that responsibility for the ongoing management and welfare of the person be shared between hospital and community mental health services.<sup>24</sup>

In attempting to ensure that people who need it actually receive continuity of care (including treatment follow-up), the transition from institutional care to home-based and clinic-based care is the most critical phase.

No matter how good your hospital care, unless you have adequate community care after the person leaves hospital, then the effort of that excellent hospital care has disappeared within six months. The psychiatric inpatient unit is one of the components [in a 'catchment area' mental health service] linked in with the rest of the service, not, as happens in most of Australia, something quite separate. The inpatient unit should be a part of the one service and staff should have access to both the hospital and the community components.<sup>25</sup>

Although the Inquiry heard numerous examples of arrangements breaking down or not being made in the first place,<sup>26</sup> it was assured that the integration of

hospital-based and community-based services has advanced significantly in some areas and that the policy has at least been introduced in others. However, the evidence also highlighted a number of complex issues involved in this shift of focus which have clearly not been effectively resolved.

These issues include redeployment and retraining of staff; union resistance and fear of job losses for hospital-based staff; the efforts required to gain the trust and confidence of institutionalised patients; and, above all, the provision of adequate resources — in terms of premises, staff, vehicles, and training — to establish fully-functioning community mental health services. The process also requires establishing effective procedures for formal and informal links with families, and with a wide range of other agencies and services, both government and non-government.

*When a patient has been discharged to a community clinic, there can be a waiting period of several weeks before their first appointment. Continuity of service is vital. The transition from hospital to community can be a critical time for both the mentally ill and their families and care needs to be taken to provide adequate support for both, with minimal waiting time for clinic appointments... For many, a community outreach service rather than a clinic-based service is indicated to link the individual with existing services in the community and to provide comprehensive rehabilitation and community integration.<sup>27</sup>*

The Inquiry was told by many witnesses about barriers which impede the successful organisation of integrated services.

*In the relocation of patients in the community, there have been considerable gains in personal freedom, but in many cases, these patients live marginal existences...often making relatively ineffectual contact with treatment services. It is clear that the appropriate service model embraces a notion of integrated comprehensive care, including both hospital treatment and community treatment. The Western Australian branch [of the RANZCP] has supported and fought to promote this model strongly... Nevertheless, there have been difficulties in [its] development... There still exists a lack of adequate integration between various components of the psychiatric hospitals and the community services. Community resources are thinly stretched and often over-taxed. The difficulties in implementing adequate comprehensive integrated care appear to involve in particular, a lack of consensus or clear goals among the various professionals involved, and administrative and bureaucratic obstacles to change. The College has...sought to assist in overcoming some of the administrative obstacles to change by acting in an advisory capacity to the Minister for Health.<sup>28</sup>*

## **Components of a Comprehensive Community Mental Health Service**

Local provision of comprehensive integrated services is the essence of the exercise.<sup>29</sup>

The Inquiry examined three Australian studies which have analysed issues involved in community care and treatment from different perspectives. Each

elucidates important principles relating to community care and considers specific requirements for providing an effective community mental health service. They are Hoult and Reynolds' 1983 research study, *Psychiatric Hospital versus Community Treatment*,<sup>30</sup> the optimal standards identified in the *Area Integrated Mental Health Services Standards Project*, undertaken in 1990 by Rosen, Miller and Parker,<sup>31</sup> and Andrews' *Tolkien Report* of 1991.<sup>32</sup>

Based on the evidence presented by several of the authors of these works and numerous other witnesses,<sup>33</sup> an effective integrated service should include the following components — in one form or another:

### *Inpatient Facilities*

Inpatient facilities should provide acute services, including assessment, diagnosis and treatment for stabilisation; medium term care for those mental illnesses which take longer to stabilise or are complicated to diagnose; and appropriate provision for some long stay patients.

The type of facility currently favoured is a discrete psychiatric clinic, unit, wing or ward (depending on the size of the community whose needs it is designed to service and on existing buildings available) situated within, attached to, or on the same site as a general hospital. This type of facility differs fundamentally from the large, old-style asylums built decades ago, to which people were once consigned for lengthy periods, or even for life — many of which are still partially or fully in use.

In addition, many consumers also called for a residential facility which would be less a treatment centre than a place for genuine 'asylum', when their illness necessitated respite and retreat from stress and tension.

The Inquiry visited a number of the smaller psychiatric facilities in cities and regional centres around Australia,<sup>34</sup> and received information about a number of new ones being planned. Their role is to provide treatment, stabilisation and continuing assessment of people in an acute phase of mental illness.

### *Outpatient Treatment Services*

These should be attached to inpatient facilities. Outpatient services are primarily for people who require clinical treatment on a less restrictive basis than inpatients, but more intensive care than would normally be provided by community treatment teams.



### *Crisis Teams*<sup>35</sup>

These 24-hour teams can respond immediately to psychiatric emergencies. Crisis team staff (usually psychiatric nurses with access to social workers and consultant psychiatrists) provide intensive intervention, short term treatment, and on-the-spot counselling, reassurance and information for the patient and family.

### *Mobile Teams*<sup>36</sup>

Mobile teams have similar staffing arrangements to crisis teams. They provide long term, in-house treatment, support with domestic matters, liaison with GPs and other health professionals, and rehabilitation services. Teams make regular visits to clients and are also available on call.

### *Community Mental Health Clinic Staff*

Community clinic staff provide a greater range of services than visiting teams. The clinics provide consultations, assessment, medication monitoring and prescriptions, day programs, therapy, counselling, group work, referrals to Living Skills programs and (often) referral to supported or unsupported accommodation, if the health area administration owns group homes or shared housing properties.

Staff of community mental health clinics may include social workers, psychologists, a consultant psychiatrist, occupational therapists, family therapists, and a receptionist-secretary. The clinic serves as the base for crisis teams or mobile teams and the administrative centre for comprehensive mental health care in the area.

### *Living Skills Centres*

Staffed by community mental health workers, Living Skills Centres work with consumers to improve their confidence and social skills through participation in group activities such as gardening, cleaning, catering, clerical work.

Although Living Skills Centres are part of the community mental health service, they usually have separate premises.

### *Accommodation Support Staff*

Staff either live in, conduct regular visits, or are on call for people with mental illness living in private houses and all types of supported accommodation.

They may monitor medication, assist with daily living skills, provide counselling and referral, help clients to manage their finances and gain access to community and recreational facilities.

### *Non-Government Organisations*

Non-government organisations play a vital part in the community care of people with mental illness. They are typically involved in providing accommodation support, living skills programs and recreation services. (Their role is discussed in detail in Chapter 5 — Mental Health Services.)

### *General Practitioners*

Community mental health services work with consumers who have regular contact with local general practitioners for both general health care and renewal of prescriptions for medication. (General practitioners are expected to play a greater role in the co-operative care of people affected by mental illness under the new Divisions of General Practice.)<sup>37</sup>

## **Case Management**

Within service delivery units, you have battles around case management. Case management is a practice which has been endorsed internationally, although we do not all know exactly what it means — and I certainly could come up with ten definitions right now. We are talking about case management as a means of guaranteeing that people who need services get the best services.<sup>38</sup>

Underpinning it all is a system whereby each person with a serious mental illness has some health professional designated as responsible and accountable for that patient's care.<sup>39</sup>

As indicated in the preceding chapter on inpatient care, many witnesses emphasised that effective case management is central to continuity of care — and particularly to continuity of care and treatment of people with mental illness when they are not in hospital.<sup>40</sup> Indeed, the necessity for case management in the community was one of the most frequently mentioned issues throughout the Inquiry, and one which drew more cynicism and more heat from witnesses than many others, principally because the promise they felt it held for more effective community care was not being fulfilled.

When people with chronic mental illness are living independently in the community, the issue of responsibility for their clinical and general welfare and access to necessary services becomes fundamental. A major US health standards organisation broadly defined case management as 'coordination of services with the purpose of providing continuity of care.'<sup>41</sup> A more comprehensive

definition includes four major elements: thorough assessment of need; comprehensive care planning; coordination of services; and effective follow-up.<sup>42</sup>

Much of the evidence to the Inquiry reflected a perception that case management is something of a panacea — and if there are problems, it is because there is not a ‘case manager.’<sup>43</sup> While case management is certainly important in preventing people with mental illness from becoming lost to the system and missing out on necessary services, effective community support services are ‘much more than just elaborate versions of case management — the concept of community support encompasses therapy and friendship, discipline and advice, companionship and coaching, and a steadfast willingness to be ‘where the client is’, emotionally or geographically, however personally inconvenient that may be.’<sup>44</sup>

The reality is that the role and responsibilities of case managers<sup>45</sup> vary greatly from area to area — and these differences largely account for the differing perceptions of their value. One significant difference appears between the ‘broker only’ model of case manager (a designated person, not necessarily part of the treatment team, who arranges referral and access to required treatment, activities and services, across the range of departmental and community service providers, and connects the consumer with these services and activities) and the ‘therapeutic’ model, where the case manager is not only a fundamental part of the community treatment team, but the first point of contact for the consumer. Some insist that case managers **must** play a therapeutic role in order to effectively assist consumers to get their needs met.<sup>46</sup>

Most of the case management problems for consumers trying to live in the community are the result of inadequate or poorly planned resources — as in the case of one consumer who had had four case managers over four months:

As soon as I warm to a case manager, they are changed — often with little or no notice.<sup>47</sup>

Other consumers reported that they were not introduced to their case manager, or noted that information about them was not passed on from one case manager to the next when there was a change-over.<sup>48</sup> On the other hand, some evidence indicated that people were benefiting from having one person take responsibility for the oversight of their treatment needs.

Everybody in our whole service, every client, is case managed by an identified person, so that you can say who is the case manager of this person, and that is the person who is responsible.<sup>49</sup>

From evidence presented to the Inquiry and from experience reported by overseas experts it appears that effective, well-planned, accountable case management is one of the bases on which the success of community care of the mentally ill will stand or fall — with two important provisos — first, that sufficient numbers of appropriately trained and skilled case managers and supporting team members are employed; and second, that mental health service providers have the benefit of clearly defined organisational guidelines and receive adequate support to enable them to function effectively.<sup>50</sup> Although the evidence indicated there are some areas where this is happening, these are atypical.

Theories aside, in reality the needs of many thousands of Australians are manifestly not being adequately met and responsibility for their care in the community ranges from patchy, to chaotic, to non-existent. (See Chapter 18 — Homeless People.)

## Treatment Follow-Up

It is no good having an extended hours service if you don't actually have the other building blocks that need to go with it to maintain people in the least restrictive environment that they need for treatment.<sup>51</sup>

People affected by chronic mental illness can usually live successfully in the community if mental health staff know where they are<sup>52</sup> and if they can receive appropriate follow-up treatment on a continuing basis.

While the Inquiry heard extensive evidence about the lack of follow-up care,<sup>53</sup> several recent proposals have been formulated to redress this deficiency.

In Western Australia, for example, the aftercare provisions for supervision of those people deemed to require it after discharge from hospital have recently been reviewed<sup>54</sup> to enforce individual follow-up and monitoring. (Also see Chapter 4 — The Legal Framework and Chapter 23 — Aboriginal and Torres Strait Islander People.) In Victoria, Discharge Planning Guidelines and an aftercare policy have also recently been released.<sup>55</sup>

The Inquiry heard evidence about a variety of strategies for providing treatment follow-up. These included:

- home visits by a mobile (or community care) team;
- making (and encouraging the consumer to keep) regular appointments at the local community mental health clinic or general practitioner;
- encouragement and assistance in attending a Living Skills program (in which medication self-management is incorporated);

- living in accommodation which is either supervised by resident community mental health staff or regularly visited by them;
- assertive outreach by community mental health staff in order to locate and provide treatment follow-up for those who are transient or homeless.

A great deal of the evidence, however, demonstrated the failure of governments to provide adequate resources to effectively pursue any of these programs.

When [my son] was discharged, there were no vacancies of any kind [in supported services]...where he could have teaching/coaching in the necessary living skills, or any form of supervision, even though the social worker at the hospital recommended it. He was discharged anyway... At the time of discharge, he was in a frame of mind and willing to go to a place and learn the necessary skills to cope with his illness, but nothing was available... There was no follow-up at all, because the community mental health nurse — who had been looking after him and with whom he had built up a good rapport — left, and was not replaced for a month. He progressively deteriorated, became ill, and started refusing medication... He was later sighted in Melbourne in a very poor condition, wandering and derelict.<sup>56</sup>

As one community-based psychiatrist said in his evidence:

You really have to provide a systems approach, that takes not only the identified client, but also their family and their network into account. We need to provide a sense of confidence that people will actually receive the support they need, at the time they need it, and in the place they need it. We need to educate the people, the families and the community.<sup>57</sup>

One key element in effective treatment follow-up is the mobile team, which can, as the name suggests, engage in active outreach work with consumers who lack the insight or motivation to go to a clinic, or who do not have transport.

### *A Model Mobile Treatment Team*

The Inquiry was impressed by evidence concerning one of these teams, the Mobile Treatment Team in the Ryde-Hunters Hill area of Sydney.<sup>58</sup> It commenced operation in 1988 and services an area with a population of 100,000 people and two major psychiatric hospitals. A significant number of people with chronic mental illness, who need long-term continuity of care, are discharged into the area.

The Ryde Team, which comprises six community mental health nurses and an occupational therapist, operates seven days a week from 8.00 am to 11.30 pm. (A Crisis Team is available on call overnight.) The Team formulates individual management plans, in consultation with the consumer and carers, which are reviewed with each consumer every three months. The average length of time for team involvement is nine months. When the person is ready to 'graduate'

from the mobile team's care, weekly consultations are provided by the clinic-based case manager.

The daily work of the team comprises visits to group homes in the area first thing in the morning to help residents prepare for the day and transport clients to work programs, Living Skills Centres or other programs. The Treatment Team then visits consumers living with their families to provide individual and family counselling, to assist with practical tasks, provide transport to appointments, or liaise with other services, such as Social Security. Team members also ensure that appointments are kept and encourage people to join rehabilitation programs.

Afternoon shift duties include assistance with household tasks and skill-building activities. Medication is supervised by team members, both in people's homes and in group houses. At weekends, the team runs recreational activities and encourages people to join mainstream leisure activities when they are ready to become more integrated with the wider community. For group home residents, the team runs a 'home meeting' each Sunday evening to help resolve any disputes between residents.

### **Medication Maintenance**

We need to give people a sense of confidence that they can actually learn how to manage their medication, their levels of stress, and the other things they require to be able to maintain their own health.<sup>59</sup>

Medication is one of the most important factors in terms of continuity of care for those with chronic mental illness.

Many of the factors involved in effectively continuing medication for consumers in the community are similar to the issues concerning medication identified in the chapter on inpatient care. However, several important factors are affected by the individual being much more of a free agent in the community. This makes administration and monitoring of medication much more the responsibility of the consumer.

The most important factors include voluntary or involuntary use of medication; frequency of administration; compliance (the expression commonly used when discussing willingness and consistency in taking prescribed medication); monitoring of dosage; monitoring and evaluation of the effects and side-effects of medication; assessment of the need to modify dosage or change the type of medication; and the appropriate time to consider ceasing medication. People

living in the community should be given as much information about symptomatology and medication as possible.

In reference to the use of depot injections of phenothiazine<sup>60</sup> to treat schizophrenia, if patients receive proper education and proper care and supportive psychotherapy, it is possible to reduce their doses of this drug to minuscule levels with the minimum of side effects, and also to ensure they receive this drug over a long period of time.<sup>61</sup>

### *The New Drugs for Schizophrenia*

A number of new drugs have recently been developed for treating schizophrenia. Drugs which have already come onto the market (Clozapine<sup>62</sup> and Remoxipride<sup>63</sup>) or should soon be available in Australia (Resperidone<sup>64</sup>) are reported to have less unpleasant side effects and more potential to control symptoms effectively than previous treatments. It is likely that problems of compliance could diminish considerably — provided these drugs are found to be safe and to perform as trials overseas have indicated.<sup>65</sup>

However, these drugs are not included in the list approved for subsidy under the Pharmaceutical Benefits Scheme (PBS) and if the price of Clozapine is any indication, the expense to consumers living in the community is likely to be very high.<sup>66</sup> Indeed, the benefits of new and better drugs will be seriously undermined if those least able to pay — people with schizophrenia and their families — are forced to meet the expense of the medication (while society is saved substantial sums in community support and hospital re-admission costs.)<sup>67</sup> If these drugs are proved effective it would be a tragedy if those affected were forced to go without and put up with the debilitating side effects and only partially effective existing medications; or to refuse medication altogether and try to bear the symptoms of the illness by other means.

### *Community Treatment Orders*

The use of Community Treatment Orders as a major method of discharge planning highlights the psychiatric services' dependence on medical treatments and the lack of sufficient attention given to psychosocial support services.<sup>68</sup>

A Community Treatment Order (CTO) may be made to compel a person (either following or without hospitalisation) to take prescribed treatment — usually medication to control symptoms of the mental illness. Such orders are specifically provided for by legislation in Victoria and NSW.

In South Australia, the Guardianship Board has the power to require a person, who by reason of mental illness is incapable of managing their own affairs, to receive treatment in the community. In Western Australia there is provision for

compulsory treatment after discharge from hospital. The Australian Capital Territory legislation allows for orders for compulsory CTOs to be issued under certain conditions. Other jurisdictions have no provision for compulsory community treatment. (See Chapter 4 — The Legal Framework.)

Community Treatment Orders can only be made when all the conditions required for involuntary hospitalisation are met and where that is the only alternative.

In NSW, Community Counselling Orders may also be issued, and may be applied to people with a history of relapse who, without such treatment, would be likely to require inpatient treatment.

Conflicting evidence was presented about the benefits, drawbacks and the efficacy of CTOs and their impact on the rights of those subject to them. A member of the management committee of the Mental Health Legal Service in Victoria told the Inquiry:

We feel that, in Victoria, the Community Treatment Order has become almost too easy an option for psychiatrists in their treatment of patients... We also feel that, on occasion, they are used as a cajoling device to manipulate patients. For example: 'If you go on your CTO, we will discharge you sooner rather than later', notwithstanding that the criteria for involuntary detention may no longer apply. Some patients look no further than the fact that they are to be discharged, and agree to this form of release... We feel that the original reason for Community Treatment Orders — that is, the provision of appropriate treatment, supports and resources in the community to facilitate recovery in a non-institutionalised setting — has been lost... In many respects, Community Treatment Orders, in our experience, seem to be no more than rubber stamps for the fortnightly administration of Modecate [and similar drugs.] This is, of course, due...to the severe lack of resources spent in this area... While one is living in one's own community, being on a Community Treatment Order does not mean that one is a voluntary patient, and that affects patients quite seriously.<sup>69</sup>

The Inquiry also received evidence critical of the operation of CTOs on a number of other grounds — including requiring attendance at inconvenient places, interfering significantly with the rights of consumers and changing the relationship between consumers and police and consumers and community mental health workers. Other problems concerned lack of choice in a treating doctor<sup>70</sup> and lack of consultation and information:

The most common cause of non-compliance with medication prescribed is the side effects...but other problems exist which have not yet been adequately addressed... Nursing strategies to address non-compliance include giving clients information about drugs, [which] would require educating them properly about medication and its effects... Clients are still placed in the child role and the sick role and generally not given responsibility for their own care.<sup>71</sup>



Service providers such as nurses and police also dislike the enforcement role CTOs place them in.

With CTOs, the police have been drawn into becoming part of the treatment, and nurses [have become] agents of social control, whose role is to coerce clients to have an injection or risk incarceration. Concern exists that community mental health nurses will start to be seen **only** as enforcers of medication and as a result, lose their therapeutic credibility with clients.<sup>72</sup>

Because of the coercive nature of an order with perceived punitive repercussions for resistance (re-admission to hospital as an involuntary patient), continuing controversy surrounds CTOs — particularly in terms of balancing the rights of people with mental illness in the community and the rights of the community in general.<sup>73</sup>

In a research study currently underway in NSW,<sup>74</sup> preliminary results appear to indicate, in the six months following the application of a Community Treatment Order, an improvement in the psychosocial functioning of nearly one-fifth of the consumers in three diagnostic categories (those with schizophrenia, schizo-affective disorders and bi-polar disorder). There also appears to be a lower rate of hospital re-admission among those under Community Treatment Orders than among the control group and indications are that workers in the community mental health service believe the benefits of the orders outweigh their disadvantages.

The value of CTOs lies in facilitating a form of involuntary treatment which is less restrictive than hospitalisation. Clearly, such a mechanism is an important element in any system relying on community-based care. Equally clearly, the value of CTOs is reduced if orders are used in a manner inconsistent with the need to maintain an appropriate balance between coercion and therapeutic relationships. If CTOs become too intrusive, they may engender resistance rather than compliance and revised safeguards may be required to avoid their over-use.

### **Community Mental Health Workers and General Practitioners**

As mentioned earlier, general practitioners play an important role in treatment follow-up. A large number of people who experience the onset of symptoms of any one of the many forms of mental illness are likely, if they see anyone, to consult their GP first.<sup>75</sup>

Mental health professionals also need to maintain close contact with general practitioners to ensure that people with a physical illness which is complicated by psychiatric or psychological factors receive the best treatment<sup>76</sup> and that,

conversely, people affected by mental illness who develop a physical illness or injury are assured of medical treatment by a practitioner who is familiar with the individual's mental health status.

Ease of referral is another important issue. A general practitioner with a sound knowledge of a patient's personal and medical history is in a good position to make an appropriate referral to a community mental health clinic or team,<sup>77</sup> or to a psychiatrist for assessment or specialist treatment.

Mental health workers may also refer someone to a general practitioner for continuing care if they are not acutely ill, or otherwise at risk, and treatment is expected to be routine.<sup>78</sup> (The necessity to assist general practitioners to gain further expertise in matters relating to mental illness is dealt with elsewhere in this report, including in Chapter 6.)<sup>79</sup>

## Alternative Treatments

Psychiatrists are in the process of agonising about the type of treatment being offered holus-bolus throughout the public psychiatric system, without [sufficient] monitoring and evaluation... We should continue to evaluate the psychological therapies... Some of the things we are working on at the moment — include training general practitioners to provide hypnosis, cognitive behavioural therapy, grief counselling and other types of counselling.<sup>80</sup>

Just as witnesses referred to a lack of alternatives to basic medical treatment in hospital, evidence about community living indicated widespread dissatisfaction among consumers, families, community support agencies and advocacy groups with the narrowness of 'the medical model' of treatment for a range of mental illnesses. (See also Chapter 8 — Inpatient Care and Treatment.)

Many consumers gave evidence that non-pharmaceutical healing activities and treatments, which may have proved beneficial, were ignored by doctors responsible for their treatment. Various suggestions were advanced concerning helpful alternatives in the pursuit of mental health.

My concern as a parent is that we need to look at alternative ways of helping, for example, yoga, meditation, dance, Tai Chi — a choice would give people pleasure. The staff at centres are too busy to pursue these needs — these activities need qualified people from the private sector to teach on a sessional basis. The facilities are available, but not the specialised staff.<sup>81</sup>

A number of witnesses told the Inquiry that the range of professional services that can be beneficial to people affected by mental illness include psychotherapy, behavioural therapy, and training in a number of areas of skill acquisition

or skill-enhancement such as communication skills, social skills, and stress management.<sup>82</sup> Evidence indicated, however, that the cost of most of these treatments is prohibitive.

The value of allied health services to patient care has been greatly under-estimated by the medical insurance system. Physiotherapy and podiatry have now been recognised to receive health insurance rebates, but there is still no provision for social work, individual or group counselling, stress management, occupational therapy, music therapy or art therapy, which are of value in rehabilitation and recovery from mental illness.<sup>83</sup>

The Inquiry received some evidence about 'non-medical' programs being undertaken, with encouraging results.

A unique program on a 25-acre property outside Dubbo called Lyndarra is run on a basically non-medical model... The major therapies used are transactional analysis and a rational-emotional therapy. It has very high client satisfaction. There is usually pressure on the five residential beds to gain access to the program.<sup>84</sup>

My daughter [who has schizophrenia] is a very allergic person... We have had many biochemical tests done, entirely at our own expense, [and have found] that if she avoids foods to which she is allergic or sensitive, she is much better and needs less medication.<sup>85</sup>

The suggestion of one consumer who advocated 'a range of health care treatments such as chiropractic care, nutritional matters, examination of allergies and intolerances, Chinese massage and hypnosis'<sup>86</sup> was typical of comments made by many witnesses. In general, however, 'alternative treatments' have not attracted much scientific interest as a legitimate area of research in this country<sup>87</sup> and, indeed, seem to have been rejected by mainstream medicine. Clearly, some 'alternative treatments' assist some people to some degree and therefore deserve consideration. In the absence of any substantial body of competent research any further generalisation is, unfortunately, impossible.

## Psychosocial Rehabilitation

Rehabilitation [for people with mental illness] is the process directed towards reducing the gap between their experience and their needs. Their experience [may be different, but] their needs are no different from those of their healthy peers — for meaningful social relationships, for purposeful and fulfilling activity, for economic and material comfort, for security and the creative use of free time, for independence and a sense of self worth.<sup>88</sup>

Rehabilitation is often taken to mean restoring a person's fitness for employment. Work-oriented rehabilitation and vocational training (see Chapter 12 —

Employment) constitute an important aspect of rehabilitation; however, evidence to the Inquiry covered a much wider range of concerns.

An emphasis on work skills as qualifications for employment should cease to intrude on and dominate the essential purpose of psychiatric rehabilitation, which should be to provide pleasure in engrossing activities, accompanied by some success in their performance... Work-readiness should be seen as an unsuitable yardstick by which to measure success in rehabilitation... it should be an added bonus, with community integration as the chief goal through which [to] realise the highly-desired aspiration of acceptance.<sup>89</sup>

This broader concept of rehabilitation, encompassing personal encouragement as much as skills training, is not only appropriate in a mental health system increasingly focussed on community-based care — it is essential!

If we confine ourselves to [considering] rehabilitation only in relation to employment, there are going to be an awful lot of people who just don't meet those criteria at all but who are still out there needing rehabilitation... They are not necessarily in the hunt for a shrinking number of jobs... There are far more basic levels of rehabilitation needed by psych patients. We need to re-learn social skills. We need to re-learn stability. We need to re-learn the niceties again.<sup>90</sup>

This total personal rehabilitation is known as 'psychosocial' rehabilitation:

Rehabilitation [of people with mental illness] is interpreted as an active ongoing process that places importance on clients making decisions about their lifestyle in an atmosphere of encouragement. Rehabilitation is done with a person, not to or for a person.<sup>91</sup>

The Inquiry received a large number of written submissions about issues related to rehabilitation, including living arrangements, vocational re-training and employment assistance, and 'psychosocial' rehabilitation.<sup>92</sup> Clearly, these facets inevitably interact and overlap. To facilitate recovery in the fullest sense, a person who has or has had a mental illness is likely to need a wide range of services and supports, from the most practical to the most intangible:

What is necessary for good rehabilitation? A supportive, calm, stable environment, where performance demands are at a minimum level, but where opportunities for self esteem, confidence-building and achievement are readily available. Stability, support and security must still be flexible enough to allow convalescence to proceed steadily through rehabilitation to maximum recovery, [in conjunction with] continuing [appropriate] medical treatment.<sup>93</sup>

Rehabilitation requires both consumers and their helpers to have a realistic assessment of the consumer's current mental health status and of the internal and external components needed to move from that level of functioning to a more satisfactory and satisfying level. Thorough assessment is necessary. The starting point can be daunting for people suffering the consequences of mental

illness — and of medication. These consequences may include a lack of confidence and extremely low self esteem; fear; loss of social and relating skills; low level of motivation to do anything; inability to concentrate; alienation from previous friends and from the general community; and a diminished capacity to carry out everyday activities.

*To be understood, strengthened and helped in being re-integrated into the community can be a daunting task for a mentally ill person... [We may be feeling] confusion; strange behaviour; awkwardness in human relationships; perceptions which can stimulate particular memories and can create tremendous problems.<sup>94</sup>*

Even when a full or partial recovery is anticipated, people need rehabilitation which recognises the damaging effects of mental illness. As one psychiatrist said:

*I think there is an important right to rehabilitative services... Intermittent follow-up between acute admissions fails to address the nature of many psychiatric illnesses. Not only schizophrenia and bi-polar disorder, but many of the 'neurotic' conditions are a horrendous and insidiously debilitating proposition for a patient... Patients with these conditions need to have robust rehabilitative treatment...<sup>95</sup>*

It is not only the illness which necessitates rehabilitation. Treatment for mental illness can be an ordeal in itself:

*I have heard patients say that while they may have had appropriate treatment for their symptoms, their 'self' was sometimes badly cut about in the process. I would say that patients with mental disorders have the right to very expert management of their 'self', if only because mental disorders can come so close to destroying it.<sup>96</sup>*

The Inquiry received relatively few complaints about the quality of the few existing rehabilitation services; but many witnesses criticised the extreme inadequacy of rehabilitation services in terms of number, type, access and location.<sup>97</sup> The absence of appropriate, accessible, comprehensive and positively encouraging opportunities for psychosocial rehabilitation, across a range of activities and personal and skills development, can sometimes induce a relapse of mental illness.<sup>98</sup>

One of the most common consequences of mental illness is social isolation,<sup>99</sup> which can work strongly against a person's overall prospects for rehabilitation. This is particularly important when the illness has undermined the individual's confidence. A large number of groups and individuals gave evidence about the range of programs and activities needed to encourage self esteem, independence and social interaction for people recovering from mental illness.<sup>100</sup> One frequent suggestion was a drop-in-type social and activities centre:

- Consumers believe that more personal development programs are needed...as part of the rehabilitative process. [They also consider] that more outlets are needed for club-like venues, and that 'Friend-Advocate' programs like those for people with intellectual disabilities would help reduce the social and physical isolation that people with mental illness experience in the community.<sup>101</sup>
- [We need] a centrally located house or suitable building, close to public transport, which could be used as a supervised gathering place, drop-in centre, meeting house...where people could meet with and be with people who understood them.<sup>102</sup>
- Drop-in centres need to be much more than 'coffee stops.' They need to be activity centres where people can learn a new skill, or enjoy a new activity. When nothing happens from daylight until dark, many hours have to be filled.<sup>103</sup>

## **Model Rehabilitation Services**

Although the number of rehabilitation services overall is grossly inadequate, the Inquiry considered evidence concerning several examples of successful programs and initiatives currently operating around Australia. Some are public mental health service programs and others are run by non-government organisations.

One such program was the subject of evidence presented in Western Australia:

I found the Robinson Unit in Victoria Park to be a well-run, effective centre for the social rehabilitation of young people with problems. They produced dramatic improvements in my daughter's social skills and her consequent ability to cope... It is run by...dedicated social workers and mental health nurses managing small groups of care recipients. They provide practical personal development skills, assisted by psychiatric expertise. Its small size provides focus and satisfaction for all participants.<sup>104</sup>

Two effective government-sponsored services are described below. (Others run by non-government organisations are described in Chapter 5 — Mental Health Services.)

### *The Young People's Program*

The Young People's Program is a therapeutic day centre attached to Cumberland (Psychiatric) Hospital in Sydney.<sup>105</sup> A rehabilitation program for mentally ill or disordered individuals aged 18-26, it aims to provide early intervention before they progress to chronicity.

Staff include a social worker, nursing unit manager, psychologist, medical officer/psychiatrist, diversional therapist and welfare officer. Nursing and social

work students also take part in the program, which provides them with valuable training.

The centre is open each weekday, offering groups focussing on concentration training, self esteem, social and living skills, remedial literacy and numeracy, work orientation, group psychotherapy, art and music therapy, sport and recreation, health education, excursions, psycho-education, family information and support, family intervention and family therapy. There is also an outpatient group.<sup>106</sup>

Participants agree to attend regularly and to avoid disrupting other members. They share tasks such as tidying up. Anyone who breaks the rules receives a warning; three warnings indicates the person has difficulty meeting the requirements of the program, so a staff meeting considers future management for the person. Obviously, the program will not suit all people equally.

Those participating in the Young People's Program are encouraged to take responsibility for the management of their own lives, including medication management. The outpatient clinic allows those who have completed their time at the unit to retain some contact by meeting on a monthly basis for continued support and encouragement.

One of the objectives is to help clients return to life in the community and to re-enter the workforce (where appropriate) or a training program. This can assist them in avoiding the 'poverty trap' which affects many mentally ill people whose employment options are severely limited without early intervention.

### *The SHIPS Program*

The Satellite Housing Integrated Program Support (SHIPS) near Orange, NSW, is a rehabilitation program for seriously mentally ill people living in a 'core and cluster' housing facility.<sup>107</sup> Of the 34 residents, 90 percent have been diagnosed as having a psychotic illness, predominantly schizophrenia. The 23 staff, who are all psychiatric nurses, except for domestic staff, are available on 24 hour rostered call.

The program includes an outpatient psychosocial psychiatry unit which provides counselling services and referral. One of the houses is on ten hectares of land, with a plant nursery and flower and vegetable gardens.

The main focus of SHIPS is on community living skills. The philosophy is that clients can make better decisions and develop essential living skills while

interacting freely within the community, which is regarded as the program's 'teaching arena.' Clients are encouraged to foster independence and responsibility for their own health and wellbeing. They make their own appointments for medical and mental health consultations with the local GP or private psychiatrist; they take their prescriptions to be filled at the chemist and pay for their medication.

The program networks with community organisations as much as possible and clients are actively involved in community activities,<sup>108</sup> including Meals on Wheels, making lunches at school canteens, selling products at street markets, helping restore old steam trains, and working for pay in a gardening program involving TAFE and the University of New England. The activity centre of SHIPS fosters work skills and has enabled participants to undertake technical courses, work experience and in some cases, full-time employment.<sup>109</sup>

### **'Living Skills' Programs**

A requirement for many people severely affected by mental illness is a basic relearning of normal everyday activities and responsibilities. This need has given rise to rehabilitation programs variously described as Life Skills, Living Skills, Activities of Daily Living (ADL), Aids to Useful Living (ATUL), and Community Living Skills (CLS) — among other titles. The concept originated with earlier programs assisting those disabled by illness or injury to relearn ways of performing daily tasks. Progressive elements in our community recognised the need for individuals with physical disabilities to become as independent as possible many years before they acknowledged that people with psychiatric disabilities have similar aspirations to independence and autonomy.

Living Skills programs aim to assist people towards autonomy and independence, within the range of their capabilities, and — hopefully — to the limit of their capabilities. Most people with mental illness may not require the very fundamental skills training undertaken in programs designed to serve the most severely disabled and chronically mentally ill: eg laundering, shopping, cooking, and house-cleaning. However, many people who are only moderately psychiatrically disabled will still require skills training in matters like structuring time, managing finances and completing Social Security forms.

#### *An Effective Living Skills Program*

The Croydon Living Skills Centre (part of the Community Mental Health Service of the Central Sydney Area Health Service) attempts to create an educative environment by providing a range of learning situations and by integrating work activities with general educational activities. The work groups



are directed towards participating in such projects as cafe work, gardening, catering, cleaning and developing work collectives as small client-managed businesses. The general educational groups are designed to meet some of the personal, social, recreational, and leisure needs of participants.

The Centre extends its range of activities to accommodate the preferences of the current clientele. This may include groups on health and fitness or stress management, or sometimes 'simple experiences like a hot bubble bath and fresh clothes [which] may allow a person to feel good, and then be better able to deal with other concerns.'<sup>110</sup> Groups operating in mid 1991 included: house meetings; arts and crafts; sports and games; self care, and a weekly outing visiting places of interest for the day.<sup>111</sup>

Evidence to the Inquiry highlighted two shortcomings, from a consumer's perspective, in Living Skills programs. First, unless the Centre succeeds in integrating its clients with local social, recreational, community or work activities, an important social outlet is lost when they have progressed as far as they can with the Living Skills programs. Some witnesses said they had been asked to stop attending when they were well enough, because so many others were waiting to join the program, leaving them stranded, without their accustomed friends and a place to go in the daytime.<sup>112</sup>

The second problem referred to was that in some Living Skills programs the groups are geared for those clients with the greatest difficulties. This means those who are less disabled often become bored.

While the Living Skills Centre was useful, it got boring once you had done the basic courses.<sup>113</sup>

It appears that a secondary transitional program needs to be considered, so that those who are considered 'too well' to keep attending Living Skills Centres, but not yet well enough or confident enough to be cast adrift in the community at large, can graduate to a higher-functioning level of programs with a stronger 'bridging' emphasis.

### **Inadequacy of Psychosocial Rehabilitation Service Provision**

Evidence to the Inquiry clearly indicated that the pressing need for psychosocial rehabilitation programs, including Living Skills Centres and opportunities for social and recreational activities, is not being met in most areas.

Lack of resources and bottom-of-the-line funding of psychiatric services would certainly seem to imply that we are not even equal under the law, [just as] I have often wondered if we are equal in the process of recovery and rehabilitation. I know the oppressive sense

of being made to feel unequal and undeserving in some way, even in essential services. It takes more than living skills and assertiveness training to acquire access to services, if society as a whole does not believe in your value. Governments fail in their duty to the psychiatrically disabled, sometimes even failing to provide basic or essential services.<sup>114</sup>

High standard, comprehensive community mental health services do exist in pockets of some metropolitan areas. However, throughout most of Australia, aftercare and rehabilitation services are very inadequate — especially when contrasted with facilities and programs in other comparable countries.<sup>115</sup>

### *Substance Abuse and Over-use Exacerbated by Lack of Rehabilitation Services*

The 'props' of the psychiatrically disabled — cigarettes, alcohol, caffeine, marijuana — are all presently being used addictively as substitutes for activity.<sup>116</sup>

The use and abuse of cigarettes, alcohol and street drugs was identified by many carers as a major risk for mentally ill people living in the community.<sup>117</sup> Witnesses considered this was due, at least in part, to the boredom and despair so familiar to many people affected by mental illness.

In the absence of active, community-based, rehabilitation programs and strategies, it is hardly surprising that people who feel aimless and miserable, stigmatised and rejected by mainstream society, constantly affected by the unpleasant symptoms of their disorder and the debilitating side-effects of some pharmaceuticals would want to use drugs.<sup>118</sup> Rehabilitation programs can alter this course before abuse becomes a habitual escape for the mentally ill individual:

Special treatment facilities [are needed] to treat the largest group of clients with dual diagnosis which would appear to be those with schizophrenia combined with drug and alcohol abuse. The prognosis for both illnesses is very poor. Special treatment facilities in the USA indicate positive treatment outcomes.<sup>119</sup>

In general, carers told the Inquiry they try to maintain and promote the health and welfare of their mentally ill relatives, particularly if they are living in the same house. Many expressed dismay and frustration about the levels of addiction, misuse and over-use of drugs, alcohol and cigarettes which they see. A number of witnesses stated that the individual's mental and physical health was clearly being adversely affected by substance abuse and over-use.<sup>120</sup> (This problem has also been documented overseas.)<sup>121</sup>

Obviously skilled workers and appropriate programs are necessary to assist people trapped on this destructive roundabout back onto a healthier, more effective road to satisfaction and recovery.<sup>122</sup>

# Health Promotion Activities

## Leisure, Recreation, Creative Expression and Cultural Activities

One thing that really helped me in my rehabilitation was...an outdoor adventure program for people with mental illness. You did activities which usually only the financially well-supported can afford, like abseiling, rock-climbing, canoeing and skiing. It was a really good confidence builder and overcomes fear, which is a really big problem for people with schizophrenia.<sup>123</sup>

Recreational activities, artistic endeavours, outdoor adventure and leisure pursuits fulfil many of the criteria for effective rehabilitation: they teach personal skills and can have significant therapeutic and rehabilitative effects.<sup>124</sup>

There are some people who may never realistically contemplate employment as an option — or in any case, not full-time employment — but who definitely need constructive and purposeful activity to occupy the day. Many consumers gave evidence about their sense of fragmentation at a very basic level of personal functioning,<sup>125</sup> and the need for a gentle re-introduction to everyday life. Structured recreation and creative pursuits not only help fill the day, but provide other benefits: learning to get to a place on time, attending activities regularly, using time effectively, goal-setting, working co-operatively, facing challenges, and self-expression.<sup>126</sup> All of these are conducive to recovering mental health and control over one's life.<sup>127</sup>

However, the evidence also revealed daunting barriers for people with mental illness attempting to find recreation and leisure opportunities:

Mental health workers and people with psychiatric disabilities lack information about leisure options; there is a general lack of understanding of the power and potential of leisure in the lives of people with a psychiatric disability; [all levels of] government have unclear commitment to leisure for people with psychiatric disabilities; there is a lack of... tertiary training in the areas of leisure and mental health; there is a lack of [relevant] leisure service models; appropriate support needs to be provided for some people whose [disability] may inhibit full participation without support; people... may lack disposable income for leisure; and policy development in the area of recreation and mental health has been minimal.<sup>128</sup>

The exclusion of people affected by mental illness from general community activities forces them into segregated activities — or none at all.<sup>129</sup> A Victorian community agency told the Inquiry:

Our clients frequently report difficulties in joining general social and recreational activities. This stems from a lack of confidence, a lack of skills, and from the reluctance of the

community to accept people who are different. To date, specialist services have been set up to provide... recreational opportunities for our clients, which has resulted in their isolation from the rest of the community... Our own agency is now providing a service which supports people in joining general community recreational activities.<sup>130</sup>

One suggested means of increasing people's access to recreation is to use mobile community mental health workers, where they exist:

Outreach services could be used to expand recreational activities available to encourage exposure to different types of activities, such as more physical exercise. Such options are available to a minute number of clients via current community outreach services. However, the majority do not have this access.<sup>131</sup>

Poetry, painting, drawing, making pottery and listening to music were cited by witnesses as important in the rehabilitation process. The arts provide personal rewards, interest, self-expression and purpose; while demanding neither continuous concentration for lengthy periods nor intense interpersonal contact, which people with mental illness often find difficult.

Music is magic — it is one of the beautiful roads to getting well.<sup>132</sup>

### **'Holistic' Health Promotion**

Many people provided evidence to the Inquiry concerning the potential benefits of activities related to general health promotion — including exercise, meditation, relaxation and massage.<sup>133</sup> These activities receive little attention in the public community mental health system, although some non-government organisations conduct such programs (see Chapter 5 — Mental Health Services).

Another group of health promotion activities referred to as highly desirable — if they were more affordable and accessible — include self-development programs such as assertiveness training, conflict resolution techniques, and self-development groups. GROW is an example of a consumer self-development organisation accessible for people on pensions and low incomes. Clearly, such programs substantially assist a number of people:<sup>134</sup>

Joining GROW was a vital part of my recovery... The program has helped me enormously... Our pain is deep and our healing is slow, [but] no longer am I in that terrible isolation and total separation from my own humanity... Something that I get from GROW that is not available to me through any other means is the love and support I get from my fellow GROWERS... I know I would not have progressed as far as I have without it.<sup>135</sup>

## Financial Issues

In one form or another, all the problems outlined in [discussions with clients about community living] have poverty at their root.<sup>136</sup>

The chronically mentally ill constitute a large proportion of people on disability pensions and benefits.<sup>137</sup> These pensions barely cover the cost of accommodation and food, unless a person is living in the family home. The small amount of money left is not enough to cover the minimum living requirements which most people take for granted — public transport, clothing, toiletries, dental expenses etc. This forces people who are already suffering the effects of their illness to live a very deprived lifestyle.<sup>138</sup>

The days are long and finances are such that there is no spare money for daily leisure activities. Many people end up very isolated... wallowing in their despair and poverty.<sup>139</sup>

The evidence indicated that the very things most likely to assist people's recovery — such as recreational activities, counselling and therapy — are often completely beyond the means of someone on a pension. This particularly applies to services provided by clinical psychologists and private social workers — services which are not rebated under the Medicare system (see Chapter 6). One Victorian witness told the Inquiry:

Even to see a private counsellor will cost you anything up to \$120 for the hour. That is half your unemployment benefit spent in an hour! Money can stop you spiralling downwards and money can certainly help people climb out of the holes they find themselves in.<sup>140</sup>

The real or presumed incapacity of people with chronic mental illness to manage their money often leads to their financial affairs being placed in the hands of a State agency. The Inquiry was told this can create long delays before people can access their pensions:

One client is still waiting after six weeks for his rent to be paid by the Protective Office. His landlady is understanding; other landlords will not tolerate the delay and threaten clients with eviction. Being forced to survive for periods without money (or more importantly for many clients, without cigarettes) or being faced with eviction is extremely stressful for mentally ill persons. Also, The Protective Office charges \$9 per month. This is a significant amount to deduct from a pension. We have been told that only one clerk in the Sydney office deals with processing the affairs of about 300 clients... An alternative might be to designate the mentally ill person's case manager as a guardian of their affairs. [He or she] could then pay their rent, bills, and provide an allowance. This already occurs informally with clients who are agreeable [who are not under the Protective Office].<sup>141</sup>

The cost of psychiatric medication was a matter mentioned by many witnesses. Some mentally ill people attempting to live independently are faced with an invidious choice: between buying the drugs which keep them mentally stable and spending their limited income on food and other living expenses.

Independence — so important to the rehabilitation process — is threatened when individuals have to be ‘rescued’ by their family. As one Canberra parent said:

[My daughter’s] medicine is expensive and should be subsidised, so that she does not have to go without food or other essentials... On many occasions I have had to bail my daughter out of a financial wilderness by paying her rent, giving her money for food, or just generally looking after her affairs.<sup>142</sup>

Mentally ill people who have no family to fall back on are often severely deprived.

The cost of prescription medication is nearly always an issue for people on pensions, even though some items are subsidised by the Pharmaceutical Benefit Scheme. Paradoxically, many who need larger doses are disadvantaged:

Bizarre anomalies exist in the Pharmaceutical Benefits Scheme, which excludes some of the largest strength anti-psychotic medications (Serenace 20mg and Stelazine 15mg) as benefit items. This forces patients to use 12 or more lower-strength tablets in order to get them as a benefit item. It is only very seriously mentally ill people who require these high dosage preparations, and these people are all on Invalid Pensions.<sup>143</sup>

## **Income Support**

Because most people with long-term severe mental illness are unable to earn money through employment, their only income is likely to be a Social Security pension — commonly the Disability Support Pension. (This replaced the old Invalid Pension after the 1990-91 Federal Budget changes.) Before becoming eligible for this benefit, applicants must be considered for a number of shorter-term allowances, each of which has different eligibility criteria and requires a fresh application. A statement from the treating doctor is often required. Eligibility is reviewed regularly, and the obligations on pension recipients do not take into account the particular effects that mental illness can produce:

Many of the eligibility criteria, registration guidelines and waiting periods are inappropriate to the fluctuating nature of mental illness.<sup>144</sup>

Some of the application requirements are difficult enough for any healthy citizen to understand and comply with. For people whose memory, concen-

tration and clarity of mind may be adversely affected by their illness and by medication, it is often extremely difficult.

Because of the nature of mental illness, there have always been problems with back-dating claims for Sickness Benefits for people with mental illness [to the date when the person first became eligible]. Many people with a severe mental illness cannot apply for a benefit until they have become well enough to know that they were sick! Prior to July 1987, a claim could be lodged within 13 weeks of the date of incapacity, but that was changed to five weeks, with not much discretion...[This] clearly discriminates against the mentally ill and some others.<sup>145</sup>

Some people affected by mental illness have trouble filling in forms:

Government Social Security forms can be a difficult hurdle for these people to fill out, and the cold public service letters can appear to be most threatening.<sup>146</sup>

Whenever eligibility requirements or benefit names and entitlements are changed, it can cause confusion and fear. Evidence to the Inquiry demonstrated that many people do in fact lose their benefits,<sup>147</sup> or at least become extremely confused and anxious about the process of applying for them. The same is true for concessions such as Health Care cards:

The complexity of applying for various kinds of concessions leads to their under-utilisation by people with a mental illness who may be entitled to use them.<sup>148</sup>

Recent changes require people on a 'temporary' benefit, which applies from month to month initially (eg Sickness Allowance), to move onto a work-training scheme. This has created major difficulties for people with mental illness, who may not know when — or if — they are going to become well enough to work part-time, full-time, or at all.

[These] measures, commendable in many respects, should not be used to force Job Search, or employment, on those who are not emotionally ready.<sup>149</sup>

Pressure to comply with inappropriate pension eligibility criteria can have deleterious effects on an individual's rehabilitation:

One of the areas of concern...[is] the period for receiving Sickness [Allowance]. If an individual is not ready to return to employment, he will be forced to apply for an Invalid Pension [Disability Allowance]. This may be in direct contrast to the therapeutic rehabilitation goal.<sup>150</sup>

The issue of incomes for people with mental illness living in the community has not been well researched. However, evidence to the Inquiry suggests that:

The level of Social Security benefit is low enough to ensure that poverty is as predictable a consequence of schizophrenia as are social withdrawal and hallucinations.<sup>151</sup>

This prediction of poverty would apply equally to individuals with other chronic mental illnesses which preclude them from secure employment.

As indicated later in this report,<sup>152</sup> the evidence shows that loss of Social Security benefits often causes mentally ill people to become homeless,<sup>153</sup> and also that some homeless people with mental illness lack the personal identification documentation needed for registering with Social Security. This prevents them even applying for benefits.<sup>154</sup>

An unhelpful attitude among counter staff was another obstacle frequently referred to in the evidence.<sup>155</sup>

I find it very stressful when I go along to the CES or I talk to a counsellor and they have no idea what mental illness is.<sup>156</sup>

CES and Social Security officers who are aware of the illness of their schizophrenia clients are often most unfeeling in dealing with them... People with schizophrenia have a right not to be embarrassed or intimidated in front of other office clients.<sup>157</sup>

These staff may have received inadequate training; or they may merely be manifesting the prejudice and ignorance about mental illness which are common in the community at large. However, it is a denial of applicants' human rights to be treated in a discriminatory manner when applying for a legitimate entitlement.

## Conclusion

There are fundamental and widespread inadequacies in the 'community care' available to the majority of Australians affected by mental illness. These deficiencies are incompatible with the rights of those individuals to appropriate care, treatment and rehabilitation and in some instances compound the ignorance and stigma still commonly associated with mental illness. The extensive implications of such an inadequate 'system' of community care are analysed in subsequent chapters (particularly those in Parts II and III).



1. J Templeman, carer, ACT. Submission, pp5,8.
2. Joanna Ross, consumer, Victoria. Oral evidence, Melbourne 10.4.91, p445.
3. G Thornicroft and P Bebbington, 'De-Institutionalisation — from Hospital Closure to Service Development', *British Journal of Psychiatry* v155, 1989, p739: 'The term 'community care' requires careful specification. The concept is ambiguous — it implies both care in and care by the community.'
4. Rehabilitation Advisory Group, Health Department of Western Australia, *Community-based Rehabilitation and Support for People with Long-Term Mental Illness*, Perth 1991, p7. 'In our culture, "community care" represents care "in the community" rather than "by the community". It is recognised that care is generally divided between the State and the family. In many cases, it is the family which bears the largest burden and is the main provider of both personal and material support.' (See also Chapter 15 — Carers.)
5. Dr John Hoult, psychiatrist, Director of Clinical Psychiatry, Glebe Community Care, NSW. Oral evidence, Sydney 20.6.91, p408.
6. Rehabilitation Advisory Group, op cit, p7.
7. Gavin Andrews, *The Tolkien Report: A Description of a Model Mental Health Service*, University of NSW, Sydney 1991, p11: 'Failure to address the precarious living skills of these patients [in the community] will result in admission because of a relapse in psychosis precipitated by some social crisis... [It has been shown in the United Kingdom] that the number of nurses in psychiatric community practice has a direct relationship to the need for hospitalisation — more community nurses, less hospitalisation.'
8. J Hoult and I Reynolds, *Psychiatric Hospital versus Community Treatment: A Controlled Study*, NSW Health Department, Sydney 1983, Addendum, p287.
9. Irene Towler, Executive Director, Schizophrenia Fellowship of South Australia Inc. Submission, p3.
10. Dr Roger Gurr, psychiatrist, Clinical Director of Psychiatry, Blacktown Community Health Centre, NSW. Oral evidence, Sydney 18.6.91, p223.
11. Dr Steve Robinson, Crisis and Assessment Team, Newcastle. Submission, p2.
12. NSW Health Department, *Guidelines for Psychiatric Crisis Teams and Extended Hours Services: Adult Mental Health Services*, State Health Publication No(RIU) 87-074, 1988, p18: 'Psychiatric crisis teams and extended hours services are only some of the total range of services necessary in any area. For continuity of care, they must maintain good liaison with other public sector service strands, private practitioners, and other community care providers at all times... The team should not cease its involvement until the client is well-linked with the service.'
13. Western Australian Council of Social Service, *Without Support*, Perth 1990, p25.
14. A Rosen, V Miller and G Parker, *AIMHS Standards: Area Integrated Mental Health Standards Project*, Sydney 1990, p36.
15. See, for example, National Health Strategy, *Help Where Help is Needed*, Discussion Paper No.5, AGPS, Canberra 1993, p29.
16. Roger Trowbridge, Department of Leisure Studies, Phillip Institute of Technology, Victoria. Submission, p1.
17. J and I Taylor on behalf of Marjorie Oke Rooming House Committee, Victoria. Submission, p1.
18. Eg Dr C Alroe, psychiatrist, Rockhampton. Oral evidence, Brisbane 15.8.91, p1638.
19. Professor Ian Webster, President, NSW Association for Mental Health. Submission, p11.

20. Eg Towler, op cit, p2: 'Psychiatric hospitals, unfortunately, seem not to have the resources to follow up patients who have been discharged into the so-called 'community'... Some sleep in parks and wander from refuge to refuge.' (See Chapter 10 on Accommodation.)
21. J Lane, consumer, Victoria. Submission, pp4,5.
22. Maria Harries, Australian Association of Social Workers, WA Branch. Oral evidence, Perth 11.2.91, p267.
23. Throughout Australia, most health administrations have adopted the catchment area model of responsibility, funding allocation and service delivery for generic health services over the last six to seven years. The mental health service model is basically accommodating itself to the same organisation of service delivery.
24. Webster, op cit, p11.
25. Hoults, (oral evidence) op cit, pp410,411.
26. See, for example, Pat Carberry, Director, ARAFMI WA. Oral evidence, Perth 11.2.91, p249; John O'Neill, administrator, Lakeside Hospital, Ballarat, Victoria. Oral evidence, Ballarat 11.4.91, pp539,540; J du Ross, carer, NSW. Submission, p5; Ray Gale, Mental Health Resource, ACT. Oral evidence, Canberra 18.3.92, p60; Ruth Raward, ARAFMI Tasmania. Submission, p2; Brian I'Anson, President, Mental Health Foundation, ACT. Oral evidence, Canberra 18.3.92, p108; L and J Peters, NSW. Submission, p3.
27. Carberry, op cit, p2.
28. Dr Simon Byrne, psychiatrist, WA. Submission, pp1,2.
29. Prof Peter Burvill, Professor of Psychiatry, University of WA. Paper provided to the inquiry by the WA Branch of the Royal Australian and New Zealand College of Psychiatry reporting the proceedings of a seminar, *The Future of Psychiatry*, Perth Aug 1991, p7.
30. Hoults and Reynolds, op cit.
31. Rosen et al, *AIMHS Standards*, op cit, pp1,3. The AIMHS Standards are designed to provide standards for quality of care by mental health service providers across the whole spectrum of care, from initial contact, through treatment and rehabilitation phases, to long-term follow-up. They are not minimum acceptable standards, but 'optimal' standards to 'set an agenda and provide a view of what a good quality mental health service looks like', including inpatient and community care as part of the whole spectrum of services needed. The standards are said by their designers to be 'process-oriented' and 'outcome-oriented... and represent a consensus of practice based on observed positive outcomes for service users, on recent research, and on practice evidence.' See Chapter 28 — Accountability.
32. Andrews, *The Tolkien Report*, op cit.
33. See, for example, David Meldrum, Chief Executive Officer, South Australian Mental Health Service. Submission, p11.
34. See Appendix 3.
35. Also referred to as emergency teams, extended hours teams, and assessment and treatment teams.
36. Also referred to as community teams, treatment teams, community psychiatric teams, and care and assessment teams.
37. \$17 million was allocated in the 1992-93 Federal budget to facilitate the establishment of local networks or divisions of general practice to assist GPs to broaden their role beyond the level of individual patient care and increase access to after hours services and allied health services.
38. Harries, op cit, p266.

39. Hoult, (oral evidence) op cit, p411.
40. See, for example, Lilian MacPherson, Secretary, Family Association for Mental Health Support, NSW. Submission, p1.
41. Joint Commission on Accreditation of Hospitals, Balanced Service Systems concept. Discussed in I D Goldstrom and R W Manderscheid, 'A Descriptive Analysis of Community Support Program Case Managers Serving the Chronically Mentally Ill', *Community Mental Health Journal*, v19 No1, 1983, pp17-26.
42. J Renshaw, 'Care in the Community: Individual Care Planning and Case Management', *British Journal of Social Work*, v18 1987, p80.
43. See, for example, du Ross, op cit, p6: 'What is a case manager? I'd love to see one — perhaps there is one in the museum?... We have stressful living, day and night — what was needed was sympathetic back-up.'
44. M Sykes Wylie, 'Revising the Dream', *Networker* July-Aug 1992, p15.
45. Burvill, op cit, 'Some areas operate separate case management and crisis teams, other areas combine them... It is not necessary that the psychiatrist be the team leader'; and Renshaw, op cit, p87, 'An issue over which there is considerable debate is whether case managers should be professionally qualified, or whether the critical liaison, coordination and monitoring tasks would be more appropriately carried out by unqualified workers'.
46. H R Lamb, 'Therapist-Case Managers: More than Brokers of Services', *Hospital and Community Psychiatry* v31, 1980, p763.
47. Consumer quoted in 'Listen to our Voices', Victorian Mental Illness Awareness Council (VMIAC), Victoria, Project Focus: Consumer Consultation Report, Melbourne, VMIAC, 1993, p7.
48. id.
49. Brodie Melvin, Director, Orana and Far West Region Mental Health Service, NSW. Oral evidence, Orange 12.7.91, p928.
50. See, for example, Harries, op cit: 'Service delivery units within themselves are divided [about the best way to go about providing continuity of care.] You have members of teams fighting each other, teams that effectively do not work. You need a lot of time and a lot of care given to the people who are providing services when you have teams under pressure and team members coming from different perspectives — those different perspectives have to be well managed. You address conflicts with case management by working harder to support the service providers.'
51. Gurr, op cit, p223.
52. Melvin, op cit, pp919-20. The witness described the development in the Orana and Far West Community Mental Health Service of a computer program titled *Client Registration/ Individual Service Plan* (CRISP), which can enter non-identifying patient data so that staff have a client register which is primarily a clinical case management tool, incorporating individual service plans, with no links to other identifiers, such as driver's licence or Medicare numbers. 'It provides good quality assurance and review mechanisms — it has enabled us to monitor and evaluate our service because it provides effective and measurable outcomes... It also has a very powerful research capacity.'
53. This evidence is also addressed in a number of other chapters in this report, including those relating to Homeless People, Boarding Houses, and People in Rural and Isolated Areas.
54. WA Health Department, Mental Health Policy Unit, Aftercare Policy, Feb 1993, p3.

55. I Robinson-Griffith and R Zimmerman, *Discharge Planning Guidelines for Psychiatric Services in Victoria*, Department of Health and Community Services, Melbourne Feb 1993.
56. Name withheld, carer, NSW. Submission No181, pp1,2.
57. Gurr, op cit, p223.
58. Michael Longhurst, team leader, Mobile Treatment Team, Ryde-Hunters Hill Area, Northern Sydney Area Health Service. Submission, pp1-8.
59. Gurr, op cit, p223.
60. Depot injections are injections with long release time, given fortnightly or monthly. Phenothiazene is one of a number of the psychotropic or neuroleptic class of anti-psychotic medications prescribed for schizophrenia and for some other disorders.
61. Alroe, op cit, p1639.
62. Clozapine (Clozil). See notes on medication in Chapter 8 — Inpatient Care and Treatment.
63. Remoxipride. See note in Chapter 8.
64. Risperidone (Resperdal). See note in Chapter 8.
65. John Anderson, Coordinator, Schizophrenia Research, Westmead Hospital, Sydney. In information provided to the Inquiry, Mr Anderson warned that overseas trials of these new 'atypical anti-psychotics' are limited and that no study of the long-term effects, or of their long-term effectiveness, is yet possible. Conclusions in the short term indicate that the drugs have been well received by the scientific community; but more time is necessary before an appropriate assessment can be reached; experts urge caution in the light of this.
66. Clozapine has been approved for supply to some hospitals, so is not charged directly to inpatients.
67. See KPMG Peat Marwick, *Economic Evaluation of Clozapine*, report commissioned by Sandoz Australia Pty Ltd, March 1993. The study presents an analytical model using the costs of treating people with Clozapine over two years for five schizophrenia patient types, according to categories of care needed. These range from acute and security inpatient care, through rehabilitation, continuing, hostel and community care, with each patient type incurring different costs in terms of treatment intensity and living costs. The study estimates that the net savings anticipated for 100 patients in the rehabilitation and long-term chronic categories, for example, would be \$4,720,000, over the two years compared with traditional treatment. Other combinations of inpatient and community costs are estimated for the five patient types. The report estimates that costs of treatment for the first year are unlikely to be significantly lower than traditional treatment, but that the financial benefit comes in the second year.
68. Cathy Wilson, Manager, St.Kilda and Southport Community Health Centres, Victoria. Submission, p3.
69. Peter Johnson, solicitor, Mental Health Legal Service, Victoria. Oral evidence, Melbourne 10.4.91, p423.
70. Wilson, op cit, p3.
71. A York, 'Community Treatment Orders, Community Counselling Orders and the Modocate Police', Sydney 1991, p2. Paper provided to the Inquiry by the author.
72. id.
73. Michael Cavadino, 'Coercion is not the Best Method', *Community Care* No806, 22 March 1990, p18: 'Just because the care of people with mental illness is moving out of the hospital into the community does not mean that the power of formal control has to move

out with it... Psychiatrists have managed well enough without CTOs until now by using persuasion and negotiation with patients to find mutually acceptable courses of action without resorting to compulsion and coercion.' The converse view is put in the same journal by J Westall, 'Balancing Rights with Real Needs', p19: 'The policy concerning Community Treatment Orders seemed to be the imposition on someone by 'those who know best' of an action tantamount to assault... Voluntary treatment is always preferable and CTOs are not welcomed; but I now see them as simply better than the slow deterioration of a person who has lost insight into their own condition — as the best of two alternatives... A good number of people who now refuse medication might agree if they knew a CTO could be enforced.'

74. J Carne, *A Study of the Effect and Outcome of the Use of Community Treatment Orders and Community Counselling Orders in New South Wales in 1991*. (Research project undertaken with funding by the NSW Health Department.) It was suggested to the Inquiry that further research into the effectiveness of Community Treatment Orders would provide more enlightening data.
75. See Andrews (*Tolkien Report*), op cit, p14.
76. id.
77. NSW Health Department, *Guidelines for Psychiatric Crisis and Extended Hours Services*, op cit, p12.
78. ibid, p18.
79. V Carr, 'Psychiatry in General Practice: A Pilot Scheme Using the Liaison-Attachment Model', *Medical Journal of Australia* v156, March 1992, pp379-382. The paper describes a pilot scheme in which senior psychiatry trainees provided psychiatric consultations part-time in four group general practices (18 doctors) over an 18-month period: 'The participating doctors perceived improvements in their own abilities to deal with psychiatric problems and regarded the quality and accessibility of psychiatric care to be enhanced by the scheme.'
80. Alroe, op cit, p1641.
81. Name withheld, NSW. Submission No257, p1.
82. Richard Wortley, clinical psychologist, Australian Psychological Association. Oral evidence, Orange 12.7.91, p944.
83. Elizabeth Bleby, social worker, South Australia. Submission, p6.
84. Melvin, op cit, p907.
85. Cant, op cit, p2.
86. Doug McIver, consumer, ACT. Submission, p10.
87. Australian National Association for Mental Health, Introduction to Theme, National Congress, 'Biological and Social Factors Affecting Mental Health', Canberra Aug 1987: 'The dichotomy between soma and psyche, so long the approach to health and ill-health, has had the effect of excluding a well-rounded, holistic approach in the management of mental disorders... [We] do not know which biological factors are capable of affecting our mental health.'
88. Rehabilitation Advisory Group, op cit, p7.
89. Frances English, carer, ACT. Submission, p5.
90. Peter Swan, Schizophrenia Fellowship Social Club, Queensland. Oral evidence, Brisbane 14.8.91, pp1498-9.

91. Walter Zyla, Sub-Regional Coordinator, Central Western Community Mental Health Service, Orange, NSW. Submission, p1.
92. Eg submissions from J Ross, consumer, Victoria; Colin Ware, carer, Queensland; Rosemary Tucker, carer, South Australia; Gail May, community worker, Tasmania; and Linden MacLeod, Secretary, Psychiatric Nurses Association, WA.
93. Assoc Prof Joan Lawrence, Department of Psychiatry, University of Queensland and Royal Brisbane Hospital. Submission, p9.
94. McIver, op cit, p3.
95. Dr Alex Caracatsanis, psychiatrist. Submission, p1. Included with submission from RANZCP (WA Branch).
96. id.
97. Eg submissions from Templeman, op cit; P Lowrey, Consumers' Health Forum, ACT; S Pearce, clinical nurse consultant, South Australia; K Rainsford, Program Coordinator, GROW, South Australia; Board of Transitional Enterprises Inc, NSW; Ruth Raward, ARAFMI; Fawdry and Roach, op cit, Tasmania; W McMahan, St Vincent de Paul Society, Northern Territory; P Hutchins, ARAFMI Sunshine Coast, Queensland; J Clarke, Central Queensland Multidisciplinary Psychiatric Team; J Briggs, carer, Victoria; M O'Donoghue, CATS (Changing Attitudes Towards Schizophrenia), Victoria; L Aylmore, carer; B. Harris, Emmanuel Centrecare, WA.
98. R Drake, M Wallach and S Hoffman, 'Instability and Homelessness among Aftercare Patients of an Urban State Hospital', *Hospital and Community Psychiatry* v40 No1, Jan 1989, p48.
99. Jeannette Muir, carer, Queensland. Submission, p6.
100. Eg Rehabilitation Advisory Group, WA Health Department, op cit, p28.
101. ARAFEMI (Association of Relatives and Friends of the Emotionally and Mentally Ill) Victoria. Submission, p16.
102. T Atkin, Secretary, Schizophrenia Fellowship of South Queensland. Submission, p2.
103. Muir, op cit, p6.
104. W Burong, Western Australia. Submission, p4.
105. Sr Pat Chapman, Nursing Unit Manager, Young People's Program, Cumberland Hospital, Sydney. Submission, pp1-5.
106. A more detailed description of the extensive support programs offered to families is contained in Chapter 15 — Carers: The Experience of Family Members.
107. The Inquiry inspected a number of the Program's facilities and was impressed by its effectiveness. (See also Zyla, op cit.)
108. Douglas Dunlap, Associate Professor of Rehabilitation at the University of Maine, USA, wrote: 'I was particularly impressed by [SHIPS'] use of general community services as resources for the daily activities of clients. Orange appeared to have the best community-integrated system I observed in Australia and it is probably the best I have seen anywhere.' Attachment to Zyla submission, op cit.
109. Zyla, op cit, pp1-2.
110. John Simpson, mental health worker, Croydon Living Skills Centre. Submission, p4.
111. *ibid*, pp1-5.
112. See, for example, consumer, name withheld, NSW. Submission No334, p10.

113. Christine Flynn, Policy and Administrative Director, Mental Health Coordinating Council of NSW. Submission based on the Council's consultations with service users, p14.
114. Simon Champ, consumer. Oral evidence, Sydney 18.6.91, p216.
115. See, for example, the Clubhouse model, which is discussed further in Chapter 12 — Employment. As well as employment, it addresses a wide range of rehabilitation and recovery needs of people with serious chronic mental illness, including daily living skills, accommodation, work readiness, relationship development, social skills and spiritual development. Many Clubhouses have been established in North America and Nordic countries.
116. English, op cit, p6.
117. For example, L and D Simpson on behalf of Great Lakes ARAFMI Group, NSW. Submission, p1; and name withheld, Queensland, submission No516, pp2,5.
118. English, op cit, p6.
119. Anthony York, community mental health nurse, NSW. Submission, p2.
120. Eg Dr Graham Martin, psychiatrist, Southern Child and Adolescent Mental Health Service, South Australia. Oral evidence, Adelaide 21.10.91, p53.
121. D Som, A Mallik, P Reed and K Gaskell, 'Differences between chronic schizophrenic patients in the hospital and in the community', *Hospital and Community Psychiatry* v43, No12, Dec 1992, p1233. Also S D Som and M Brownlee, 'Alcohol abuse in chronic schizophrenics: Implications for management in the community,' *Acta Psychiatrica Scandinavica* v84, 1991, pp272-6.
122. See Chapter 21 — People with Dual and Multiple Disabilities.
123. Ross, op cit, p446.
124. P Deany, *Mind and Body: Health Promotion for the Mentally Ill*, Victorian Health Foundation, Melbourne 1992, pp4-5. Also R Trowbridge, 'Issues of integration and recreation for people with a mental illness', *New Paradigm* v1 No4, Nov 1990, p19.
125. See, for example, McIver, op cit, p3.
126. Several effective programs are described in Chapter 5 — in the section on Non-Government Services.
127. Alison Byrne, recreation officer, Richmond Fellowship of Tasmania, 'Recreation in Mental Health', Paper provided to the Inquiry, 1992, pp2-3.
128. Thea Bates, Director, Victorian Community Managed Services (VICSERV). Submission, p23.
129. Tracy Antill, Senior Occupational Therapists' Group, Osborne Park Hospital, WA. Submission, p1.
130. Maurice Mead, Executive Director, Outer East Council for Developing Services in Mental Health, Victoria. Submission, p3.
131. Anita Holmes, assistant senior social worker, Woodleigh House, Modbury, South Australia. Submission, p2.
132. Unnamed consumer. Quoted in 'Listen to our Voices', op cit, p12.
133. Eg McIver, op cit, p10, who suggests Tai Chi, the Alexander Technique, yoga and various types of exercise. Also 'Listen to our Voices,' op cit, p12.
134. John Lizzio, National Administrator of GROW; Joe Gillies, GROWER; Warren King, GROWER. Oral evidence, Sydney 18.6.91, pp175-187. Glenise Payne and Kirsty, GROW. Oral evidence, Darwin 21.7.92, pp49-57. Pauline Bourke, GROW. Oral evidence, Hobart 13.11.91, pp293-301.

135. Kirsty, op cit; see also the section on Non-Government Services in Chapter 5.
136. Joan Clarke, Executive Director, Prahran City Mission, Melbourne. Submission, p9.
137. Brodie, op cit.
138. Bates, op cit, p32; Meldrum, op cit, p4.
139. Muir, op cit, p6.
140. Frank Hytten, Chairman, Mental Health Legal Service, Victoria. Oral evidence, Melbourne 10.4.91, p415.
141. Peter Scollay, clinical psychologist, Newcastle. Submission, p1.
142. E Barry, ACT. Submission, p2.
143. Robinson, op cit.
144. Meldrum, op cit, p5.
145. Di Gordon, President, Australian Association of Social Workers, ACT. Submission, p9.
146. Orme Hodgson, former President, Schizophrenia Fellowship of South Queensland. Submission, p22.
147. Queensland Government. Submission, p35.
148. Flynn, op cit, p20.
149. ibid, p21.
150. Meldrum, op cit.
151. Robert Bland and Monica O'Neill, 'Rediscovering welfare concepts in social work practice in community mental health', *Australian Social Work* v43 No4, Dec 1990, p6.
152. See Chapter 18 — Homeless People.
153. John Quinn, psychiatric nurse, Queensland. Submission, p2.
154. Netty Horton, Coordinator, Victorian Council to Homeless Persons. Submission, p14.
155. Flynn, op cit, p21; Hodgson, op cit, p22; Miami Special Interest Mental Health Group, Queensland. Submission, p6.
156. M Smith, Depression and Manic Depression Association of NSW. Oral evidence, Sydney 17.6.91, p89.
157. Hodgson, op cit, p22.



## Chapter 10

### ACCOMMODATION

Some examples of housing, or lack of it, for the mentally ill are a disgrace to our society. There are crowded halfway houses in the cities... They're packed into caravan parks along the east coast...and there are long waiting lists for public housing.<sup>1</sup>

#### Introduction

One of the biggest obstacles in the lives of people with a mental illness is the absence of adequate, affordable and secure accommodation. Living with a mental illness — or recovering from it — is difficult even in the best circumstances. Without a decent place to live it is virtually impossible.

Yet finding suitable accommodation is a frustrating enterprise; keeping it is often even more difficult.

She wasn't offered any alternative accommodation — although she was actually taken to the local women's refuge, where she caused so much trouble that after three days they rang me up and said she cannot stay here.<sup>2</sup>

For many mentally ill people and their families, this type of experience is all too familiar.

Access to appropriate accommodation is regarded by many as the most important determinant in the success or failure of people with chronic mental illness living in the community.<sup>3</sup> All the evidence considered by the Inquiry established that the policy of deinstitutionalisation cannot succeed unless it is complemented by appropriate policies on housing — and a commensurate allocation of resources.

Evidence to the Inquiry also indicated that neither of these requirements has yet been met. There is not enough housing<sup>4</sup> — and not enough funds to provide more. The accommodation available is often expensive, substandard or inappropriate. Crowded, dilapidated boarding houses have become the 'new institutions' (see Chapter 11). Government programs frequently exclude mentally ill people, because of rigid demarcation and poor coordination between departments and agencies. Support services are inadequate for mentally ill people living in independent housing — and for those living with their families there is not enough respite care.

Secure and affordable accommodation is the right of all people. To a person with a mental illness...[it] is essential to provide stability in a sometimes very chaotic and confusing world where reality and their imagined reality becomes blurred. A financial commitment by governments to providing this accommodation is essential.<sup>5</sup>

## **Barriers to Appropriate Accommodation**

A belief is widespread...that because a person is mentally ill, any housing is sufficient; in many cities patients released from mental hospitals have been placed in housing that would be deemed unfit for anyone else. [But] one can argue on humanitarian grounds that a person who has the misfortune to be seriously mentally ill deserves better housing than other people, not worse.<sup>6</sup>

### **Accommodation Shortage**

There's still boarding houses with up to four people in one room and there is no privacy, there's high rents. I can't imagine what that would be like if I had to live sharing a room with three other people, especially if I'd had a mental illness.<sup>7</sup>

The shortage — and in many cases total absence — of appropriate accommodation for people with a mental illness was one of the most common complaints made to the Inquiry.<sup>8</sup> Many saw it as the single biggest obstacle to mentally ill people's treatment and quality of life.

Witnesses from the Hunter Region mental health service in NSW (one of the largest regional areas in the country) described a housing shortage which is reflected across Australia. In the Hunter, approximately 560 places are available in different agencies which can accommodate people with a mental illness. But most of these facilities have serious shortcomings: some are reluctant to accept mentally ill residents; some are in very isolated locations; some provide low standard accommodation, in an institutional atmosphere, with very few activities for residents. Only 120 of the 560 places are considered suitable for people leaving hospital. Demand is consequently so high that only a handful of those places are ever available — and then only for people who are relatively easy to deal with.<sup>9</sup>

In the absence of suitable housing, many clients resort, for a time, to accommodation that is too expensive for them. Others sleep on the streets, or turn to emergency accommodation which is only temporary. Many must be referred to accommodation out of the area. Some — especially psychogeriatric patients — are forced to remain in hospital.<sup>10</sup> Others end up there because they cannot cope:

People with chronic mental illnesses are generally highly vulnerable to stress. The stresses involved in living in accommodation poorly suited to their needs can often be such as to seriously impede recovery and to precipitate relapse. The constant 'making do' and 'putting up with' can be so exhausting and depressing for them as to undermine their health and their capacity to cope with the demands of independent living.<sup>11</sup>

Thus the lack of accommodation leads directly to higher rates of hospital admissions and readmissions, and longer hospital stays. Mentally ill people are denied their right to rehabilitation and normal living; they are also left vulnerable to exploitation.<sup>12</sup> All of these effects cause distress and frustration, and can sometimes lead to violence.<sup>13</sup>

The facilities that do exist lack the support services they need to care for mentally ill people. Even in a major population centre like the Hunter Valley, crisis and community mental health services are virtually non-existent outside Newcastle city itself. (The Lake Macquarie area, for example, with a population numbering 165,000 and growing rapidly, has no crisis team.) This means services in Newcastle are overstretched, while tens of thousands of people living outside the city in rural and regional centres have little or no access to treatment or rehabilitation programs.<sup>14</sup>

The Inquiry heard similar evidence in other parts of Australia. The shortage of accommodation is particularly acute away from the major cities. For example, in South Australia:

There's the Housing Trust in Whyalla and there's private rental, and nothing in between... We have one accommodation unit for seven people which is a mini-institution, termed as a hostel, which was very up and going twelve years ago, but not now...<sup>15</sup> [For youth] there's only the one shelter in Whyalla, which is what they classify as medium term, so there's not much option on (a) how many youth we can house, and (b) for how long. So we often have to refuse support — if we get somebody with alcohol or drug [dependency], psychological problems, any mental illness [or] intellectual disability.<sup>16</sup>

There are no hostels, no boarding houses, there is no form of accommodation in Port Lincoln.<sup>17</sup>

A Tasmanian witness told the Inquiry that State has no long-term accommodation specifically for people with mental illness.<sup>18</sup> (The Richmond Fellowship in Hobart runs a rehabilitation house for ten young people with schizophrenia, who stay 8-12 months,<sup>19</sup> and a medium-term group home which houses three residents.<sup>20</sup>) This witness estimated the unmet need for accommodation in Hobart alone to be at least 100 people — mentally ill Australians, currently living in 'very unsatisfactory, unstable accommodation':

There are a lot of people who are constantly moving around from pillar to post simply because they do not get on with the other people there, or they are asked to move on by the landlord, or for whatever reason.<sup>21</sup>

### **‘Deinstitutionalisation’**

Deinstitutionalisation is fine for people who do not have to find somewhere to live.<sup>22</sup>

The policy of deinstitutionalising psychiatric patients (or of not hospitalising them in the first place) was conceived in the belief that most people with a mental illness would be better off living and being treated in the community. It assumes they will have somewhere to live — an assumption which is frequently unfounded. Mentally ill people have great difficulty finding and keeping accommodation — due to poverty, discrimination and the nature of their disability.

The scarcity of accommodation impacts as soon as a mentally ill person is discharged from hospital. In parts of Melbourne about one-third of all patients discharged have no secure accommodation for the following 48 hours.<sup>23</sup> This is a scandal. Similarly, in NSW:

It is reported that a third of patients admitted to Wollongong Hospital Psychiatric Unit have acute accommodation problems and have nowhere to reside.<sup>24</sup>

Unsuitable accommodation (or none at all) can erode or destroy the benefits of treatment and rehabilitation received in hospital. A young woman in Sydney told the Inquiry the initial placement after hospital was crucial to her successful deinstitutionalisation:

My most pressing concern at the moment is that the Department of Community Services and Health has decided to put residents...straight into situations without support, so that after hospital, instead of living in a situation where staff are present for reduced hours, as I did when I first left hospital, I would have to go straight to the kind of situation I am in now — a situation I was not ready for when I left hospital, a situation that would frighten me if I was offered [it] in hospital, a situation which once implemented could stifle the good work that was started.

Yes, there should be more places like the one I'm in. There should be stepping stones.<sup>25</sup>

Deinstitutionalisation has left many mentally ill people and their families in a quandary over accommodation. Most families, however loving they may be, are ill-equipped to handle living with a person who has a severe mental illness. Yet the realistic alternatives are often highly undesirable: marginal accommodation such as substandard hostels or boarding houses, or even homelessness. As one psychiatrist told the Inquiry:

Two groups of people, the deinstitutionalised from the long-stay wards and the non-institutionalised, have paid the price... The price was losing their rights to adequate treatment, and their relatives lost their rights to relief from excessive burden because of this.<sup>26</sup>

## **Gaps in Service Provision**

Experience has taught us that if we don't get the housing needs of people right, care in the community just doesn't work.<sup>27</sup>

In accommodation, as in so many other areas, one of the biggest problems cited by witnesses to the Inquiry was the rigid demarcation between services and agencies. This disadvantages people with a mental illness because they tend not to fit neatly into the categories specified.

The classic example (and the most disturbing — given governments' professed concerns for the weak and vulnerable) is in public housing. Mentally ill people need supported accommodation, not just a roof over their heads. But housing departments protest that their role is merely that of landlord — not a support agency for people with disabilities.<sup>28</sup> Health departments, on the other hand, recognise that mentally ill people need support from trained staff — but insist they are not in the business of providing housing:

Government departments don't seem to interconnect on these matters, and it's a problem. Health looks at it as a sociological issue. The Supported Accommodation Assistance Program says: look, we're not therapeutic, we can't fund it, it's a mental health issue.<sup>29</sup>

The consequence of this inexcusable lack of co-operation between departments is that supported accommodation in the public housing sector is virtually impossible to find. Mentally ill public housing tenants pay the price: denied the support they need, many deteriorate until they have an acute episode and are admitted to hospital. Others end up homeless or in marginal accommodation like boarding houses or shelters, where at least they are provided with meals and some supervision for medication.

There is...no public sector agency which has any responsibility at all of that sort, so the picture that emerges is one of systemic discrimination against hidden populations of people whose existence, in fact, has not been normalised by the process of deinstitutionalisation at all.<sup>30</sup>

Services designed specifically for people with disabilities also tend to define their 'target market' very rigidly. Many people with a mental illness need those services, but find they are excluded because:

They somehow don't fit the criteria. They've been out of the system too long, their children are too old, they're in their own accommodation — so they don't fit somehow or other.<sup>31</sup>

Several witnesses contended that people with intellectual disabilities have better access to housing and services than people with mental illness. This leaves mentally ill people and their families bewildered — it appears there are some disabilities which 'deserve' support and others, just as serious, which do not:

I feel one disability service discriminates against another: they've got very nice group homes [in our town] but of course, we're not eligible for group homes because it's the wrong label once again<sup>32</sup>... Unless you're intellectually disabled. There are two fully supervised homes for the intellectually disabled, beautiful homes.<sup>33</sup>

One common reason for exclusion from housing and other services is that an individual is too disabled — or not disabled enough.<sup>34</sup> For example, affordable supported accommodation may be available for people in the acute stage of their illness, only to be discontinued when they begin to stabilise. Yet their ability to remain stable may depend on that very support:

In some cases I was too well to have access to facilities... For example, there was a group home where you were rehabilitated and then sent (if you wanted to) to a group of flats for cheaper accommodation; and because they considered me to be too well I didn't have access to cheaper accommodation. I was on the waiting list for the Ministry of Housing, but that could be ten years down the track as far as they were concerned.<sup>35</sup>

Inexcusably, some of the most disabled people with mental illness are excluded from services altogether — because their needs overlap several services. This is generally the fate of those with dual or multiple disabilities (see Chapter 21).

### **The NIMBY Syndrome — Not In My Back Yard**

Persons discharged from psychiatric hospitals...have been declared mentally fit by their doctors, but mentally ill and probably dangerous by their would-be neighbours.<sup>36</sup>

Recognising the acute shortage of accommodation for people with a mental illness, some community groups have attempted to establish supported accommodation in their areas. Apart from the organisational and financial difficulties involved, they frequently confront resistance from the local community:

People are not too kind if it might look like there will be a hostel for the mentally ill close by!<sup>37</sup>

Opposition from local residents is sometimes expressed in terms of specific concerns about maintaining real estate values and aesthetic standards in the neighbourhood (there appears to be a widespread belief that mentally ill people have untidy gardens!)<sup>38</sup> But more common is a generalised fear and rejection of people with mental illness. Typical comments related in evidence to the Inquiry included statements such as:

This is just an ordinary street with lots of old people and young parents. Why should we have to put up with people like that living here?<sup>39</sup>

This is just an ordinary country town. We can't be expected to deal with big city problems. They should be put on a one-way bus and taken to some place where they belong.<sup>40</sup>

One witness from the mental health support group ARAFMI recounted her association's fight for a halfway house in Coffs Harbour, NSW. The witness, whose son has a mental illness, said:

[Eventually] I did go public in the local newspaper and invite anyone that wanted to, to come out to my house and meet my son and see what sort of people would be living in that halfway house, and see that they were no danger to them.<sup>41</sup>

Similarly in Hobart, responding to local objections took on the characteristics of an election campaign:

We canvassed every house, we knocked on the door, we told them who we were, what we were doing, who we were doing it for and invited them to come and have morning or afternoon tea with us.<sup>42</sup>

These two witnesses' efforts were finally successful, both in establishing supported accommodation and in operating it without adverse consequences:

We did get the halfway house, and after 12 months there had never been one complaint from the other residents — and they had the best kept yard in the street.<sup>43</sup>

[Once the home was set up] we have not had any problems. In fact, we have had quite a lot of support from the neighbours. The chap next door belongs to the wharfies; he invites us to the wharfies' picnic every year and all our clients have a whale of a time...<sup>44</sup>

However, it was clear from other evidence to the Inquiry that worthwhile, much-needed housing proposals are frequently blocked by local residents' prejudice and fear.<sup>45</sup> One such project also in Hobart was a hostel where young people with schizophrenia, past the acute stage of their illness, would have received rehabilitation and training in living skills. The hostel was proposed for a residential neighbourhood, close to shopping areas and various

community services — an ideal location to help young mentally ill people adapt to ordinary life.

Area residents objected strongly, claiming the hostel would affect the amenity of the neighbourhood because its clients might display anti-social or dangerous behaviour. The local council accepted these objections and refused the development proposal. The mental health service then appealed to the Tasmanian Planning Appeals Board. The Board, assisted by expert evidence about the likely behaviour of young people recovering from schizophrenia, decided the residents' fears were unfounded. Nevertheless, it upheld the local council's decision against the proposal — on the grounds that the residents' fear, apprehension and intolerance were themselves likely to affect the amenity of the neighbourhood.<sup>46</sup> Thus prejudice, even if groundless, was accepted by the tribunal as a valid legal reason to deny people recovering from mental illness their rights to accommodation and rehabilitation!

It is outrageous that people who have been mentally ill are supposed to live in the community — pursuant to government-sponsored policies of deinstitutionalisation — but have no legal **right** to be there.

Even if supported accommodation is established and operates successfully, some neighbours still refuse to be convinced. People with a mental illness continue to be stigmatised, however ordinary their behaviour. Examples of this common double standard cited to the Inquiry included:

- 'They are terrorising the neighbourhood.'  
'What exactly are they doing?'  
'Standing at the front gate looking at people.'<sup>47</sup>
- 'It's inexcusable — he is allowed to walk around by the school every morning. Who knows what he might do?'<sup>48</sup>
- 'We keep a pretty tight ship — we do not do things that may upset the neighbours. We do not have excessive noise, we keep the place clean, we are conscious of the fact that perhaps you or I can leave our lawns and gardens unattended, but we find that places like ours get, 'Oh, have you seen that place? What a pigsty it is.'<sup>49</sup>

## Housing Options

The rhetoric...[is] that people should have the option of the least restrictive environment, but the resources really aren't there to provide the alternatives to hospital... particularly in areas such as crisis accommodation and respite care.<sup>50</sup>



## Public Housing

Most people who have a severe mental illness are poor enough to qualify for public housing programs operated by State housing departments. Yet the proportion who live in public housing is quite low: for example, one survey of mentally ill people in Wollongong found only 7 percent lived in public housing.<sup>51</sup> This could be because mentally ill people do not realise they are eligible for public housing, or do not know how to apply successfully; or because the housing available is not appropriate for their needs.<sup>52</sup> They may also be deterred from applying by the length of waiting lists.<sup>53</sup>

Waiting lists for public housing are notoriously long — and increasing.<sup>54</sup> The waiting time in Sydney is estimated at up to ten years,<sup>55</sup> and even in North Queensland it is 18 months.<sup>56</sup> In principle, people with disabilities receive priority; but in practice,

It is common for mentally ill people not to seek special assistance for which they may be eligible. This is due to the stigma they feel is attached to mental illness, and a fear that they may not receive housing if it becomes known that they are mentally ill.<sup>57</sup>

The lack of coordination between housing and health departments has already been mentioned. One of its consequences is that even when mentally ill people are allocated public housing, their accommodation problem is by no means solved:

The Housing Trust [of South Australia]...can provide priority housing to mentally ill [people]...[but] when you put a mentally ill person into a two or three-bedroom house without furniture and without supervision, it probably isn't doing them all that much good.<sup>58</sup>

Very often it's three-bedroom unfurnished homes...and that in many ways sets them up to fail — specifically the youth, because they have friends around and they trash the place, and then they've got bills to pay and the whole cycle sets up and it's just hopeless.<sup>59</sup>

For people with a mental illness, housing must be more than physical shelter. Their disability means they need support from mental health workers. Without that support, 'what you're doing is setting people up to fail inside their own home.'<sup>60</sup>

The drawbacks of unsupported accommodation are especially acute in high-rise public housing complexes:

[Many] people have been placed in public housing but without access to support services. If you are living in a block of 200 flats on your own, and you have recently recovered from a mental illness, it is very difficult to access any kind of support services you need.

[Other] people who live in public housing are often having problems themselves, and there is often a lot of harassment...<sup>61</sup>

Mentally ill people commonly meet with fear or suspicion from other tenants in public housing — and as one Victorian witness pointed out, close-quarter, high-rise living itself can create difficulty enough between neighbours.<sup>62</sup>

Lack of flexibility in public housing is also a problem. For example, the concept of a household recognised by State housing departments is usually restricted to 'families' or single people living alone. Yet many people with a psychiatric disability are only able to live in the community if a friend or supporter is staying with them.<sup>63</sup> The NSW Housing Department now allows tenants to share accommodation with a 'carer', but only for people with a severe medical problem or physical disability. If this were extended to include people with a psychiatric disability,

The advantage is that [the person] can then access two-bedroom accommodation, the lease being in the disabled person's name, and the carer can change without the individual losing their right to tenancy.<sup>64</sup>

## **Private Rental**

While many mentally ill people have insufficient income to enter the private rental market,<sup>65</sup> those who can afford it suffer from the same lack of support as those in public housing.

An attempt at living singly in a flat, even though it was close to a clinic, resulted in an overdose and very nearly death.<sup>66</sup>

In addition to lack of support, the private rental market poses two primary obstacles: cost and discrimination.

### *Cost*

Most people with a severe mental illness suffer from long-term poverty, surviving on a very low income from a pension or benefit. Many also have difficulty managing their money, are vulnerable to being economically exploited and are sometimes robbed. They simply cannot afford the normal costs of securing accommodation in our major cities.

The cost of obtaining a flat is out of the reach of people who have continually been in receipt of the invalid pension. The cost of bonds and weekly rent, plus 'moving in' costs, mean that many are continually at the mercy of boarding house proprietors — and park street benches.<sup>67</sup>

Obviously, the scarcity of low-cost accommodation is one important factor leading to homelessness.<sup>68</sup>

### *Discrimination*

Many who are fortunate enough to have sufficient funds to...obtain appropriate accommodation are regularly discriminated against.<sup>69</sup>

Most Australian States have anti-discrimination laws, but some do not include psychiatric disability as a ground for complaint. Even where it is included, mentally ill people have found it difficult to lodge complaints of discrimination, because 'psychiatric disability' has been interpreted very narrowly. The new Federal disability legislation<sup>70</sup> addresses this problem, but obviously it will not, of itself, effect attitudinal change and eliminate discrimination overnight.

In the area of housing, discrimination is common.<sup>71</sup> Witnesses to the Inquiry identified two sources: accommodation providers and neighbours.

Accommodation providers are landlords, real estate agents and managers of hostels or refuges. Some evidence suggested estate agents discriminate against people whose financial affairs are managed by the State Trustee.<sup>72</sup> Other evidence indicated some estate agents discriminate against people whose existing accommodation is a refuge.<sup>73</sup> One carer in Queensland told the Inquiry:

The thoughts of real estate agents toward the psychiatrically ill [are] of contempt.<sup>74</sup>

Hostility and harassment from neighbours — usually based on ignorance — was reported by many witnesses:

Well, the neighbour is a good person in many ways — but when it comes to mental illness utterly biased and utterly misunderstanding.<sup>75</sup>

### **Private Hotels**

Small private hotels are home to many people with psychiatric disabilities — often as a last resort when no other accommodation is available.<sup>76</sup> On the other hand, 'upstairs from the pub' is low-cost accommodation which can have several advantages over housing designated for people with disabilities. It is perceived as 'normal' (often mixed-sex accommodation, including some people who are in employment), is affordable and is usually centrally located.<sup>77</sup> In some areas, an activities officer from the mental health clinic or local council

visits the private hotels to encourage disabled residents to participate in activities like art classes.<sup>78</sup>

However, private hotels are by no means supported accommodation. The staff may be understanding and helpful, but they generally have no mental health training. Hotels are not subject to government regulation under mental health or disability programs — not even the very minimal licensing requirements applying to boarding houses.

### **Living with Family**

My son 'exists' in a caravan in the backyard.<sup>79</sup>

*It is socially unjust to expect families and other carers to bear without respite the burden of those who are seriously and chronically mentally ill. There is a great deal of talk about 'community', but for most people with schizophrenia it is still a hollow concept, there being totally inadequate resources.*<sup>80</sup>

For a great many individuals with mental illness, living at home with their parents or other relatives is the only affordable housing option.<sup>81</sup> This has substantial drawbacks — for both the family and the mentally ill person. (See Chapter 15 — Carers.)

Life with a mentally ill relative can exact a high personal cost — emotionally and financially:

Many sufferers need and receive 24-hour care which is an enormous strain on families, often leading to carers becoming ill, marriage breakdown and often a strain on siblings living at home. This latter concern has been almost totally ignored by medical professionals.<sup>82</sup>

*[It] makes great demands on the other family members for understanding the sufferer's problems and giving her support. The brothers and sisters suffer from a disruption of their own social lives, and there is stress on their emotions and on their studies. Some members of the family can cope; others can't. When the other members leave home they become reluctant...to come [back] to visit.*<sup>83</sup>

Family members may endure physical assaults and terrifying threats:

Parents also put up with intolerable situations at home, [when] someone is getting sick again and there is no support or early intervention... We've actually had people say that they need to put locks on the bedroom doors and hide all the knives in the house when someone's really psychotic and they can't get help for them.<sup>84</sup>

Eventually some families reach breaking point and throw the mental illness sufferer out:

This is where the great problem arises when this young sufferer is unable to find other accommodation and may finish up in compulsory institutions, in jails or on the street.<sup>85</sup>

Clearly, most families are simply unable to provide the skilled support which many sufferers need — and which is their right. Yet the information and support services which could help families cope better are simply not available.

Living with family entails another significant disadvantage for mentally ill people themselves: it prevents them becoming independent. Continued dependence tends to undermine one's self respect; it also hinders the development of the living skills needed to survive when relatives are no longer able to care for them.<sup>86</sup> For many parents, this becomes an overwhelming worry:

Going back to the family isn't always the answer. Parents become older, they come to me and say, what is going to happen when I die — my son or daughter hasn't learned to survive by themselves. They couldn't survive in the family home.<sup>87</sup>

I am now 66, a pensioner, have angina and am very worried and depressed and am trying to support my daughter in every way I know how. But what happens when I am unable to do this? For all parents and relatives of sufferers this is their main concern. Who will care?... I saw the care my mother-in-law lavished on her husband who was afflicted similarly and who, once his wife died, slowly and systematically went downhill, until as an old man he ended up on skid row. Only those in similar situations seemed to notice his plight or care. Will this happen to my daughter?<sup>88</sup>

Some carers suggested that some form of transitional supported accommodation immediately following discharge from hospital could lighten the long-term burden for everyone:

Even if the government would buy a motel close by the hospital, so when at first the sufferer is released that is where they can go to relearn basic living skills. As it is now, when...they go straight home, there is an enormous strain and stress in the family — and they can become very dependent, which is a great concern for elderly parents.<sup>89</sup>

### *Respite Care*

There is now a respite care house — this is the only positive thing that has happened to us in the last 14 years... Apart from that we have no family relief.<sup>90</sup>

For families trying to care for a person with a severe mental illness, respite care can make the difference between success and failure. A psychiatrist in Sydney told the Inquiry:

As a clinician I am very aware that stresses and breakdowns in the home environment very often precipitate a relapse and often readmission to hospital... It's cheaper in the long run to provide people with good basic support.<sup>91</sup>

The stress on carers — most often mothers — is enormous, and can itself exacerbate the difficulties experienced by the mentally ill person. Considering the burden borne by family carers, their demands are very modest:

If we could have a weekend's break with other members of our family and be like a normal family...<sup>92</sup>

Respite centres provide temporary supported accommodation,

so the ill member of the family can go away to a situation where the family doesn't have to feel guilty for sending them away, where the ill member could have a holiday and the family some respite.<sup>93</sup>

One carer, whose son constantly takes taxis without having the money to pay for them, told the Inquiry:

I'd desperately like some respite care. Somewhere where we could take him and know that he is in pleasant surroundings, that people are kind to him, but we don't have to worry about being at home with \$21 or whatever for a taxi.<sup>94</sup>

Respite care is obviously one of the most cost-effective mental health services — because it allows families to continue carrying a burden which would otherwise fall on the state. Yet evidence to the Inquiry established that this fundamental need goes largely unrecognised and poorly addressed.<sup>95</sup>

In the interests of the health and wellbeing of all concerned, it is essential that adequate support services be provided for sufferers continuing to live in the family home — and for their caregivers, including respite care from time to time... However, it is also essential that facilities and services be put in place to enable as many sufferers as possible to leave the family home and establish independent living at an age when they will be at their most adaptable.<sup>96</sup>

## **Emergency Accommodation**

Emergency accommodation for people with a mental illness is drastically undersupplied — in fact in many parts of Australia it is non-existent. This throws the burden onto the homeless men's shelters and youth and women's refuges:

There's growing concern in the women's shelters in South Australia about the high number of psychiatrically disturbed women coming in... Quite often these women are ones that

have been dismissed from mental institutions in Adelaide, have no accommodation on the streets, been referred to shelters through crisis care, FACS or other agencies, and...we are not able to work with them in women's shelters.<sup>97</sup>

Quite apart from their psychiatric disability, mentally ill people need crisis accommodation in the same circumstances as anyone else (eg anyone can become homeless due to poverty or domestic violence). The need may also arise when a person's mental illness becomes too oppressive for family carers to cope.

There are very few refuges specifically for people with a mental illness. But most youth and women's refuges are reluctant to take in psychiatrically disabled residents, because their staff have no training in mental illness.<sup>98</sup> In these circumstances, the presence of a mentally ill person in a refuge can be extremely disruptive for other residents. Yet there may be nowhere else for that person to go. (This issue is discussed further in Chapter 18 — Homeless People.)

With crisis accommodation for the mentally ill so scarce, the general services are being overloaded by a flood of mentally ill clients whose real need is for long-term accommodation — including many coming straight from hospital. The Inquiry was presented with quite specific evidence on this subject by Crossroads, an accommodation program for the chronically homeless run by the Salvation Army in Melbourne.

Crossroads staff said they are constantly frustrated by hospitals which regard it as acceptable to discharge psychiatric patients directly into crisis accommodation. This is totally unsuitable housing for a person immediately after hospital. The practice also indicates a serious deficiency in hospital planning: discharge from hospital should be a routine, planned event — not a crisis.

Similarly, Crossroads receives frequent referrals from local community health teams, whose own accommodation workers have even less success in finding housing for mentally ill people. Witnesses suggested that if a government service lacks the expertise needed in this area, it should use agencies like Crossroads as consultants earlier in the process — rather than waiting until the last minute.<sup>99</sup>

Referral to a crisis centre is not a housing placement. Hospitals and health services are merely passing on responsibility for their patients, and creating delays, disruption and misery for people who are already in a vulnerable state.<sup>100</sup>

## Supported Accommodation

My daughter has had frequent admissions to the psychiatric ward...and I was strongly advised not to have her living with me as 'she would never grow up and become independent.' So now she shares a flat with a male alcoholic who is unemployed. She cannot live alone and cannot make friends with so-called normal people — and isolation is the worst possible plight for a sufferer of schizophrenia.<sup>101</sup>

Supported accommodation, bridging the gap between health and housing, is the single greatest need for people with a psychiatric disability. It can take many forms — ranging from people living in their own home with regular assistance from community health teams, to group homes where a support worker visits daily or weekly, to fully supervised mental health hostels.<sup>102</sup> The extent of support needed varies between individuals and at different times.

The essential components of supported accommodation are a) secure, affordable housing and b) reliable support from staff who have adequate training and resources. Beyond these core criteria there is no single housing paradigm for people with psychiatric disabilities: their needs and tastes vary as widely as anyone else's in the community. Some houses are single-sex; some cater to particular age groups; some provide individual bedrooms and others require residents to share.

The balance between supervision and independence can be difficult to find, especially when the range of accommodation options is so restricted. For example, one witness complained of her experience in a group home:

You tend to get the attitude that you are a vegetable and incapable, and get treated like a child, pushed around...because you are a bit slowed down by medication and not so capable of looking after yourself.<sup>103</sup>

However, the benefits of appropriate supported accommodation are amply demonstrated by the few mentally ill people lucky enough to have it. A number of witnesses told the Inquiry that having adequate supported accommodation had allowed them to remain stable and out of hospital for years.<sup>104</sup>

In Queensland,<sup>105</sup> Victoria,<sup>106</sup> South Australia and Western Australia, supported accommodation for people with a mental illness consists mainly of privately owned hostels.<sup>107</sup> Elsewhere the main accommodation providers are government and non-profit agencies like the Richmond Fellowship and the After Care Association. Some non-government groups own the housing they use, while others lease it from state or local government departments.



It is clear from evidence presented to the Inquiry that Australia has several very high-quality supported accommodation schemes for people with psychiatric disabilities — but not nearly enough. As one expert witness said:

There is no doubt in my mind... They are outstanding and certainly provide excellent support for people who are mentally ill. However, they only meet a small fraction of the needs that are out there... In the area in which I work we [have] about 1500 people with mental illness living in a population of 320,000. We are providing about 100 beds for people with mental illness, so we are about one tenth of the way there.<sup>108</sup>

Apart from being scarce, supported accommodation is unevenly distributed: some areas have none at all.<sup>109</sup> (As already noted, Tasmania has no long-term supported accommodation in the whole State.<sup>110</sup>) For mentally ill women with children, even short-term supported accommodation is virtually non-existent.<sup>111</sup> (Charmian Clift Cottages in Sydney is a rare example.<sup>112</sup>) A few areas, on the other hand — for example Warrnambool in Victoria — are quite well served by supervised group homes, but severely lacking in community support services which would allow many other people with mental illness to keep living in their own independent housing.<sup>113</sup>

Most non-profit supported accommodation has a designated limit on the time residents can stay. The theory is that people who have been mentally ill will move through a graded system of accommodation, becoming increasingly independent as their rehabilitation progresses.

However, reality often belies the theory. Rehabilitation for most individuals living in the community is seriously deficient — so that many do not reach their potential in the allocated time. In addition, with housing so scarce and its provision so poorly coordinated, it is rare for a mentally ill person leaving one supported accommodation program to find another one at an appropriate level. The lack of continuity after 'graduating' from a housing scheme, abruptly throwing people onto their own resources, also erodes the beneficial effect of having lived in supported accommodation. As one resident of a scheme for mentally ill women told the Inquiry:

Eventually, women receive Housing Commission accommodation, often to become more isolated and depressed. There is no follow-up worker for the purpose of helping women cope with the transition.<sup>114</sup>

In addition, the reality is that some chronically mentally ill people will never be capable of living totally independently. They need supported accommodation not just long-term, but permanently.

Evidence to the Inquiry repeatedly illustrated the need for accommodation to be suited to the residents' needs, rather than requiring people to fit in with administratively convenient solutions. People generally — whether mentally ill or not — obviously prefer to live in housing which is appropriate for their needs and lifestyle. But for people with a mental illness it is not simply a matter of personal taste. For them,

housing must be seen as not just a means of putting an affordable roof over [their] heads, but as an important part of a therapeutic system of rehabilitation and enablement that will help recovery. Housing that is really appropriate to individual needs is likely to add to stability and promote improvement, while unsuitable housing is likely to have detrimental effects in most cases.<sup>115</sup>

Even well-intentioned supported accommodation schemes can fail spectacularly for residents whose needs do not conform to the design. For example, a young woman with suicidal tendencies, living in a halfway house in Sydney, had a psychotic illness the symptoms of which included hearing voices. Her family in Wollongong received a distressed phone call from her after hours, when staff at the house had gone off duty. According to her mother,

there is someone on call [after hours], but I don't know what they mean by 'someone on call', or how it could help my daughter. I don't know whether they mean they can press a buzzer and someone will come... You see with my daughter, if the voices are too bad she can't call for help at all. If the voices are really bad, those voices will tell her not to bother.<sup>116</sup>

Another more disturbing account received by the Inquiry came from a resident of a semi-independent housing scheme. The scheme leases houses and units from the NSW Housing Department and sublets them to women with psychiatric disabilities. Residents pay the normal public housing rent, plus a moderate fee toward the cost of administering the scheme. The resident said it is 'an excellent concept, and basically sound, but for major flaws in its design and funding'.<sup>117</sup>

One of these flaws is that the staff are not trained mental health workers. Yet the need for skilled staff is especially great, because living with other mentally ill people can aggravate individual residents' conditions:

Residents are frequently more in crisis within the scheme, due to difficulties living with other women [who are] seriously ill, who are not receiving an appropriate or even qualified standard of care.

Living in this scheme is akin to a lottery: residents have little control or input about who shares with them. Tensions are often at tinderbox intensity. Seriously ill women can be

placed with anyone — often to others' detriment, or with poor hygiene and living skills.<sup>118</sup>

Such support as staff do provide is only available during business hours. This means any crises arising after hours must be dealt with by the other residents — all of whom have psychiatric disabilities themselves:

It is not uncommon for a resident to deal with another's suicide attempt, or crisis. There is nowhere else to turn... Who is around at 5am when your flatmate is vomiting into a bucket and in the throes of panic attacks? Why should I have to make fundamental decisions about whether or not my flatmate is so ill that I should call the police?

I have been a resident for two years, and have seen and experienced this phenomenon many times. I am dismayed by situations that arise, and the stress invoked for other residents because they have had to 'do the work' in providing care.<sup>119</sup>

The resident stressed that the fault does not lie with the staff:

The design of the scheme is at fault, in need of an overhaul with more emphasis on mental health experience rather than simply administrative ability...so people recognise symptoms and deal with them early — this doesn't often happen as it stands now. There needs to be more emphasis on appropriate placement of residents rather than the 'fill the bed' way of things now. (The scheme pays rent whether vacancies are filled or not.)<sup>120</sup>

The scheme does have some benefits:

The opportunity to experience some level of community, to form friendships and socialise. As well, it provides an informal setting for developing a relationship with the workers; this is invaluable for some women, who have serious difficulties with 'the system', having had harsh experiences with psychiatry and in [hospital] wards, not to mention difficulties with family and friends who don't understand mental illness.<sup>121</sup>

Nevertheless, those benefits are clearly liable to be undermined or negated by the serious deficiencies just outlined.

### **The Balance Between Accommodation and Support**

The non-government sector...is still judged on its ability to provide beds within a given area or region. Constant lobbying to challenge the notion that beds are not necessarily the issue when it comes to support needs has, so far, been unrecognised at the official level.<sup>122</sup>

Many people with chronic or severe mental illness obviously need full-time support from trained staff in a residential program. Many others, however, require less intensive support.

The term 'supported accommodation' is generally used to refer to residential support programs based in specific houses or hostels which are owned or rented by the support agency. An alternative approach is to separate the support function from the housing function — with workers who visit regularly to provide support for people living in otherwise independent accommodation.

The former approach has traditionally been taken by the Supported Accommodation Assistance Program (SAAP), which is the main funder of crisis accommodation. It is obviously appropriate for people who are literally homeless and in crisis, eg those people who would normally look to a refuge for immediate help. However, it has the drawback of being relatively inflexible: it requires people to fit the accommodation rather than vice versa. As residents become more independent they may be asked to move on, to make room for someone more disadvantaged. Frequent moving is disruptive and expensive.<sup>123</sup> On the other hand, residents who stay on in a house which offers too much support can become dependent, failing to develop the living skills they need.<sup>124</sup>

Tying support and housing together can also be inefficient if it means support is only available to people who can find a bed within designated accommodation services. For many this is impossible — due to the serious shortage of vacancies. For others it is inappropriate, because communal living does not suit their individual needs. Some people's main need is for housing itself, with only a low level of support; they may therefore be irritated — to a point which is counterproductive — by the degree of supervision entailed in having a roof over their heads.<sup>125</sup>

Recognising these problems, some disability housing groups are increasingly favouring the separation of the support and housing functions:

The After Care Association of NSW, for example, is providing fewer actual beds while increasing the number of people being supported in a variety of settings.<sup>126</sup>

Thus mental health workers go out to see clients in their homes, rather than requiring them to move into an accommodation scheme. This reflects recent recommendations that accommodation support be part of every community mental health service.<sup>127</sup> This approach is also being taken by a group of adjacent community health centres in Melbourne, in an area with one of the highest rates of psychiatric disability in Australia — St Kilda, Prahran and Southport. The centres have an Accommodation Team of three workers, who provide assistance to supported residential services and homeless shelters.<sup>128</sup>

A former hostel resident described to the Inquiry the kinds of supports which are needed:

There ought to be a visiting psychiatrist from the hospital once a week. He or she should speak with every resident... There ought to be a visiting social worker twice each week. Residents should be given advice about outings, recreation, Social Security problems, personal problems of integration, money management, future aims...direction on diet, cleanliness, personal hygiene, and housekeeping.<sup>129</sup>

This approach allows more people to be assisted, and recognises that individuals' needs for support exist along a continuum, even though their need for housing remains the same. It allows individuals affected by mental illness to have the support they need — even if they do not live in a designated 'supported accommodation' scheme, but rather in a boarding house or hostel, at home with their parents, or in public or private housing on their own. It also avoids the disruption of having to move house as a client grows more independent — instead, the level of support provided can simply be reduced.

Apart from being cheaper, more flexible, and more appropriate for some individuals, separating the housing and support functions is more consistent with the philosophy of community care and rehabilitation.<sup>130</sup> It should allow more people to live in the community, in ordinary housing, without paying the price of their illness escalating because of lack of support. It respects an individual's right to choose where to live, and avoids the 'warehousing' of people with disabilities.<sup>131</sup> Clearly, the most important consideration is that the combination of housing and support be appropriate to each person's needs — and that more intensive supervision and support be provided for people when they need it. The alternative is not only undesirable — it is uneconomical.

### **Hostels and Special Accommodation Houses**

Many of these places destroy what is left of the human spirit, and all dignity.<sup>132</sup>

Hostels are the traditional form of supported accommodation for people with mental illness. Established in the 1960s and 1970s as part of deinstitutionalisation,<sup>133</sup> hostels are larger than group homes and more institutional in character. They are often very similar to boarding houses, and suffer many of the same problems (see Chapter 11 — Boarding Houses). However, hostels are generally intended specifically to house people with some kind of disability. In Victoria (where they are called 'special accommodation houses') they provide 8500 beds, of which about one-quarter may be occupied by people with a psychiatric disability.<sup>134</sup>

The Inquiry heard numerous complaints about hostels, especially private ones. They can be expensive, and the living conditions substandard:

Unscrupulous operators [can] take advantage of this already disadvantaged and vulnerable group, both by charging high rates...and [providing] a standard of living below that which would be tolerated by other members of the community: by overcrowding, high levels of noise, and the lack of specialised facilities to deal with the behavioural problems of some patients and minimise the impact of that behaviour upon other residents.<sup>135</sup>

Hostels tend to foster a sense of dependence, by assuming total control over residents' meals, medication, finances etc. This can have a particularly damaging effect on people who previously lived independently, but who have been hospitalised and then discharged to a hostel: they risk losing whatever living skills they previously had.<sup>136</sup>

Notwithstanding that hostels are intended specifically to cater for the mentally ill — and that they are home to many of the most severely disabled members of our community — they generally offer a dismally low standard of support. In fact, many are not actually providing supported accommodation, but only room and board. The 'support' in 'supported accommodation' is intended to come from appropriately trained and resourced workers. But the reality is quite different:

There are very few activities for the residents of hostels, and very often there is no regular psychiatric follow-up... And none of them to my knowledge have any trained staff. At night there would be one person on call; during the day other staff provide meals and do the cleaning...<sup>137</sup>

To work in a special accommodation house one does not necessarily need any particular qualification. The staff [to resident] ratio called for by regulation is 1:30. The support provided... [is] therefore also somewhat spartan.<sup>138</sup>

One expert witness pointed out that recent legislative amendments require the operators of special accommodation houses which look after psychiatric patients or the elderly to have rehabilitation plans for those people. But 'most of them are ill-prepared to develop or deliver such a plan.'<sup>139</sup>

Indeed,

The degree of disadvantage is immense... To some extent these special accommodation houses have in years past simply replaced the back wards [of psychiatric hospitals] for some people who, in the absence of casework, are going to stay in that state.<sup>140</sup>

For many hostel residents, 'treatment' for their mental illness consists solely of a regime of medication. This medication is generally given out or supervised

by staff with no relevant training whatsoever. At the very least, hostel staff should be appropriately educated for this task.<sup>141</sup>

A lack of trained staff on the premises may be acceptable if hostels had regular, adequate support from the community mental health services. But that support is rarely there: most community health teams are understaffed and can only visit individual clients by specific request — usually in a crisis. They have very little time for advocacy or to help mentally ill people link up with the other services they need.<sup>142</sup> For example, in the Morisset area of the Hunter Valley, close to the main psychiatric hospital, some 200 people, mainly older, chronically mentally ill, live in hostels. Most have no access to rehabilitation programs of any kind, and many receive no psychiatric follow-up at all.<sup>143</sup>

Witnesses said mental health workers are acutely aware of this endemic neglect, but put the blame on the distribution of mental health resources, which still heavily favours the psychiatric hospitals and allocates very little to people living in the community. This is blatant discrimination in the allocation, availability and dispensing of the resources sick people need for a decent existence.<sup>144</sup>

In only one State, Western Australia, was it claimed that the standard of living in hostels is generally acceptable:

The physical standards of these private hostels are quite high — some are very high. There is 24-hour cover, medication is stored and given out, all meals are provided, the physical medical needs are met by visiting GPs, and psychiatric care is delivered by regional psychiatric clinics or psychiatric hospitals.<sup>145</sup>

Standards are monitored by the State Health Department and by a board of visitors, analogous to the official visitors in psychiatric hospitals:<sup>146</sup>

[They] visit each hostel about every six weeks, usually in the evening around supertime, 5[pm] or so. That is unannounced, so people do not know they are coming. There are also occupational therapists who go into most hostels either to pick people up, to take them out or otherwise [work with them].<sup>147</sup>

A witness from the WA Health Department claimed most hostel licensees fulfil their responsibilities to clients, including liaising and co-operating with mental health teams:

I do believe that the present system of hostels is needed, it is very efficient, it offers a necessary service and is pretty well run... However, there are some shortfalls with the system as there are with any system.<sup>148</sup>

However, these claims were contested. According to the WA Branch of the Australian Association of Social Workers, not all licensees have fully cooperated with the Department on standards of care. The Association pointed to particular problems — including untrained staff, lack of privacy and high cost for hostel residents.<sup>149</sup> Certainly the rent charged can take most of residents' income: WA regulations set the maximum rent at 87½ percent of the basic pension, plus the full amount of State Government rental assistance.<sup>150</sup> Individuals paying this maximum rate are left with only \$19 per week after rent and meals are paid for.<sup>151</sup>

So basically after paying for cigarettes there is nothing left at all.<sup>152</sup>

In addition, some hostels are very large (the largest has 70 residents),<sup>153</sup> and many require residents to share rooms:

A couple of the [private] hostels might have one or two single rooms but, by and large, they are shared rooms. And a lot of hostels have two to a room, but there are others that have three, four, five or even six to a room — which, I might add, is okay with the local council; it meets the requirements.<sup>154</sup>

Not all of Australia's hostels conform to this bleak description; the Inquiry also heard evidence from conscientious hostel operators who try to ensure their clients have access to rehabilitation and other community mental health services.<sup>155</sup> But the evidence clearly established that such facilities are the exception.

One indicator of the prevailing poor standards is the significant vacancy rate in hostels, even in the midst of a serious shortage of accommodation. There are some hostels in NSW where mental health workers would not even consider referring a mentally ill person to live.<sup>156</sup> The supported accommodation houses in Melbourne's St Kilda are said to have a 20 percent vacancy rate, indicating consumer discontent even among people who have virtually no other options.<sup>157</sup> Similarly, in Perth, many younger mentally ill people refuse to go to hostels which they consider too expensive and lacking privacy.<sup>158</sup>

The Australian Association of Social Workers expressed concern about private sector provision of housing for people with psychiatric disabilities:

This can lead to a conflict of interests in some cases where a profit-making business has the day-to-day responsibility for a vulnerable group of people.<sup>159</sup>

The Association believes supported accommodation should be run by government or non-profit groups:



In this way there would be lower charges, better types of accommodation (because charitable groups can access [government] funds; in the case of disagreements there can be an appeal to a government body or board of management, instead of just to the private owner, and therefore conflicts of interest would be less likely.<sup>160</sup>

## **Group Homes**

Group homes usually accommodate three to six residents, with a support worker either living in or visiting regularly.<sup>161</sup> Residents have the normal responsibilities of daily life, such as cooking and housework; but they also have assistance — not only in managing their mental illness, but in areas such as budgeting and dealing with the Department of Social Security.

Group homes can be expensive to run: some believe 24-hour supervision is needed to manage medication and prevent problems.<sup>162</sup> They are also not suitable for all mentally ill people, because they require a high level of motivation and responsibility.<sup>163</sup>

Nevertheless, group homes are the type of accommodation preferred by members of many community mental health support groups. While there are relatively few of these homes, those that exist are strongly supported:

I cannot commend [it] too highly. The charge leaves the occupants with enough money for other matters. The location was within easy reach of shops, of places where you could have adult education courses, and activities such as art classes.<sup>164</sup>

As already indicated, one area well provided with group homes is Warrnambool, in Victoria, where the Glenelg Psychiatric Service has 21 homes which 'almost meet the need' for the area.<sup>165</sup> These provide supervised accommodation in State Government houses, operating as an integrated part of the mental health service. Four of the homes are actually in the grounds of a hospital. A fifth is close to the rehabilitation ward. Patients 'graduate' to it from rehabilitation, then progress to other group homes or out into the community. (The remaining 16 houses are in the community.)<sup>166</sup>

## **The Supported Accommodation Assistance Program (SAAP)**

SAAP is the main source of funding for crisis programs for homeless Australians. On any one night, according to government estimates, SAAP services accommodate approximately 10,000 people.<sup>167</sup> A joint program between the Commonwealth and States, SAAP provides recurrent funds for salaries, rent and operating costs. A related facility, CAP (Crisis Accommodation Program), provides capital for building or buying accommodation. Most SAAP services are run by non-government organisations.<sup>168</sup>

The program has had a major impact in increasing the number and scope of services for homeless people. In the 1991-92 financial year it spent \$160 million providing about 1600 services throughout Australia.<sup>169</sup> (The first phase of SAAP began in 1985; SAAPII began in 1989.)

There is no doubt that a significant number of people affected by mental illness make use of SAAP-funded services — including youth and women's refuges, homeless shelters and day centres. However, these are generic services designed to help people who are not mentally ill — so they are frequently ill-suited to the needs of those with psychiatric disabilities. SAAP does not fund any refuges or services specifically for people with mental illness — in fact its guidelines specifically exclude such services from eligibility for funding.<sup>170</sup> The guidelines even prevent SAAP from funding a mental health worker to join the staff of a refuge or shelter, or training for existing staff in how to deal with individuals affected by mental illness.

Thus the homeless mentally ill — one of the most vulnerable and needy groups in our community — are excluded from the major funding program for the homeless. Yet such individuals are among those most likely to fall into homelessness (see Chapter 18), and least able to escape it again. The consequences of homelessness are also worse for them than for others — including exacerbation of their illnesses.

The rationale for SAAP excluding services for people with mental illness is that 'there are, or should be, other programs that meet [their] needs'.<sup>171</sup> Unfortunately, however, these other programs rarely exist at all.

SAAP operates 'after the event', providing services for people who are already homeless and in crisis. Preventing homelessness in the first place is not its aim.<sup>172</sup> The first discussion paper produced in the course of a current national evaluation does suggest that the program could expand to cover prevention of homelessness. However, according to the authors,

The causes of homelessness are many and varied but underlying factors include a lack of economic opportunity, family breakdown, domestic violence, abuse, unemployment, lack of social power and limited employment and educational opportunities.<sup>173</sup>

Mental illness does not appear in the list. Yet it is an important cause of all the factors listed, and of homelessness itself.

Programs funded by SAAP have traditionally been short-term accommodation for people who are temporarily homeless, aimed at enabling their return to

independent housing. It is 'transitional' accommodation, offering homeless people the support they need while in crisis, but assuming that

in general these needs will also diminish over time and/or will be replaced by ongoing community support structures.<sup>174</sup>

The assumption is that homeless people only require supported accommodation for a limited time before 'getting back on their feet'. While this may be generally true, people who have a mental illness will often require more protracted support. As the assistant manager of one refuge told the Inquiry,

I think [secure accommodation] is a prime factor, because the first thing they want to know is 'how long can we stay?'.<sup>175</sup>

In addition, the progress of individuals affected by mental illness is unlikely to involve a smooth upward path toward independence; mental illness, often episodic, frequently involves relapses or setbacks.

Since these aspects of SAAP are open for reconsideration in the national evaluation, it is imperative there be a recognition that medium and long term accommodation is needed for many SAAP users to make the transition to independent housing. Encouraging longer term solutions would be of particular benefit to people with psychiatric disabilities.

## **Special Needs Groups**

Such accommodation as is available for people with a mental illness is often geared toward

'middle-of-the-road patients...people who impose no difficulty and who are to some extent model patients'.<sup>176</sup>

Some groups of mentally ill people have greater needs — and therefore are far harder to place. These groups include: Aboriginal people; adolescents; women with children; people with dual and multiple disabilities and forensic patients.

### **Aboriginal People with Mental Illness**

Aboriginal people discharged from psychiatric facilities face particular problems obtaining accommodation. One reason is discrimination by hostels catering for people with disabilities:

We ring up and say, look is there a place available, this is the Aboriginal Medical Centre; they say, 'Oh I'm sorry — we're full.'<sup>177</sup>

The accommodation that is available is frequently inappropriate. There appear to be virtually no accommodation programs for Aboriginal people with a mental illness. But the usual practice of turning patients out to fend for themselves is especially unsatisfactory for Aboriginal patients who — according to evidence presented to the Inquiry — often have a drug or alcohol addiction as well as a mental illness.<sup>178</sup> If they come from a community where alcohol abuse is widespread, returning home may result in exacerbation of their illness and/or rapid readmission to hospital.<sup>179</sup>

We had no choice but to return [him] to the mission area that he came from, and straightaway he was back involved in alcohol and drug-taking... The placement was totally inadequate.<sup>180</sup>

The burden imposed on the families of these patients is immense:

When they come out of the institutions it's back into the same old things... it's very frustrating for the community and the family. They take them back to their homes for a while — and because there's sometimes two to three families living in one house, it's very upsetting for the children.<sup>181</sup>

So desperate is the housing situation that some Aboriginal health workers shoulder the burden personally. A health worker from one Aboriginal Medical Service told the Inquiry:

My husband and I take patients home because there is just nowhere for them to go. I had a lady from Walgett who was 19 years of age, who...was there [in hospital] five days before the social worker rang me and said, 'Look we're discharging her tomorrow, we've got nowhere to put her, can you give us some idea?'... I took that lady home with me for three days while I organised the mental health nurse from Walgett Hospital to come down and help me and pick her up and take her back home.<sup>182</sup>

### **Young People with a Mental Illness**

We have quite a large number of young people...who have psychological and psychiatric disorders, and quite frankly there is absolutely nowhere in town where we can place them in supported accommodation.<sup>183</sup>

Accommodation for adolescents who become mentally ill is one of the most serious deficiencies in the mental health system. Mental illness can easily lead young people to become homeless and be picked up by police. Police officers frequently try to place disturbed young people in youth refuges. However, this may achieve nothing more than passing the problem on: many refuge workers

are no better equipped for dealing with severe mental illness than police. As one former refuge worker in Adelaide told the Inquiry, refuges are seen as the 'bottom line agencies':

When anyone had a kid to refer, a street kid that was in danger, [who] had come in for the hype of the city and was off their face or whatever — the police and crisis care brought them to us. So if we couldn't contain it, there wasn't anywhere else.<sup>184</sup>

This witness described several frustrating attempts to find treatment and accommodation for mentally ill teenagers who had been inappropriately referred to her refuge. One example involved a young woman who was so seriously disturbed that refuge staff felt she needed 24-hour care. Her behaviour included incoherent babbling, dribbling and injuring herself by running into walls.

We took her to the Royal Adelaide Hospital as our first port of call, because she'd actually dislocated her arm. As she was waiting for treatment, the doctors were given a lengthy account of her presenting behaviour at the shelter... The youth workers suggested quite strongly an assessment and perhaps detention in the hospital. Doctors attended to her physical injury, made an on-the-spot diagnosis that it wasn't psychiatric and asked us to remove her from the hospital bed...<sup>185</sup>

Frantic episodes like this one are exhausting and distressing for workers who are supposed to be providing a stable, supportive environment for other homeless youths already under some pressure. Many refuges feel they simply cannot jeopardise the wellbeing of their other residents by accepting a mentally ill young person (see Chapter 18 — Homeless People). If the delay is long enough the young person's condition may deteriorate and require temporary admission to hospital — but this is at best a short-term solution. The need for crisis accommodation for young people remains largely unmet. (See Chapter 20 — Children and Adolescents.)

Longer term accommodation is also practically non-existent. Some families are unable to cope with caring for an adolescent with mental illness — especially if it means travelling long distances for treatment, sometimes on a daily basis. Frequently the young person ends up being made a ward of the State — but even then there is very little accommodation outside the penal system.<sup>186</sup>

Young people who become mentally ill are very easily 'lost to the system' — becoming homeless and doing without regular income or health care. Adolescents released from institutions — whether psychiatric units or juvenile detention centres — too often find no safety net awaiting them:<sup>187</sup>

[And] if they're on medication, you have the ludicrous situation where a mentally ill young person is not adequately housed but has two pocketsful of medication, and that puts young

people in the street at extreme risk. That young person is either not going to be hanging on to his medication for very long, or is not going to be taking it properly.<sup>188</sup>

Evidence to the Inquiry indicated that homeless, disturbed adolescents are poorly served by traditional services. Young, intelligent schizophrenia sufferers, for example, frequently do not even see themselves as mentally ill. Many disturbed young people have been in the refuge system and have no links with their families; they may be extremely streetwise, yet lacking in social and living skills. They need reliable long-term accommodation with trained people providing support. But services must also be flexible enough to recognise 'that adolescents need to challenge everything':<sup>189</sup>

There is sometimes a driving force within a young person to escape what they perceive as yet another control over their lives. Permanency has not been part of their living model and it is difficult to achieve. Initially they have little respect for the property where they are housed, they express a lot of anger — and staff [working with them] need a lot of support during the settling-in period.<sup>190</sup>

One South Australian witness gave an example of the disrupted accommodation pattern followed by many disturbed adolescents:

He was placed in a string of foster homes which broke down quickly, and then in a facility for intellectually disabled male offenders. He had no intellectual disability — and may not have been mentally ill — but he had serious emotional and mental health problems which didn't fit any services.<sup>191</sup>

This witness told the Inquiry that for young people who become mentally ill, South Australia has virtually no appropriate accommodation:

St Stephens therapeutic shelter has four beds, but staff aren't trained to deal with mental illness. [Another agency] does take the mentally ill, and has trained staff on duty 24 hours, but a long waiting list.<sup>192</sup>

### **Mentally Ill Women with Children**

What is the greatest gap in the service that you see now?

What the women's forum has been advocating for quite some time — in fact, about ten years — is that we need some sort of supported accommodation for women with psychiatric mental illnesses in the first instance so they can go there with their children.<sup>193</sup>

Crisis accommodation for women with children is generally provided by women's refuges, but those refuges are increasingly reluctant to accept women with a psychiatric disability (also see Chapter 18 — Homeless People). At the

same time, those crisis facilities which accept people with a mental illness usually will not accept children.

In Darwin the Inquiry was told that mentally ill women fleeing domestic violence, or who become homeless for other reasons, have virtually no emergency accommodation options:

There is an urgent need for the provision of accommodation for women suffering domestic violence and mental illness... 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>194</sup>

Evidence in Tasmania also indicated that that State has no supported accommodation at all for women with mental health difficulties who have children.<sup>195</sup> The one shelter in South Australia (Catherine House) that accepts women with a mental illness — will not do so if they have children.<sup>196</sup> This rules out a large proportion of mentally ill women. Another possibility is boarding houses — but, being mixed-sex accommodation, these are usually not appropriate for women escaping from violent men.<sup>197</sup> Most boarding houses will not take children either — and few could be considered to be supported accommodation.<sup>198</sup>

### **People with Dual or Multiple Disabilities**

Mentally ill people who also have another disability are particularly disadvantaged in finding and keeping suitable accommodation. Those with an intellectual disability or a brain injury are especially vulnerable.<sup>199</sup> A witness in Adelaide cited the case of a 15-year-old intellectually disabled girl who had been sexually abused as a child and was apparently mentally ill as well:

When she was taken into care she was put into several foster placements and they failed. A long-term residential young women's program was approached... Its focus was on child sexual abuse. [But] while she was on the program her behaviour did not improve — in fact it regressed. She actually became more angry, less happy, and felt the difference between herself and the non-intellectually impaired young women...

At this stage the intellectually disabled services council had been involved and they deemed her to fit their model — but she couldn't use the service until she became 16 years old...

There was a cottage program at Hillcrest [Hospital] for the intellectually disabled: that was explored as an option, but things escalated into a crisis before more could be done. She had a fascination with knives and had spent one whole night with a Staysharp deciding who she was going to attack... The staff clearly did not have the skills and the service wasn't appropriate to treat her real condition... They were trained to deal with child sexual abuse. She didn't seem to fit any service at that time.<sup>200</sup>

Another extremely difficult group to house is mental illness sufferers with drug or alcohol addictions. For example, some housing schemes accommodate people with a mental illness — but not if they also have an alcohol or drug addiction. The same people might also be rejected by residential addiction treatment schemes. (Such programs typically require participants to be totally free of drugs, including psychiatric medication.)

If they are admitted to substance abuse treatment programs at all, they frequently refuse to comply with treatment:

Problems between them and the proprietors of hostels arise, and as a result people develop bad reputations, whether rightly or wrongly, and [then] they're extremely difficult to place.<sup>201</sup>

Such a 'reputation' can extend throughout a city, and especially through the welfare and supported accommodation agencies. Even the charitable agencies which provide emergency accommodation may be reluctant to take people with a mental illness and a substance addiction.<sup>202</sup>

There is now a list, for want of a better way of putting it, of people who have become labelled as unworkable. No agency will take them, no agency addresses their issues, and they have nowhere to go.<sup>203</sup>

One solution is to place them in hostels away from the area where they are known — and especially out of the city, 'where there are very few hotels, very few chemists, and overall very few temptations for this particular group'.<sup>204</sup> While this approach has the advantage of reducing access to alcohol and drugs, it can also be a 'very inadequate placement', because it removes these vulnerable individuals from their families and friends:

These people need a specialised kind of placement, but certainly not as far away as that.<sup>205</sup>

### **Forensic Patients and Those With a History of Violence**

Individuals with a history of violence and mental illness may be condemned to live in hospital long after their behaviour becomes manageable with medication. The label of 'potentially dangerous' is difficult to shed — even specialist residential programs run by mental health services will reject people who have been dangerous in the past, because staff numbers are too low to guarantee appropriate supervision.<sup>206</sup>



This means the only accommodation option for formerly violent patients may be with their families — who generally have no training in mental health care and can offer little in the way of rehabilitation.

Similarly, forensic patients (mentally ill people who have been charged with or convicted of an offence) need high levels of supervision, rehabilitation and support to allow them to reintegrate to the community. If that support is not available, there is simply nowhere they can live successfully.<sup>207</sup> A witness in Newcastle told the Inquiry there were forensic patients remaining in Morisset Psychiatric Hospital — despite the Mental Health Review Tribunal's opinion that they should be treated in the community — only because there were no other facilities for them.<sup>208</sup>

The long waiting time for supported accommodation has drastic consequences when a person affected by mental illness is convicted of an offence for which a community service order is normally the sentence. The magistrate may want to order community service — but if the offender has no secure accommodation, that sentencing option is not available. Prison becomes the only choice — however inappropriate or harmful the effects may be.<sup>209</sup>

The same problem arises when a prisoner is due for release on parole:

being placed on a waiting list for some form of accommodation [isn't] adequate for the purposes of the parole order to be granted.<sup>210</sup>

Witnesses in Melbourne, recounting to the Inquiry the experience of the Epistle Post Release Service in attempting to establish a halfway house for former prisoners who had had a mental illness, said it is virtually impossible for such individuals to organise supported accommodation in the community. Most supported accommodation services have a complicated referral process which, among other things,

usually means going out to the accommodation, visiting it a number of times and often having a meal with residents... Coming from custody on a leave, [even] if that could be arranged, is not the best way to meet your prospective housemates — especially if you're escorted in handcuffs. It adds to the perception that the person's probably violent and very dangerous.<sup>211</sup>

When such prisoners have served their sentences, they are released into the community with no supervision or follow-up:

Often if they have drifted into low-cost accommodation then it's very hard for them to keep appointments at local community health clinics...and so they tend either to relapse

or drift back into an offending pattern of behaviour, and are either returned to prison or, in some cases, back to a psychiatric institution.<sup>212</sup>

As with Aboriginal people, ex-prisoners frequently find discrimination excludes them from the services they need:<sup>213</sup>

The first problem that they encounter is getting accommodation, especially with services set up to help psychiatrically disabled people. There appears to be a resistance to psychiatrically disabled people who are ex-prisoners.<sup>214</sup>

It's the perception that they're violent.<sup>215</sup>

Another problem for this group, as for so many individuals affected by mental illness, is the lack of co-ordination between government departments:

If one goes to the Health Department, [they say.] 'They are ex-prisoners, isn't that the responsibility of Corrective Services?' If one goes to Community Services, they say, 'Well, we've been told from higher up that we're not able to help either ex-prisoners or people with psychiatric disabilities.'<sup>216</sup>

[The Department of] Housing says, 'We are only in the business of providing the physical accommodation. If you want to provide support, go to Community Services, go to Health or even to the Office of Corrections. We are only in the business of providing the housing stock.'<sup>217</sup>

The supported accommodation that does exist for mentally ill ex-prisoners falls far short of the demand. For example, the Epistle Post Release Service in Melbourne can accommodate 13 psychiatrically disabled ex-prisoners, who stay for 30-40 days.<sup>218</sup> But this is the only such service, and at least 200 prisoners in Victoria have a serious mental illness.<sup>219</sup>

## **Model Services: Supported Accommodation**

People who become mentally ill quite often lose living skills they may have had prior to the illness — but these, we believe, can be regained within a supportive, hopeful, caring environment.<sup>220</sup>

### **The Supported Accommodation Network in St Kilda**

Crossroads, an accommodation program for the chronically homeless run by the Salvation Army in Melbourne, houses about 115 people each night. The program operates a crisis accommodation centre, a youth refuge, long-term youth housing in State Government flats, and adult accommodation in boarding houses and community houses. A crisis contact centre in St Kilda provides

assessment and referral, crisis intervention, material aid, emotional and domestic support, and a meal program feeds 200-250 people each night. Crossroads also has a skills training and employment program for homeless people.

Crossroads' pilot housing program for people with a psychiatric disability is called SANS (Supported Accommodation Network in St Kilda). The SANS model focusses primarily on what support mentally ill people need, rather than what their specific diagnoses are. Staff told the Inquiry they are concerned that the process of classification can have the effect of 'locking people out of networks of support'.<sup>221</sup>

[Mentally ill people] are identified and labelled as suffering particular disorders, with little examination of their lifestyles in context. It's a system which not only defines people's problems and behaviour, but [also] clearly determines their future options on the basis of scanty evidence.<sup>222</sup>

SANS therefore operates on a 'key worker' principle — to provide individuals with an integrated, supported accommodation service. This means that instead of expecting clients to seek aid for specific problems from a psychiatrist, a social worker, a housing officer etc:

we're asking our workers to own the whole ball game...and use other support services only in a secondary capacity.<sup>223</sup>

Another important feature of SANS is that 'there's no eviction clause':

Once we accept them we will not drop them, and we will track them through either prisons, interstate or psychiatric services and hospitals... we will always offer a response once they've come out [of the formal mental health system].<sup>224</sup>

SANS believes the essential focus must often be on maintenance rather than cure:

We accept the individual for who they are...accepting their worst possible behaviour as well as their best possible behaviour... We have no illusions of cure... [A] lot of people are just not going to change, are just not going to be the John and Mary citizens that we'd like them to be.<sup>225</sup>

SANS is, in essence, a small, flexible program which leases accommodation for its clients, then concentrates on giving them the support they need to stay there. It usually accommodates only eight clients at a time, but they come from the most difficult client group — suffering chronic, long-term, severe mental illness

which otherwise would be managed poorly (if at all), and at enormous cost, by frequent crises and readmissions to hospital.

Staff gave the Inquiry several examples of their success with clients who were undeniably 'hard cases'. One individual had been admitted to a psychiatric hospital 53 times in six months. After two years in the SANS network, his admissions averaged about three per six months. Another person who had been repeatedly in and out of hospital for over 18 years has now been stable in the community for seven months. A man who for four years never stayed anywhere longer than two months, has lived where he is now for eight months.

What that indicates to us is that if you can provide an intensive, resourceful sort of approach to the individual, in which 1) you're tracking them through; and 2) you're stable and will always be there — then I think you can make inroads.<sup>226</sup>

### **Independent Community Living Association: Rotorua**

'Rotorua' is a block of flats at Bondi Beach in Sydney, where 22 people with long-term psychiatric disabilities live. It is also an illustration of the battles which mentally ill people fight to find and keep appropriate accommodation, and a monument to the confidence and determination of a small group of community mental health workers.

The original building was a private boarding house in Bondi Junction. While the premises were run down, Rotorua transcended the boarding house norm in that it had a capable and caring manager, and was considered a well-run, therapeutically sound mental health resource, highly valued by its residents and by mental health agencies in the area.<sup>227</sup> The house had strong links with the local community through residents' extensive use of facilities like the library, local milk bar, RSL club and community health centre.

In 1984 the building was sold. This was a common occurrence in the property boom of the 1980s, which left many boarding house residents homeless when they could not find anywhere else suitable to live. For the residents of Rotorua, who had lived together for ten years, uprooting and relocating was likely to prove disastrous:

[They] would most likely be rehoused outside their community and their health and social network. They would be at extreme risk of deterioration in their mental health, with subsequent hospitalisation and/or increased use of health services. Whatever direction was taken, their continued ability to live in the community would be jeopardised.<sup>228</sup>

A handful of mental health workers, calling themselves the Independent Community Living Association (ICLA), were determined to avert this. The

residents wanted to stay together as a group; the Rotorua community had become their 'family' over the years. But finding appropriate supported accommodation in the Bondi area for a large group of psychiatrically disabled people, many of them elderly and all of them poor, was a major undertaking.

The ICLA appealed to State and Federal government departments for help, but as usual:

we found ourselves against the 'wall' of the establishment... confronted by bureaucratic 'newspeak' ('Yes, your project is worthwhile but you fall outside our guidelines'), with one department emphasising another department's responsibility.<sup>229</sup>

For example, supported accommodation for people with psychiatric disabilities ordinarily would qualify for assistance from the NSW Department of Community Services. ICLA decided the preferred form of accommodation was a block of flats, where the residents would still be together but also develop greater independent living skills and lead more normal lives. However,

The project did not qualify for financial assistance from the Department... they [would] have contributed to running costs if the residents were accommodated in a series of geographically separated group homes... [But] the Department did not consider residents living in units in one block of flats as being normalising.<sup>230</sup>

Eventually, after a traumatic eviction, endless lobbying and 18 months in interim accommodation, ICLA did get a block of flats, rented from the Department of Housing, and founded the new Rotorua. The residents now have a permanent home in their traditional area, with none of the institutional disadvantages of boarding houses:

The change in environment and daily living routines has engendered changes in residents' behaviour and attitudes. Residents are now responsible for their own units. During the first day in the new premises, one resident requested a broom to sweep her kitchen, which was remarkable as she had previously shown little interest in her environment.

The residents have invited guests from a local convalescent home...for afternoon tea. The 'social noise' would have rivalled any cocktail party.

That fact that people are required to knock, and that residents have a choice as to who gains entry to their home, increases the sense of control and ownership of their living space. Personal keepsakes are appearing in loungerooms as the residents extend ownership to previously public areas.<sup>231</sup>

Residents pay Housing Department rent plus a fee to cover electricity, groceries, etc. They do their own cooking and housework, with help from staff and volunteers when necessary. They have hobbies and are involved in local

neighbourhood activities; some also have ordinary paying jobs. As in any community, residents have different skills and abilities which they use co-operatively.

Rotorua has two full-time and one part-time staff (including the original Rotorua manager), funded by the Health Department. Staff manage the facility, help solve conflicts, organise the grocery shopping, teach living skills, supervise medication and keep in close contact with residents' caseworkers at the community mental health service. Rotorua also receives support from volunteers, offenders serving community services orders, mental health students on placements, and from the local council, police and community groups.

The residents are living much more independently — and happily — than they or their caseworkers would previously have thought possible. Hospitalisations have also been reduced.

ICLA members told the Inquiry they still have some worries about maintaining Rotorua — the Health Department funding does not cover the cost of replacing furnishings as they wear out, for example, and the operation is slightly understaffed, relying heavily on the good will and unpaid overtime of its workers.<sup>232</sup> However, the project is an undeniable success. On the same principles, ICLA has also established another similar block of flats, a hostel and several group and individual houses, accommodating about 80 people in total. Not surprisingly, there is a waiting list of prospective residents.

### **Richmond Fellowship of Victoria (RFV)**

Among the anger and frustration expressed by witnesses describing the search for appropriate accommodation, the Richmond Fellowship provided another rare example of consumer satisfaction.

[My daughter] has been very fortunate in the last year... she has gone into the Richmond Fellowship House. She went from there to a satellite house and she is now on the point of buying her own flat with the money from the sale of the [previous] house. I am not sure that she is going to be able to manage this but it has got to be tried.<sup>233</sup>

The Fellowship operates in five States and the ACT, catering specifically for people with psychiatric disabilities. The largest branch is the Richmond Fellowship of Victoria (RFV), which is also that State's largest community-based provider of services for the mentally ill. It runs seven residential programs, an outreach service supporting people in their own homes, and a day program, serving a total of about 200 people with mental illness. The primary emphasis is on providing a community — somewhere to belong:

This is a place — an environment — where individuals can actually feel attached, heard, seen, valued, tolerated — a place to BE. We see this is as a necessary ingredient if individuals are to be able to move through their struggles and eventually feel and believe they have got somewhere.

Obviously there may be therapeutic spin-offs to this in relation to developing social skills, self-esteem, confidence, etc. However, the main emphasis or priority is that this community be a relative haven from the consumers' current life storm, and that this haven be available to them for as long as they need it.<sup>234</sup>

RFV recognises that people with psychiatric disabilities need more than merely help with practical living skills: they have difficulty coping with the emotional issues involved in ordinary daily life, like dealing with anger, conflict and intimacy. The Fellowship therefore aims to help clients develop insight into their condition and the problems they are struggling with — and also to become aware of their own patterns of coping.

This provides opportunities for consumers to heighten their awareness of how these themes crop up in their day-to-day life, and how they currently tend to deal with them. It also highlights that for much of what all humans struggle with there are no set formulas or solutions, but rather a whole variety of options with varying consequences.<sup>235</sup>

[Thus] consumers will at least have some moments in their life when they actually experience empowerment. And we are optimistic that, over time, if they are with us long enough some of it will stick.<sup>236</sup>

Since individuals have quite disparate needs, RFV offers a range of housing options for people of different ages and different levels of disability. One provides permanent accommodation for older people who have been deinstitutionalised; two are for adolescents and young people; several others provide different levels of support for those in their 20s and 30s. Some residents move through different types of RFV housing as their rehabilitation progresses. There is also transitional accommodation which focusses on living skills for people who are about to go into independent accommodation.

Apart from the residential programs, RFV runs an outreach scheme and a day program for people living in ordinary private or public housing. These programs effectively turn independent housing into supported accommodation. In 1992 a pilot outreach scheme was approved for young homeless women.

Two other important aspects of RFV programs are worth mentioning. The first is an emphasis on continuity: most clients are involved for at least two to three years, and some for much longer. The second is a commitment to consumer rights: eg giving clients opportunities to influence the development of

programs, as a means of reducing the 'mental health apartheid' which separates mental health professionals from their consumers.

## **Model Services: Accommodation Support**

### **Community Accommodation Support Service (CASS)**

The Community Accommodation Support Service (CASS)<sup>237</sup> is part of the South Australian Health Commission. The service assesses each client to determine what type of accommodation is appropriate and develop a support plan for each resident. Social workers provide help with managing finances, social activities, personal relationships and accessing community services. Occupational therapists run skills programs for independent living.<sup>238</sup> CASS support staff provide day-to-day assistance where needed and supervise residents' activities.

CASS staff assist other agencies in planning, developing and operating supported accommodation for people with functional disabilities resulting from a mental illness. The Service also monitors standards of care in privately-owned mental health hostels licensed under the South Australian *Mental Health Act*, and hostel managers are offered consultation and training seminars. Community support services are provided to residents in some private boarding houses in Adelaide, and to tenants in public housing owned by the State Housing Trust.

In addition, the service provides assessment and case management for residents of a long-term shared unit project owned by the South Australian Association for Mental Health.

CASS workers have identified specific resource problems which hinder the effectiveness of their work. These include a lack of suitable community venues where residents can go for structured activities; lack of awareness in the community about the residents' difficulties; lack of finances; and limited staff resources:

We are currently able to offer program activities to a minimal number of people in a minimal number of boarding houses in a small designated area... The need to expand is urgent, given the social isolation of the environments [not yet being covered].<sup>239</sup>

### **The Crest Project**

The Crest project, run by the Outer East Council for Developing Services in Mental Health in Melbourne, provides various levels of support to 29 people in public housing accommodation in the surrounding area and a further 20



people who are renting accommodation on the open market. Crest is also encouraging other community organisations to provide accommodation, for which Crest's workers will provide support to residents.<sup>240</sup>

### **Safe Accommodation for Everybody (SAFE)**

We believe many people with psychiatric disability can be successfully integrated into the community through the use of private hostel accommodation. However, there will need to be guidance and assistance with daily living.<sup>241</sup>

In Brisbane, a group called Safe Accommodation for Everybody (SAFE) has taken a novel approach to providing support to people with psychiatric disabilities. SAFE persuades the owners and managers of private hostels, homes and special accommodation facilities to promote the provision of affordable accommodation with support or supervision, thus improving residents' quality of life:

We believe their rights and interests are best served by living in an integrated community with support from various government agencies, together with community programs...so that hotel managers can seek professional help for residents when required... Features of accommodation offered by SAFE affiliates vary, but there is a responsible adult in attendance who ensures that the resident is receiving the support he requires — assistance with financial affairs, contacting friends and relatives or health professionals, help with medications, which may be numerous or complicated.<sup>242</sup>

1. Name withheld. Oral evidence, Newcastle 9.7.91, p788.
2. Name withheld. Oral evidence, Sydney 21.6.91, p548.
3. P O'Brien, Brisbane Psychiatric Social Workers Interest Group. Submission, p1.
4. Dr Chris McLeod, PALA. Oral evidence, Sydney 21.6.91, p625.
5. Joy Said, Executive Director, After Care Association of NSW. Oral evidence, Sydney 17.6.91, p36.
6. Schizophrenia Fellowship of South Queensland. Submission, p16.
7. Maggie Dobson, Schizophrenia Fellowship of South Australia. Oral evidence, Adelaide 22.10.91, p306.
8. eg Dobson, op cit, p306; McLeod, op cit, p624-5.
9. Noni Hodgson and Alan Rose, Mental Health Services, Hunter Area. Submission. Also Noni Hodgson, oral evidence, Newcastle 9.7.91, p832.
10. id. This problem reportedly also affects young mentally ill people. 'Well patients use hospital as hotel', *The Mandy Daily* 3 Sept 1992.
11. Alliance for the Mentally Ill, *Housing in the Community for People with Chronic Mental Illness*, Consumer Issues in Mental Illness No 2, p2.
12. Hodgson and Rose, op cit, p2.
13. B Horwood, Melbourne District Health Council. Oral evidence, Melbourne 8.4.91, p117.
14. Hodgson and Rose, op cit, p2.
15. Ruth Breen, Accommodation Services, Excell Enterprises. Oral evidence, Port Lincoln 18.10.91, p115.
16. ibid, p117.
17. Vicki Gould, Family and Community Services Department. Oral evidence, Port Lincoln 18.10.91, p16.
18. John Pyrke, Richmond Fellowship. Oral evidence, Hobart 11.11.91, p115.
19. ibid, p118.
20. ibid, p117. It is self-funding because the house is rented cheaply from the Housing Department.
21. id.
22. Name withheld. Submission No477, p5.
23. Horwood, op cit, p117.
24. M Nair-Stuber, C Bullock and J Keany, *Housing People with a Mental Illness*, A Wollongong study produced for the Illawarra Community Housing Trust Ltd, Aug 1987, p24.
25. Name withheld. Oral evidence, Sydney 21.6.91, p588.
26. Dr John Hout, Director of Clinical Psychiatry, Glebe Community Centre. Oral evidence, Sydney 20.6.91, p409.
27. Hon Brian Howe, the Minister for Health, Housing and Community Services. Speech for the official opening of the Mental Health Services Conference, 24 Sept 1992.
28. The NSW Housing Minister said in October 1990 that his Department's policy is not to provide housing for the psychiatrically disabled: NSW Association for Mental Health. Submission, p8.
29. Julie Felus, Irene Women's Shelter. Oral evidence, Adelaide 22.10.91, p288.

30. Dr Ian Siggins, Health Services Commissioner for Victoria. Oral evidence, Melbourne 8.4.91, p58.
31. Felus, op cit, p288.
32. Name withheld. Oral evidence, Ballarat 11.4.91, p614.
33. ibid, p618.
34. J Said, 'Housing Issues', Paper delivered at the National Policy Conference, National Coalition of Mental Health and Psychiatric Disability Groups, 11 April 1992, p1.
35. Name withheld. Oral evidence, Melbourne 10.4.91, p446.
36. Schizophrenia Fellowship of South Queensland, op cit, p14.
37. Name withheld, Submission No452, p2.
38. Dr Alan Rosen, psychiatrist. Oral evidence, Sydney 19.6.91, p371.
39. Comment made at a public meeting opposing a suburban housing project for people with psychiatric disabilities. O'Brien, op cit, p2.
40. id (comment by a local government official).
41. Name withheld. Oral evidence, Newcastle 9.7.91, p847.
42. Margaret Nielsen, Executive Director, Langford House. Oral evidence, Hobart 11.11.91, p131.
43. Name withheld, op cit (endnote 41), p847.
44. Nielsen, op cit, p132.
45. See also Chapter 18 — Homeless People, for other instances of community opposition defeating housing proposals by charities.
46. *Mental Health Services v Corporation of Hobart*, Tasmanian Planning Appeals Board J115/89, 11 Jan 1990. Dr Saxby Pridmore, Director, Division of Psychiatric Services, Tasmania. Submission, pp5-8.
47. O'Brien, op cit, p2.
48. id.
49. Nielsen, op cit, p132.
50. Lisa Brophy, Association of Mental Health Social Workers. Oral evidence, Melbourne 9.4.91, p228.
51. *Housing People with a Mental Illness*, op cit, p8. In 1988 3 percent of public housing tenants in NSW were listed as having a psychiatric disability: Said, 'Housing Issues', op cit, p5.
52. *Housing People with a Mental Illness*, op cit, p8.
53. Sach and Associates, *The Housing Needs of People with Disabilities*, AGPS, Canberra 1991, p10.
54. In 1990-91 about 52,000 households were newly accommodated in public housing around Australia, but the public housing waiting lists still grew from 195,000 to 203,000. National SAAP Evaluation, Consultation Paper 6, p4.
55. Said, op cit ('Housing Issues'), p5.
56. Margaret Herring, Schizophrenia Fellowship of North Queensland. Submission, p1.
57. *Housing People with a Mental Illness*, op cit, p21.
58. Chris Lowings, community mental health nurse, Whyalla Community Health Service. Oral evidence, Port Lincoln 18.10.91, p63.

59. Breen, op cit, p115.
60. Felus, op cit, p288.
61. Meg Smith, Disability Council of NSW. Oral evidence, Sydney 21.6.91, p551.
62. Margaret Ray, Social Development Committee, Victorian Parliament. Oral evidence, Melbourne 9.4.91, p262.
63. Judy Magub, Queensland Association for Mental Health. Submission, p11.
64. Said, op cit ('Housing Issues'), p2.
65. Brophy, op cit, p229.
66. Name withheld (A witness whose daughter has schizophrenia). Oral evidence, Melbourne 10.4.91, p369.
67. Name withheld. Submission No477, p5.
68. See Chapter 18 — Homeless People.
69. Name withheld. Submission No477, p5.
70. *Disability Discrimination Act (Cth) 1992.*
71. Robin Gurr, President, NSW Council of Social Service. Oral evidence, Sydney 17.6.91, p80; Magub, op cit, p11.
72. Marg Hamley, Crossroads. Oral evidence, Melbourne 8.4.91, p103.
73. Chris Pollard, Oasis Community. Oral evidence, Hobart 11.11.91, p128.
74. Name withheld. Submission No477, p5.
75. Name withheld, op cit (endnote 66), p370.
76. Hodgson, op cit, p839.
77. Name withheld, op cit (endnote 66), p369.
78. *ibid*, p370.
79. Irene Towler, Schizophrenia Fellowship of South Australia. Submission, p3.
80. Name withheld. Submission No452. See also Chapter 15 — Carers: The Experience of Family Members.
81. Estimates on the proportion of mentally ill people who live with their families vary, but are consistently high: Two-thirds (Alliance for the Mentally Ill, op cit, p1); 60 percent (Said, op cit ('Housing Issues'), p6); 53 percent (*Housing People with a Mental Illness*, op cit, p3); 50 percent (Pat Carberry, ARAFMI. Oral evidence, Perth 11.2.92, p251).
82. Herring, op cit, p3.
83. Name withheld, op cit (endnote 66), p368.
84. Dobson, op cit, p307.
85. Name withheld, op cit (endnote 66), p368.
86. Alliance for the Mentally Ill, op cit, p1.
87. Dobson, op cit, p307.
88. Anonymous. Submission No814. Similarly, Name withheld, op cit (endnote 66), p368.
89. Name withheld. Submission No452, p2. Also Schizophrenia Fellowship of South Queensland, op cit, p15.
90. Name withheld, op cit (endnote 32), p614. Note that the issue of respite care is also addressed in Chapter 15 of this Report.

91. Dr Andrew Campbell, RANZCP, and Chairman, Richmond Fellowship. Oral evidence, Sydney 17.6.91, pp106-7.
92. Name withheld, op cit (endnote 41), p849.
93. Lisbet de Castro Lopo, Hunter Area Health Service. Oral evidence, Newcastle 9.7.91, p814.
94. Name withheld, op cit (endnote 41), p849.
95. Pyrke, op cit, p116; *Housing People with a Mental Illness*, op cit, p3; Name withheld, op cit (endnote 35), p614.
96. Alliance for the Mentally Ill, op cit, p2.
97. Moira Shannon, Lower Eyre Peninsula Children's Emergency Hostel; also representing women's shelters in South Australia. Oral evidence, Port Lincoln 18.10.91, p17.
98. A Western Australian study of supported accommodation services for people with disabilities found that 46 percent of agencies contacted said they cannot cope with psychiatrically disturbed people, and prefer not to admit them if the disability is known: WA Council of Social Service, *Without Support*, June 1990, p96.
99. Hamley, op cit, p102.
100. ibid, p101.
101. Anonymous. Submission No814.
102. Campbell, op cit, p106.
103. Name withheld, op cit (endnote 35), p451.
104. eg Name withheld. Oral evidence, Adelaide 22.10.91, p301.
105. In Queensland an estimated '75 percent of existing residential support services are provided in private profit-making facilities.' The Hon Wayne Goss, Premier of Queensland. Submission, p21.
106. The Hon Joan Kirner, then Premier of Victoria. Submission, p15.
107. Di Gordon, Australian Association of Social Workers. Submission, p7.
108. Campbell, op cit, p106.
109. ibid, p107; Chris Coopes, Community Accommodation Support Program, Health Department of WA. Oral evidence, Perth 10.2.91, p70.
110. Pyrke, op cit, p115.
111. Topsy Evans, Domestic Violence Action Group. Oral evidence, Hobart 13.11.91, p315.
112. Charmian Clift Cottages Inc, Fifth Annual Report, 1990-91. Charmian Clift accommodated 32 women and 65 children over the year 1990-91, and always has a waiting list. It is seen as a model by mental health and accommodation services in other states: WA Council of Social Service, op cit, p113-4.
113. Ken Burnett, senior social worker, Glenelg Psychiatric Services. Oral evidence, Ballarat 11.4.91, p570.
114. Name withheld. Submission No370, p6.
115. Alliance for the Mentally Ill, op cit, p2.
116. Quoted in *Housing People with a Mental Illness*, op cit, p44.
117. Name withheld. Submission No370, p4.
118. ibid, p5.
119. id.

120. *ibid*, p6.
121. *id*.
122. Said, *op cit* ('Housing Issues'), p1.
123. National SAAP Evaluation, Consultation Paper 6, Dec 1992, p6. Also Said, *op cit*, ('Housing Issues'), p3.
124. National SAAP Evaluation, Consultation Paper 4, Dec 1992, p7.
125. *id*. Also Said, *op cit* ('Housing Issues'), p1.
126. *id*.
127. G Andrews, *The Tolkien Report: A Description of a Model Mental Health Service*, University of NSW, Sydney, 1991, p29: community mental health centres should have staff 'whose specific responsibility is the supervision of patients in nursing homes, hostels, boarding houses...cottages, group homes or in private accommodation. Supervision can range from a staff member always in attendance in a high-dependency hostel, to a staff member visiting every other day... At the lowest level, staff input will also be required, to aid a group of patients setting up rental arrangements...when they move into an independent living situation. Staff will also supervise psychiatric patients in licensed boarding houses, hostels and nursing homes'.
128. Cathy Wilson, Manager, St Kilda and Southport Community Health Centres, Victoria. Submission, p1.
129. Ivan Pitcher, former Eastwood Lodge resident, South Australia. Submission, p1.
130. SAAP, which is currently undergoing a national evaluation, is considering a greater emphasis on the separation of housing from support. SAAP sees this as a better way of enabling homeless people to move into independent housing as soon as possible. In principle this should hold true for many people with mental illness, as long as housing itself is available.
131. National SAAP Evaluation, Consultation Paper 4, *op cit*, p10.
132. Doug McLaughlin, ARAFMI, Queensland. Submission, p1.
133. Alan Rose, Mental Health Services, Hunter Area. Oral evidence, Newcastle 9.7.91, p840. Also Coopes, *op cit*, p66. In Western Australia there are over 600 approved hostel beds, mostly in 14 privately owned facilities. Maria Harries, Australian Association of Social Workers, WA Branch. Submission, p6.
134. Kirner, *op cit*, p15.
135. Stephanie Tonkin, Queensland Council for Civil Liberties. Submission.
136. Coopes, *op cit*, p69.
137. Hodgson, *op cit*, p836.
138. Siggins, *op cit*, p57.
139. Dr Michael Duke, RANZCP, Victorian Branch. Oral evidence, Melbourne 10.4.91, p363.
140. Siggins, *op cit*, p57.
141. Prof Neil Buhrich, Acting Director, St Vincent's Hospital psychiatric department. Oral evidence, Sydney 18.6.91, p138.
142. Hodgson, *op cit*, p838.
143. Hodgson and Rose, *op cit*, p2.
144. Siggins, *op cit*, p58.
145. Harries, *op cit*, (endnote 133) p6.

146. id.
147. Coopes, op cit, p75.
148. ibid, p68.
149. Harries, op cit, p6.
150. Coopes, op cit, p67.
151. id. The witness said that in practice few establishments charge the maximum rate, but 82½ percent of the pension is a common fee. This still leaves only \$26.50 per week for all other expenses.
152. ibid, p69. (Unfortunately, smoking is a very common 'pastime' among those affected by mental illness — see Chapter 18.)
153. Harries, op cit, p6.
154. Coopes, op cit, p69.
155. eg Nielsen, op cit.
156. Hodgson, op cit, p832.
157. 'Crisis Accommodation', op cit, p8.
158. Harries, op cit, p6.
159. Gordon, op cit, p7.
160. id.
161. This description reflects the evidence given to the Inquiry. There is a view, however, that group homes have external support and hostels or refuges have live-in support.
162. Buhrich, op cit, p143.
163. Name withheld, op cit (endnote 66), p368.
164. ibid, p369.
165. Burnett, op cit, p577.
166. ibid, p569.
167. Department of Health, Housing & Community Services, *Annual Report 1991-92*, AGPS 1992, p235.
168. National SAAP Evaluation, Consultation Paper 1, September 1992, p1.
169. Department of Health, Housing and Community Services, op cit, p235.
170. National SAAP Evaluation, Consultation Paper 1, op cit, p4. Several witnesses referred to this as a source of anger and frustration for accommodation agencies: eg Tony Calabro, Epistle Post Release Service. Oral evidence, Melbourne 8.4.91, p149.
171. ibid, p8.
172. ibid, p6.
173. ibid, p5.
174. National SAAP Evaluation, Consultation Paper 4, p3.
175. Denise Marshall, St Vincent de Paul. Oral evidence, Darwin 21.7.92, p42.
176. Hodgson, op cit, p832.
177. Marilyn Wilson, Aboriginal Medical Service. Oral evidence, Newcastle 9.7.91, p854.
178. The particular problems commonly faced by Aboriginal people with a mental illness are discussed more fully in Chapter 23.
179. Rose, op cit, p835.

180. Hodgson, op cit, p835.
181. Wilson, op cit, p858.
182. *ibid*, p854.
183. Russell Stewart, Youth Link outreach worker. Oral evidence, Cairns 9.8.91, p997.
184. Jackie Nelson, Irene Women's Shelter. Oral evidence, Adelaide 22.10.91, p290.
185. *ibid*, p289.
186. Judith Player, ARAFMI coordinator. Oral evidence, Melbourne 10.4.91, p367.
187. Bernie Geary, Brosnan Centre Youth Service, Catholic Prison Ministry. Oral evidence, Melbourne 9.4.91, p294.
188. *ibid*, p295.
189. Said, (oral evidence) op cit, p35.
190. *id*.
191. Felus, op cit, 290.
192. *id*.
193. *ibid*, p294.
194. Creina Scally, DAWN House Women's Shelter. Oral evidence, Darwin 21.7.92, p63.
195. Evans, op cit, p315.
196. Sister Anne Gregory, Catherine House. Oral evidence, Adelaide 22.10.91, p240.
197. Grimes, op cit, p284.
198. More detailed concerns about boarding houses being appropriate for women and children are outlined in Chapter 11.
199. Nielsen, op cit, p132. For brain-injured people with psychiatric problems, there is usually nowhere suitable. Thus they end up inappropriately placed, eg in aged care hostels intended for the mentally well elderly. Maria Vidovich, Australian Nurses Federation. Oral evidence, Melbourne 10.4.91, p398.
200. Nelson, op cit, pp291-2.
201. Rose, op cit, p833.
202. Hodgson, op cit, p834.
203. Felus, op cit, p287.
204. Rose, op cit, p833.
205. Hodgson, op cit, p834.
206. *id*.
207. Rose, op cit, p835.
208. *id*.
209. Kaye Lancefield, Epistle Post Release Service. Oral evidence, Melbourne 8.4.91, p147.
210. *id*.
211. *ibid*, p148.
212. *id*. Similar evidence was given by Marion Leach, Outcare Civil Rehabilitation Council. Oral evidence, Perth 10.2.92, pp49,51.
213. Leach, op cit, p50.
214. Calabro, op cit, p146.



215. Lancefield, op cit, p148.
216. Calabro, op cit, p149.
217. ibid, p150.
218. id. Marion Leach from Outcare in WA said her service is similarly unable to even begin meeting the demand. Leach, op cit, p56.
219. Kaye Lancefield, *Ex-offenders with Psychiatric Disabilities – An Investigation of Accommodation Needs and Services*, Aug 1990, p6.
220. Name withheld, GROW. Oral evidence, Brisbane 16.8.91, p1754.
221. Paul McDonald, Crossroads. Oral evidence, Melbourne 8.4.91, p107.
222. ibid, p109.
223. ibid, p107.
224. id.
225. ibid, p108.
226. ibid, p109.
227. Bill Davies and Bruce Greetham, *From Boarding House to Apartment Living: Rotorua, Opening Community Living Options for People with Psychiatric Disabilities*, Department of Community Services & Health, IYSH Documentation Series, 1987, p6.
228. ibid, p8.
229. ibid, p10.
230. ibid, p12.
231. ibid, p20.
232. Bill Davies, ICLA. Evidence provided to the Inquiry after the close of formal hearings.
233. Name withheld, op cit (endnote 2).
234. Richmond Fellowship of Victoria. Submission p2.
235. ibid, p5.
236. ibid, p3.
237. Kevin Duke, Director, Community Accommodation Support Service (CASS), South Australia. Submission, pp1,2.
238. J Azzopardi, S Redman and A Thoday, *Community Accommodation Support Service*, Southern Boarding House Occupational Therapy Service, Adelaide, p4.
239. id.
240. Frank Wright, Executive Director, Outer East Council for Developing Services in Mental Health, Victoria. Submission, p3.
241. Paul Jones, President, SAFE, Queensland. Submission, p1.
242. ibid, pp1,3,5.

# Chapter 11

## BOARDING HOUSES

My initial reaction to boarding houses in this area just made me cry... I wonder how such conditions can exist in this world, and what I have seen I will never forget.<sup>1</sup>

Rooms in private boarding houses are a major form of accommodation for people with a psychiatric disability. Many witnesses to the Inquiry expressed serious concern about the living conditions in these houses, which are poorly regulated and often substandard.

There have been constant reports about the problems of people in boarding houses but there seems to have been little action. The Slatery Royal Commission into deep sleep therapy's Volume 13...has Chapter 22 devoted to boarding houses, and...the headline in the *Sydney Morning Herald* was: This will be the next Chelmsford, conditions in boarding houses. I think there is a lot of truth in that. It is very likely this will be where the next scandal comes from.<sup>2</sup>

One psychiatrist, referring to a 1990 report that the NSW Government had 'agreed to conduct an urgent inquiry into the treatment of mentally ill people living in inner-west boarding houses,'<sup>3</sup> commented:

Well, we seem to have heard no more of that urgent inquiry. And this has been a constant picture of people urging that something be done and no action being taken.<sup>4</sup>

A number of reports concerning conditions in boarding houses were produced by consumer advocacy groups as part of the International Year of Shelter for the Homeless (1987).<sup>5</sup> These reports resulted in a greater effort by community services to reach boarding house residents, but conditions inside the houses rarely improved.<sup>6</sup>

### Background

Hospitals should not be an alternative accommodation industry, yet there is no alternative provided by the Government. The choice is a privately run hostel...where people may be exploited — or the streets.<sup>7</sup>

Boarding houses have undergone a major change from their original purpose — as a temporary but nonetheless respectable form of housing for people visiting the city for work or on holiday. As the housing market changed and the policy of deinstitutionalising the mentally ill was implemented,

a pooling of people with disabilities gradually started to occur...boarding houses became convenient repositories for [a] chronic — but rarely [hospitalised] — clientele.<sup>8</sup>

An expert witness in NSW told the Inquiry that in the 1960s, at the beginning of deinstitutionalisation, the psychiatric hospitals continued to provide some support for their patients who went to live in boarding houses.<sup>9</sup> But that support has dropped away and, from the evidence presented to the Inquiry, has rarely been replaced.

While it is rarely stated publicly, this ‘evolution’ in the role of boarding houses means they have become a de facto part of the mental health system, housing a large number of that system’s clients. The advantage of this situation for boarding house owners is that it provides a generally docile clientele who are easily controlled and prepared to accept minimal standards; it also guarantees a reliable regular income generated by pensions and benefits.<sup>10</sup> But the evidence indicates that boarding houses have failed to fulfil the accompanying expectation that they would contribute in some way to community care.<sup>11</sup>

Boarding houses provide accommodation and some residential services — often cleaning, laundry and three meals per day. Generally some level of ‘supervision’ is inherent in their operation. However, unlike ordinary private tenants, boarding house residents have no lease, no security of tenure and no right to exclude the landlord from the rooms they rent.

## **Prevalence of Mental Illness in Boarding Houses**

Many thousands of mentally ill Australians live in boarding houses. According to an Adelaide outreach team working with people in boarding houses, about 70 percent of its client population have a psychiatric disability.<sup>12</sup> The single most prevalent disability is schizophrenia.<sup>13</sup>

An expert witness giving evidence to the NSW hearings estimated that of 1,300 people in boarding houses in central Sydney, 70-80 percent are seriously mentally ill (the majority with schizophrenia). This is, he said, equivalent to the average population of three psychiatric hospitals.<sup>14</sup> However, these mentally ill people rarely if ever see a mental health worker — unless their illness escalates and they are hospitalised during an acute episode.

The incidence of mental illness varies between boarding houses because ‘there is a fair degree of vetting...in respect to the type of clientele.’<sup>15</sup> However, it appears that in our major cities many boarding houses cater predominantly (and some exclusively) for people with psychiatric disabilities.<sup>16</sup>

Many boarding house residents have dual or multiple disabilities (a subject dealt with in more detail in Chapter 21).

## Living Conditions

Some boarding houses are run by caring people who make a conscientious attempt to provide a decent 'home' for their residents. But the conditions in many are a national disgrace.

- The physical conditions are appalling. If they are not the same as institutions, they are actually worse.<sup>17</sup>
- The environment is very bleak. There is sometimes overcrowding, there is poor diet, there is no protection of the person's rights.<sup>18</sup>
- There is very little heating or cooling in boarding houses. Where that does exist it tends to be used...quite sparingly. Quite often the reason cited is that radiators would be a fire hazard and that the cost would be too great.<sup>19</sup>
- The long hallways are dark and pungent with the smell of cats. In the industrial-style communal kitchen, two residents argue over a sink. No one challenges you, and a request for the manager meets a shrug and an averted face.<sup>20</sup>
- It is known that there are malpractices with food, money, forced dependency, overcrowding, theft and cleanliness.<sup>21</sup>
- This is the worst place I've been in my life.<sup>22</sup>

The evidence presented to the Inquiry in all States indicated that the physical conditions in many boarding houses are depersonalising, depressing and completely uncondusive to any dignified normal life.<sup>23</sup> Many boarding houses have no living space appropriate for any form of leisure activity. Security is poor: rooms often have no locks on the doors. Many rooms are dark, cramped, crowded, dirty, unsafe and poorly maintained. The decor tends to be sparse, without plants or pictures on the walls to make the environment homelike.

Residents have no say in matters as simple as decoration of common areas and their bedrooms; personal clothes [are] laundered in bulk, resulting in the loss of one's own clothes and clothing being exchanged between residents.<sup>24</sup>

Personal hygiene is frequently 'disgusting'.<sup>25</sup> The standard of food is variable:

Some boarding houses supply a well-rounded diet for the three meals a day and nutritious in content. However, some...follow the 'fritz and white bread' philosophy of food.<sup>26</sup>

Nothing's disposed of. It's dished up again until finished...[with] repetition of [the] same ingredients all the time.<sup>27</sup>

**Mealtimes are often regimented strictly to suit staff,**

for example dinner being served at 4pm, with minimal time allowed for the residents to eat their food before staff start cleaning the dining room. Thus a potential opportunity for a leisurely social event is reduced to a rapid mechanical consumption of food.<sup>28</sup>

## **Privacy**

Residents of boarding houses commonly live in shared rooms with no other space of their own. They generally have no say about who they share with.<sup>29</sup> In boarding houses of the lowest standard there may be four or even six residents per room.<sup>30</sup>

Quite often the only private space a person has is their immediate section of residence around their bed.<sup>31</sup>

There's no way their life needs can be addressed... People go four to a room and there is no area where they can live a normal, ordinary life.<sup>32</sup>

**This lack of private space makes it impossible for residents to entertain visitors with any dignity in what is supposed to be their 'home'. One social worker who visits boarding houses regularly said:**

It also means nearly all interactions are of a public nature, and open to scrutiny both by other residents and the boarding house manager, who often has a great interest in what occurs... We have come across very crude listening devices that have been placed to listen to [residents'] interaction, and certainly to listen to social workers' interaction with clients.<sup>33</sup>

**Living with so little personal space makes many residents feel aggressively territorial; the lack of privacy also produces sexual frustration. These factors contribute to erosion of self esteem and loss of dignity, and result in a level of tension between residents which sometimes erupts into conflict.<sup>34</sup> This atmosphere would be difficult for anyone to live in; for someone with a mental illness it is especially destructive.**

**Despite the deprivation they endure, few mentally ill boarding house residents would prefer to be confined to a hospital:**

Consistently...80-90 percent of patients say they'd rather be outside a hospital than inside, even in poor circumstances like this... People prefer their liberty, even when it is not in good circumstances.<sup>35</sup>

Boarding house life can have its advantages: 'there are few responsibilities and fewer questions are asked.'<sup>36</sup> Expert witnesses told the Inquiry that some people like the anonymity of boarding houses;<sup>37</sup> many could actually enjoy living in boarding houses if physical conditions were substantially improved and problems such as the lack of privacy were remedied.<sup>38</sup>

## Placement in Boarding Houses

People are just gravitating to boarding houses, where there is little support.<sup>39</sup>

Many people affected by mental illness live in boarding houses because they are cheap. However, evidence was presented that mentally ill individuals are frequently discharged from psychiatric wards directly to a boarding house, without having any choice in the matter. One expert witness suggested the placement system is open to corruption:

It is reported that sometimes placement officers from mental hospitals get kickbacks for placing patients in certain boarding houses.<sup>40</sup>

While the Inquiry could not conduct a detailed investigation to verify this allegation, it should be noted that the Chelmsford Royal Commission also heard evidence concerning health workers receiving commissions for referring on their former patients. One doctor who had visiting status at Rozelle Psychiatric Hospital also acted as a 'spotter' for a particular boarding house, arranging the placement of patients there even though the hospital social worker disapproved. The Royal Commissioner called for proper procedures after discharge from hospital to prevent this 'abhorrent' practice.<sup>41</sup>

The Royal Commission report also refers to the practice of boarding house residents being sold to other boarding house proprietors — again, with the residents having little or no choice.<sup>42</sup> One witness told the Inquiry that during Sydney's property and tourism boom of the 1980s:

Private boarding houses offered a bounty per head for relocating lodgers: turning poor and sick people into a commodity with a steady pension income.<sup>43</sup>

Several witnesses to the Inquiry mentioned the practice of proprietors closing a boarding house and moving all the residents at short notice to another facility — often in a totally different area of town. This appears to occur when a proprietor leaves the boarding house industry (for example if the building itself is sold for redevelopment), or else when unscrupulous landlords feel they are about to attract attention from the authorities:

For example...at one stage there were many boarding houses in the Blue Mountains. Pressure was finally put on to upgrade some facilities using inadequate legislation, such as it was. [Departmental] staff would turn up the following Monday to see one boarding house...to find all the patients had disappeared. The owner had taken them to another boarding house down in Sydney.<sup>44</sup>

Some boarding houses are in prime real estate areas and you could suggest that the clients are in fact just in a holding pattern until the real estate becomes of more significant value.<sup>45</sup>

## Treatment for Mental Illness

We have come across instances in [different] special accommodation houses where there have been over 60 people suffering from Alzheimer's, or [more than 40] people with alcohol-related brain damage...with no casework, with no access to psychiatric outpatient facilities, with minimal contact with any community-based organisation outside.<sup>46</sup>

For many people with a mental illness, living in boarding houses or hostels is effectively a form of scaled-down re-institutionalisation. Boarding houses share some of the main drawbacks of psychiatric hospitals: an abnormal environment, strict rules and very little control by residents over their lives. However, boarding houses also lack the major advantage of hospitals — the provision of treatment.

Psychiatrically disabled people living in boarding houses tend to receive little treatment for their illness — or none at all.<sup>47</sup> Rehabilitation programs, according to one Sydney expert, are non-existent:

Patients have no activities; they just sit and watch television for most of the day, or they wander around the streets ill-kempt, behaving in a bizarre and menacing fashion — sometimes because of the untreated symptoms.<sup>48</sup>

This constitutes not merely a lack of treatment, but also a contributing factor to mental illness:

Residents display a lack of initiative to be involved in activity, apathy, withdrawal, submissiveness to authority, excessive dependence on the boarding house management, and often feelings of helplessness, worthlessness and dehumanisation. Although considered to be part of the schizophrenic process (an illness which many boarding house residents suffer), these behaviours are most certainly exacerbated by the minimal stimulation within their environment.<sup>49</sup>

Another way in which boarding house life exacerbates disability is by fostering substance dependency. Over-use of alcohol and benzodiazepine drugs is rife; residents' legitimate medications are sometimes stolen by other residents. There is an obvious need for 'dry' boarding houses, for people who have beaten their drug or alcohol addictions. But as far as the Inquiry could ascertain relatively few of these exist.<sup>50</sup>

The scandalous extent of neglect suffered by boarding house residents is illustrated by evidence presented to the Inquiry in Sydney. As previously mentioned, an estimated 1300 people live in boarding houses in the central city (Redfern to Strathfield).<sup>51</sup> Of these, the majority are seriously mentally ill — and, based on surveys from other areas, most of the remainder also have some form of disability. Yet their only regular contact with the health system is when a general practitioner visits. Even then, the quality of care is extremely disturbing: the Inquiry was told that a single GP ‘services’ about 60 percent (700-800) of those boarding house residents.<sup>52</sup>

Given the poor health of most boarding house residents, this approach to health care is, according to experts,

wholly inadequate... We are talking about Third World standards... It cannot be justified... a gross example of neglect, that’s all it could be called... Any one doctor cannot look after 600 or 700 patients in the community.<sup>53</sup>

It appears that some boarding houses have arrangements with particular doctors, giving them exclusive visiting rights.<sup>54</sup> This means residents are virtually compelled to adopt the boarding house doctor as their regular GP. A boarding house clientele can provide a lucrative ‘franchise’ for a doctor, with the danger of exploiting both the patients<sup>55</sup> and (through overservicing) the taxpayers:<sup>56</sup>

The doctor comes every Friday. He does a number of these places. He’s a very rich man.<sup>57</sup>

The doctor comes every week — watches my blood pressure and makes prescriptions. When you come here you can’t bring your own doctor.<sup>58</sup>

Clearly, clients should be able to choose their own GPs, rather than being compelled to use one chosen by a landlord.

Even if the mentally ill do receive primary health care from the boarding houses’ GPs, those doctors generally do not have adequate professional training to treat a serious mental illness. Yet, according to at least one expert witness, the doctor who services 60 percent of Sydney’s inner city boarding houses

doesn’t welcome the attention of the community mental health services, inadequate as they are, when they attempt to go and see people there.<sup>59</sup>

Evidence was presented indicating that mental health workers, including crisis teams, are sometimes denied access to residents by boarding house managers.<sup>60</sup> The Chelmsford Royal Commission also heard similar evidence.<sup>61</sup>

The right to informed consent is rarely respected in boarding houses:



The residents may have had no input into the decision regarding their placement...and few opportunities to discuss their needs with a professional person. The medical attention they receive from the visiting doctor is likely to be cursory. The doctor's lack of expertise in the use of psychotropic medication...combined with the proprietor's need to maintain order, represent potential for abuse, or at least denial of residents' rights to seek the most appropriate medical treatment.<sup>62</sup>

Expert evidence to the Inquiry indicated that 'treatment' received is extremely variable: some patients seem to be heavily drugged, while others are not medicated at all.<sup>63</sup> The dispensing of medication is another area of major concern.

In contrast...with hospitals, where strict attention is paid to handing out of medication to the patients — just two days ago I was told by one patient in a boarding house that the cook puts out the tablets for the patients to take. So goodness knows what mistakes get made in medication. And yet we have such excessive legislation in hospital, [and] nothing out there.<sup>64</sup>

Apart from the GPs' regular visits, many boarding house residents have absolutely no contact with support services for mental health care or rehabilitation.<sup>65</sup> In some cities social workers from a community health centre or accommodation support service visit the boarding houses. However,

[A community health centre worker] said it was possible for a tenant to 'go really, really mad' in their room without anyone noticing, especially in the spookier houses where the workers only visit in pairs.<sup>66</sup>

There are a few exceptions to this general pattern of neglect, indifference and abuse. Adelaide has a boarding house team funded by the State Government through the Community Accommodation Support Service.<sup>67</sup> The team has achieved significant improvements by making contact with mentally ill people who have 'strayed' from the major agencies. One of the reasons for its success is that it not only provides individual social work support, but also runs an activities program which develops living skills and counters boredom.

## **Boarding House Management**

Under some sections of the [Queensland] *Mental Health Act*, supervision is legally required post-discharge. The landlord, with no medical training and some with few humanitarian principles, then becomes [the client's] 'keeper'. Where are the human rights in this circumstance?<sup>68</sup>

The transformation of boarding houses into 'mini-institutions' for many people with serious and sometimes multiple disabilities has made the role of proprietors and managers much more complicated:

In their traditional role the landlords would have had the function of keeping the peace, cooking the meals and general maintenance. [Now] the manager has basically the job of managing very complex and diverse disability groups within a very confined space.<sup>69</sup>

Evidence to the Inquiry indicated that many boarding house managers have failed to develop the skills needed to meet these new responsibilities.<sup>70</sup> While disturbing, this is not surprising. Most managers have had little or no training for managing disability or for handling disputes with clients. Their communication with residents is often poor:

If you go to speak, he just closes his mouth, walks away and says he's too busy.<sup>71</sup>

[There's] no information — you just get told. You do as you're told so they don't throw you out of the place.<sup>72</sup>

The failure to resolve conflict, and a tendency to control and punish angry or unruly outbursts rather than to conciliate, contribute to further tension.<sup>73</sup>

Admittedly, boarding house proprietors are often faced with situations where they have no way of knowing the appropriate course of action. For example, new residents frequently arrive with no background medical information and no arrangements for continuing treatment or care:

A proprietor told [the Health Services Commissioner] that her residents were sent with no indication about who their doctor was, whom to contact in an emergency, no behavioural information for staff, and their medication given to them in a plastic bag. Consequently, she is not in a position to know what to encourage or dissuade the person about and has no background information to work with, yet she is expected by the Health Department to provide services which no regulations require she be skilled enough to provide.<sup>74</sup>

## **Management Practices**

Operators of boarding houses are unable, and often unwilling, to provide anything beyond the most basic services to their residents. Anything beyond minimal human requirements not only cuts into profit margins, but runs the risk of raising the level of functioning of some residents to the point where they could be overly demanding, ie articulating their rights; or, due to their increased functioning, move to less restrictive accommodation, thereby depriving the proprietor of a source of income.<sup>75</sup>

Not all boarding house owners are dreadful, but I think there are actually a subclass of them that actually exploit people with disabilities, and particularly people with a psychiatric disability.<sup>76</sup>

The management practices in some boarding houses clearly amount to exploitation of the residents. One practice, for example, is to press residents into unpaid work.

An 84-year-old man was living in a boarding house and doing the washing up for the boarding house without any significant remuneration, or money coming off his weekly rent.<sup>77</sup>

Other practices also constitute clear breaches of basic human rights. For example, the Inquiry heard evidence of a person whose incontinence was managed 'by a regime that is akin to a deprivation of liberty': the manager simply did not allow the resident to leave the boarding house.<sup>78</sup>

In many boarding houses the manager controls all the residents' money — because their pensions are simply paid into accounts which the manager operates. Residents are frequently subject to a form of debt bondage based on cigarette and coffee tabs. Most people in boarding houses are heavy smokers and are also poor;<sup>79</sup> the management provides cigarettes and coffee on credit, sometimes beyond the residents' capacity to pay.

We've had instances where the cigarette tab has become so significant...that when a resident wanted to leave [they were told] yes, they can leave, it's their right to leave — but [only] when they have paid the cigarette tab off, and the cigarette tab was \$200.<sup>80</sup>

Some boarding house practices reported to the Inquiry are clearly dangerous for people with a psychiatric disability — for example inappropriate allocation of roommates (a recovering alcoholic being assigned to share a room with an active substance abuser).<sup>81</sup> Danger also arises from managers hoarding residents' medication or dispensing it inappropriately.<sup>82</sup>

For mentally ill women, boarding houses are a particularly inappropriate form of accommodation. Sexual abuse by managers or other residents was cited in several States in evidence to the Inquiry, and sexual harassment is such a significant problem that some emergency housing agencies will no longer refer female clients to boarding houses.<sup>83</sup> Most boarding houses do not accept children, but some mothers, desperate for accommodation (and homelessness is an increasingly common problem),<sup>84</sup> lie and hide their children in their rooms.<sup>85</sup>

### *Financial practices*

*Clients often question the value for money of boarding houses, especially...when there is a rise in rental which is usually linked to the pension index. There never seems to be much of a raise in the value for money that they are getting.*<sup>86</sup>

As the pension goes up — so does the hostel price.<sup>87</sup>

Evidence to the Inquiry from most States showed that people living in boarding houses generally pay 85-90 percent of their pensions for room and board.<sup>88</sup> This leaves them very little money to buy anything else they need or want:

I get about \$2.50 to \$3 per week. It's not enough.<sup>89</sup>

It must be noted (and indeed underlined as a substantial factor in the evolution of the current situation) that, unlike nursing homes and some hostels, boarding houses receive no government subsidies. All their income is derived from rent paid by residents. This means the profit margins are not large:

I think it's just horrendous that this group of terribly needy people is so poverty stricken. The houses...take every penny they've got; and not because they are profiteering — that's what it costs... I don't think one should turn around and say the people who run [these] houses are monsters for taking all their money. They are providing an extraordinarily cheap service for the government. What we ought to do is give the clients income support, and look at some of these places caring for them...and provide some support for them — provided it meant appropriate standards of care.<sup>90</sup>

Since many residents tend to be extremely passive (and some are incapable of looking after their own finances), boarding house managers often convince them to hand over control of their bank accounts. The resident's pension is paid into the account, the manager deducts the rent and gives the resident an allowance from the remainder. This ensures the rent is always paid, but it forces residents to ask the manager for money whenever they want to buy anything for themselves:

If you want to get money to buy clothing you can't get it — you get taken upstairs to a pool of clothing.<sup>91</sup>

This practice is obviously open to abuse. Boarding house proprietors set their own fees, so sometimes residents receive no change from their pensions at all. Instead they may be paid in kind, for example with a packet of cigarettes or with toiletries.<sup>92</sup> Not surprisingly, there have been reports of proprietors simply plundering clients' accounts.<sup>93</sup> Clearly, the likelihood of exploitation increases when residents are in such a dependent position:

At present there is nothing to stop the proprietor taking a person's passbook and getting the person — because many mentally ill people really aren't very assertive — getting the person to sign withdrawal forms for whatever the proprietor thinks they need withdrawal forms signed for.<sup>94</sup>

## Regulation of Boarding Houses

There needs to be some mechanism to protect the rights of people who are in those boarding houses so that [doctors] feel comfortable about placing patients there, and [so] there is a feeling that there is no rip-off.<sup>95</sup>

In most States — at least in theory — boarding houses must be licensed if their clientele includes people with disabilities.<sup>96</sup> Generally, both State and local

governments are involved in licensing — although in Queensland it is purely a local council responsibility. However, in Brisbane at least, it appears that accommodation for people with disabilities is specifically exempted from the requirements of licensing (or registration, as it is known).<sup>97</sup> This exemption is presumably intended as an incentive to boarding house operators to accept disabled people as residents.

But the clear effect of such a policy is quite outrageous; it is to deny the benefits of government regulation to the most vulnerable people in our community — those who most need protection. (The evidence concerning conditions in boarding houses in Queensland was as disturbing as anywhere else in Australia.)

Even where licensing is required, the reality is that existing regulations impose only minimal standards on boarding houses. These standards are mostly concerned with physical criteria such as room size, doorsize, windows etc — rather than with quality of life.<sup>98</sup> The chief health and building surveyor of one Sydney council effectively summarised the situation:

We have nothing to do with the way people are treated in these places — we issue a licence on building and structural standards.<sup>99</sup>

Even in these areas, however, the system often fails dismally to guarantee acceptable minimum standards of accommodation:

The building/health inspectors walk around with their eyes closed. They don't know the ordinances, they don't know the laws. Nothing has been done about it — no electric lights, doors bashed in, no locks on doors; the inspectors are as blind as bats.<sup>100</sup>

NSW is one State where the licensing regulations do extend beyond physical criteria.<sup>101</sup> For example, every person on the staff of a licensed boarding house is required to be 'sympathetic to the welfare of handicapped persons'<sup>102</sup> and have 'adequate knowledge, understanding and experience to recognise and meet the needs of handicapped persons'.<sup>103</sup> Residents' 'physical, dental and mental health... shall be maintained and cared for';<sup>104</sup> and sufficient competent staff are required 'to perform all duties necessary for the care of handicapped persons at all times'.<sup>105</sup>

These principles are excellent — on paper. However, it is obvious that in practice they may as well not exist at all. The prevailing conditions in boarding houses demonstrate these standards are routinely breached or ignored.

One major difficulty is the short-staffing of licensing and monitoring agencies. For example, in 1985 NSW had five public servants to inspect, license and

investigate complaints at over 1000 residential facilities for people with disabilities<sup>106</sup> (the number of inspectors has now risen to seven). By 1988 there were 1200 facilities, of which only about half had been licensed. The rest continued to operate without a licence — and therefore illegally. The level of effectiveness of this farcical ‘monitoring regime’ can be judged from the fact that by 1989 only one prosecution for operating an unlicensed facility had occurred!<sup>107</sup>

Ironically, in NSW it is the issue of a licence which makes a facility subject to monitoring of its standards. In a boarding house which is (or has applied to be) licensed, officers of the Department of Community Services can receive complaints from residents and enter the premises to investigate. In an unlicensed facility, residents have no right to assistance from the Department, and inspectors require a warrant to enter the premises.<sup>108</sup> Thus it is precisely in those boarding houses which are operating illegally, where conditions are likely to be worst, that residents have the least protection of their rights.

A further serious shortcoming of the licensing system lies in the sanctions available, and the effect of their being invoked. Boarding houses which breach the minimum standards can be punished by being refused a licence — either by the State Government or the local council. A prosecution for operating an unlicensed facility can then force the boarding house to close. But this leaves the residents (most of whom will have a mental illness) with nowhere to live — exchanging a boarding house problem for a homelessness problem.<sup>109</sup> Governments may be reluctant to take this step, and some advocates for the mentally ill also oppose it. (In any event, proprietors forced to close down their boarding houses can easily start up others.<sup>110</sup>) The only option left is to license the substandard facilities, which at least gives inspectors access to the premises.<sup>111</sup> This makes a mockery of the licensing scheme:

I think we need to ask...can the government properly regulate the private sector, and especially the private sector that doesn't receive funding directly from government?<sup>112</sup>

## **Improving Support for Boarding House Residents**

Legislation alone won't do the job... We would need supports as well as legislation.<sup>113</sup>

Surely an alternative system could be provided where the person has independence and freedom, is not in hospital yet still has a reasonable standard of accommodation without exploitation.<sup>114</sup>

Given longstanding concerns about sub-standard conditions in boarding houses, some State governments have undertaken inquiries and/or drafted legislation to improve the position of boarders at law.<sup>115</sup> However, the rights of these

impoverished and disadvantaged individuals obviously have low priority: witnesses told the Inquiry the reforms appear to have been hopelessly delayed.<sup>116</sup>

One of the boarding house social work teams in Adelaide presented to the Inquiry a proposal to identify and remove from boarding houses those who would be capable of living in more independent — but still supported — accommodation.<sup>117</sup> Mentally ill people particularly need support when they decide to move out: they may be capable of living elsewhere, but they need help to actually leave the boarding house and find alternative accommodation.<sup>118</sup>

In addition to improving some individuals' quality of life, this proposal would remove some of the pressure from overcrowded boarding houses. It would allow licensing officers to close the worst houses — knowing there would be room elsewhere to rehouse displaced residents. The proposal relies, of course, on appropriate alternative accommodation being available.

It is also clearly desirable for boarding house licensees to receive appropriate training regarding their responsibilities to mentally ill people.<sup>119</sup> Proprietors who understand the importance of treatment for mental illness can make an enormous difference:

Quite a number of the proprietors in boarding houses are caring people, and they welcome support...and we have psychiatric staff going into some of their boarding houses.<sup>120</sup>

One witness suggested that in addition to appropriate legislation to regulate boarding houses, accountability is needed for health workers who place people there inappropriately.<sup>121</sup>

## Conclusion

If the present scandalous situation is allowed by the States to continue, then the Commonwealth must become more involved with standard-setting for boarding houses — as it is for nursing homes and hostels. The income for boarding houses comes almost entirely, albeit indirectly, from Commonwealth pensions and benefits.<sup>122</sup> Certainly, in human rights terms, our Federal Government has a responsibility for the protection of these extremely vulnerable Australians.

1. Maree Touma, voluntary worker quoted in M Miller, 'Abuse goes on: made me cry', *The Glebe*, 17 Oct 1990.
2. Dr John Hoult, Director of Clinical Psychiatry, Glebe Community Care. Oral evidence, Sydney 20.6.91, p408.
3. *ibid*, p412.
4. *id*.
5. R Chapman and J Provis, *Fritz & White Bread*, Report and Review of the South Australian Community Accommodation Support Service Southern Boarding House Social Work Team, Aug 1991, p244. Submissions to the Inquiry also included several other such reports, mainly from South Australia: P Hefferan, *Review of Boarding and Lodging Accommodation in Metropolitan Adelaide*, 1988; Community Accommodation Support Service, *Southern Boarding House Occupational Therapy Service Report*; Community Accommodation Support Service, *Northern Boarding House Report*, Jan-June 1991; South Australian Health Commission, *Psychiatrically and Intellectually Disabled Residents in Boarding Houses*, April 1988; Ministerial Review of Special Accommodation Houses (Victoria), *Interim Report*, Aug 1986.
6. Raphael Chapman, Community Accommodation Support Service. Oral evidence, Adelaide 22.10.91, p257.
7. Carol Kerr, occupational therapist, Prince Charles Hospital, Brisbane. Submission, p1.
8. Chapman, *op cit*, p244.
9. Hoult, *op cit*, p411. The living conditions were so bad that in the late 1960s some former patients were removed from boarding houses and returned to hospital.
10. S Couani, *Issues in the Regulation of Supported Accommodation for People with Disabilities*, Department of Family and Community Services, Sydney 1989, p14.
11. Chapman, *op cit*, p245.
12. *ibid*, p247.
13. Drug and alcohol abuse are also common. *ibid*, p246.
14. Hoult, *op cit*, p416. A 1987 survey by the Department of Family and Community Services also indicated that approximately 80 percent of residents in licensed boarding houses had a psychiatric disability: Trish Benson, Consumers Health Forum. Oral evidence, Sydney 18.6.91, p151.
15. Chapman, *op cit*, p247.
16. Couani, *op cit*, p14.
17. Benson, *op cit*, p151.
18. Hoult, *op cit*, p413.
19. Chapman, *op cit*, p247.
20. J Sinclair and M Griffin, 'Bleak outlook for destitute in rooms without views', *Emerald Hill, Sandridge & St Kilda Times*, 21 May 1992, p1.
21. Schizophrenia Fellowship of South Queensland. Submission, p15.
22. Cited in K Freytag, *If Only I'd Known*, Australian Consumers Association, 1986, p39.
23. Chapman, *op cit*, p247.
24. B Davies and B Greetham, *From Boarding House to Apartment Living — Rotorua, Opening Community Living Options for People with Psychiatric Disabilities*, Department of Community Services and Health, IYSH Documentation Series, 1987, p3.
25. Miller, *op cit* (endnote 1).



26. Chapman, op cit, p250.
27. *If Only I'd Known*, p30.
28. Davies and Greetham, op cit, p3.
29. ibid, p3.
30. Couani, op cit, p12.
31. Chapman, op cit, p248.
32. Maggie Dobson, Schizophrenia Fellowship. Oral evidence, Adelaide 22.10.91, p307.
33. Chapman, op cit, p248.
34. ibid, p250; Dobson, op cit, p307; *If Only I'd Known*, p25.
35. Hault, op cit, p413.
36. Sinclair and Griffin, op cit, p9.
37. id.
38. Chapman, op cit, p258.
39. Barbara Harris, Coordinator, Emmanuel Centacare, WA. Submission, p3.
40. Hault, op cit, p412.
41. The Honourable Justice J P Slattery, *Report of the Royal Commission into Deep Sleep Therapy*, v13, p308.
42. id.
43. Bruce Greetham and Bill Davies, Independent Community Living Association. Evidence to the Inquiry after the close of formal hearings.
44. Hault, op cit, p417.
45. Chapman, op cit, p248.
46. Dr Ian Siggins, Health Service Commissioner for Victoria. Oral evidence, Melbourne 8.4.91, p57.
47. Couani, op cit, p15.
48. Hault, op cit, p412.
49. Davies and Greetham, op cit, p3.
50. Dr J Tierney, 'One Doctor — As I See It', *Parity* (Council to Homeless Persons newsletter), Issue 9 v4, Nov 1991, p10. (There are a number of boarding houses in inner-city Melbourne which effectively ban alcohol on their premises, but this is not common.)
51. Hault, op cit, p419.
52. ibid, p412.
53. Prof Derek Silove, psychiatrist. Oral evidence, Sydney 21.6.91, p577.
54. *If Only I'd Known*, pp32-3. It was also suggested to the Inquiry that this practice also existed in the nursing home industry: Bill McMahon, St Vincent de Paul Society. Oral evidence, Darwin 21.7.92, p40.
55. Prof Ian Webster, University of NSW, visiting medical practitioner at Matthew Talbot Hostel, Sydney. Oral evidence, Sydney 20.6.91, p457.
56. Slattery Report, op cit, p305.
57. *If Only I'd Known*, p32.
58. id.
59. Hault, op cit, p412.

60. eg Davies and Greetham, op cit, p8; Hoult, op cit, p413.
61. Slattery Report, op cit, p305.
62. Couani, op cit, p15.
63. Hoult, op cit, p412.
64. ibid, p413.
65. Dr Jean Lennane, psychiatrist, NSW. Submission, p1.
66. Sinclair and Griffin, op cit, p9.
67. Chapman, op cit, p244.
68. Kerr, op cit, p1.
69. Chapman, op cit, p248.
70. One manager in Melbourne was cited as insisting that ‘managers are exactly that, and can’t afford to function as social workers or advocates’: Sinclair and Griffin, op cit, p9.
71. *If Only I’d Known*, p41.
72. ibid, p42.
73. Chapman, op cit, p249.
74. Cheryl Taylor, Office of the Health Services Commissioner, Victoria. Submission, pp7,8.
75. Davies and Greetham, op cit, p3.
76. Benson, op cit, p151.
77. Chapman, op cit, p249.
78. ibid, p249.
79. Kerr, op cit.
80. Chapman, op cit, p249.
81. id.
82. ibid, p250.
83. Benson, op cit p151; Sinclair and Griffin, op cit, p9.
84. See Chapter 18 of this report.
85. Sinclair and Griffin, op cit, p9.
86. Chapman, op cit, p250.
87. Kerr, op cit.
88. id; Hoult, op cit, p412; Lisa Brophy, Association of Mental Health Social Workers. Oral evidence, Melbourne 9.4.91, p229.
89. *If Only I’d Known*, p44.
90. Dr Michael Duke, RANZCP. Oral evidence, Melbourne 10.4.91, p363.
91. *If Only I’d Known*, p44.
92. ibid, p45.
93. Couani, op cit, eg p56.
94. Hoult, op cit, p416.
95. ibid, p413.
96. eg *Disability Services & Guardianship Act (NSW)*, *Health Act (Vic)*, *Health Act (SA)*, *Mental Health Act (SA)*.

97. In the Ordinances of the Brisbane City Council, Chapter 5 (Permits and Licenses) makes no mention of mental illness or any other disability. But two ordinances provide exemptions from registration of multiple dwellings. Ordinance 22 allows the Council to exempt 'premises which in its opinion are conducted on a basis which is substantially benevolent'. Ordinance 28(b) exempts 'any part of a boarding-house or tenement building used...for the accommodation of children or destitute or incorrigible persons or discharged prisoners.'
98. Benson, op cit, p152.
99. Maurie Smith, chief health and building surveyor for Marrickville Council, quoted in M Miller, 'FACS recognises there's a problem', *The Glebe*, 17 Oct 1990.
100. *If Only I'd Known*, p51.
101. Youth and Community Services (Amendment) Act 1979, Regulations.
102. Regulation 39(1)(h)(i).
103. Regulation 39(1)(h)(ii).
104. Regulation 47A(u)(i).
105. Regulation 47A(v)(i).
106. Couani, op cit, p27.
107. *ibid*, p4.
108. *ibid*, p24.
109. Chapman, op cit, p256. The closure of boarding houses due to redevelopment for tourist accommodation or for 'gentrification' is already one important contributor to urban homelessness: Human Rights and Equal Opportunity Commission, *Our Homeless Children*, Canberra, AGPS 1989, p207.
110. Hoult, op cit, p417.
111. Couani, op cit, p23.
112. Benson, op cit, pp151-2.
113. Hoult, op cit, p416.
114. Kerr, op cit.
115. eg the Victorian Ministerial Review of Special Accommodation Houses (1986), South Australian Human Services Committee of Cabinet Review (1988), *NSW Disability Services and Guardianship Act* (1990).
116. Pat Jones, NSW Association for Mental Health. Oral evidence, Sydney 19.6.91, p296. Also Benson, op cit, p151.
117. Chapman, op cit, p252; *Fritz & White Bread*.
118. Chapman, op cit, pp249, 251.
119. *ibid*, p253.
120. Hoult, op cit, p413.
121. Dobson, op cit, p308.
122. This argument was supported by several witnesses, eg Brophy, op cit, p229.

# Chapter 12

## EMPLOYMENT

The major social mechanism which individuals in our society use to maintain themselves both independently and financially is employment. This is also the major social mechanism through which we define who we are — that is, where we belong and how we contribute in society.<sup>1</sup>

In Western societies, including Australia, employment plays a central role in individuals' development. Apart from providing economic independence, employment is a fundamental factor in the way individuals perceive themselves and relate to others.

For the individual struggling for recovery after mental illness, unemployment, and all that implies, may be, indeed, '[the] last straw'.<sup>2</sup>

### Background

Evidence to the Inquiry and recent research<sup>3</sup> clearly indicate that employment in the open labour market has a number of beneficial effects for most people with psychiatric disabilities. The establishment of economic independence widens their choices and opportunities to fully participate in society. Employment can enhance personal satisfaction and self respect and provide daily stimulation and challenge, monetary compensation, social interaction and related opportunities for recreation and enjoyment. It can also be a constant impetus for further personal and professional growth.

As the outcome of major mental illness...appears to be more affected by employment (and associated benefits) than by other variables, there is a strong case to be made for the mentally ill to be employed, either in full-time, part-time or sheltered positions. I have no doubt that a significant percentage of the mentally ill could be gainfully employed to their benefit and to the benefit of the [employer] organisation.<sup>4</sup>

However, in spite of the growing recognition of these benefits, vocational rehabilitation for people with a psychiatric disability has received very little priority in overall service provision (a fact recently conceded by the Federal government).<sup>5</sup> This has meant that for many Australians, their opportunity to participate in employment has been extremely limited.<sup>6</sup>

While accurate statistics on the numbers of unemployed Australians affected by psychiatric disability are difficult to obtain, overseas research<sup>7</sup> in comparable

countries indicates that as few as 10 percent of such people are in paid competitive employment. On the basis of the evidence presented to the Inquiry it is clear that a large majority of Australians with a psychiatric disability are excluded from the labour market.<sup>8</sup>

One of the most often cited issues for people with psychiatric disabilities...[is] the lack of paid employment.<sup>9</sup>

The Inquiry was told that a number of barriers combine to deny most people with a psychiatric disability the opportunity to obtain work commensurate with their abilities and interests.<sup>10</sup> The factors most frequently mentioned in evidence were: lack of access to vocational and educational training, the debilitating effects of psychiatric illness and treatments, job design and negative employer and community attitudes (frequently manifested in overt discrimination).

Exclusion from the labour market can cause a number of substantial problems. Unemployment is a major source of inequality and poverty. Limited economic independence reduces the choices individuals can make about their lives. For many people, being affected by mental illness is accompanied by extreme financial hardship. Unemployment may also place great strains on carers, particularly immediate and extended family members.

Studies of the interaction between unemployment and mental illness certainly highlights a correlation. What is harder to elucidate is cause and effect. Even stronger and more fundamental connections exist between poverty and mental illness. Unemployment usually leads to economic hardship...

Links have been shown between unemployment and increased mental hospital admissions during periods of economic recession in the US, and readmission rates of mentally ill have been reported to increase during periods of high unemployment.<sup>11</sup>

When people who have been affected by mental illness do manage to obtain or regain employment, they generally receive little assistance or back-up to ease this major adjustment. The first few months in a new job can be particularly stressful for a person with a psychiatric disability. This may be compounded if the work environment itself is not sympathetic to their needs.<sup>12</sup> For example, work places that are noisy or isolating may be detrimental to achieving successful long term employment. People in these situations frequently need consistent support to alleviate work-related stress and anxiety which could trigger another episode of their illness.

Submissions to the Inquiry repeatedly emphasised several related issues. These were: the importance of paid employment for people with psychiatric disabili-

lities;<sup>13</sup> the need for greater access to work opportunities — particularly competitive employment;<sup>14</sup> the need for a range of flexible employment options in integrated settings (such as structured work experience arrangements);<sup>15</sup> the need for increased incentives to employers to encourage the employment of people with psychiatric disabilities;<sup>16</sup> the lack of continuous support for those in competitive employment<sup>17</sup> and the lack of training for employment service providers.<sup>18</sup>

The Inquiry was told that many people with psychiatric disabilities continue to encounter one, more or all of these difficulties and that recent reforms<sup>19</sup> have not, as yet, adequately addressed their vocational needs.<sup>20</sup>

## **Barriers to Employment**

Evidence presented to the Inquiry concerning the specific factors just identified was similar in all States and Territories.

### **Attitudes**

My husband is...mentally ill... In spite of that he is able to cope very well in the community without medication. He's obsessed with the desire to get back to work. He cannot understand why his employers have not rehabilitated him back into the workforce.

How can I tell him that in a private phone conversation I was advised that he was in the too-hard basket? How can any human being be shuffled from medical to interview in an endless circle of ineptitude and end up being represented by an enormous file of paper that comes down to a bottom line of 'too hard'. My own feeling is that the people dealing with my husband's case hope that just by ignoring him some miracle will occur and he will go away.<sup>21</sup>

Attitudes of employers towards people with psychiatric disabilities are part of a wider problem. Evidence presented by witnesses is supported by studies<sup>22</sup> which have established the general unwillingness of employers to hire individuals with disabilities — an attitude based largely on ignorance. The problem has been that employers tend to see, and judge, someone who admits to a psychiatric disability more on the basis of assumptions about the disability than on any real assessment of the individual's capacity.

It is not fair to people with mental illness — nor is it sensible to businesses that are looking for qualified workers — to attempt to screen out all people with histories of mental illness. It is not fair — nor is it accurate — to attempt to brand all people with mental illness as being alike.<sup>23</sup>

Employers generally view people with mental illnesses as unproductive workers who lack commitment.<sup>24</sup> In addition, employers are sometimes apprehensive

of potential disruptive or violent behaviour in the workplace and the possible effect on other employees and clients. They tend to perceive people with disabilities as much more expensive to hire, train, place and support than other workers. Additional factors include a perceived lack of flexibility to adapt to changed conditions and take on new responsibilities.

In Sydney the Inquiry heard about the Psychiatric Rehabilitation Association's unsuccessful attempts to obtain employment for people affected by psychiatric disabilities. The Association approached 1,067 businesses in the Redfern/Mascot area:

They were told that the candidates would be carefully selected and they were offered terms which we, as an organisation, believed that no employer could refuse. We guaranteed a labour input and...no absences — by us providing substitute employees. We would have guaranteed productivity, reduced labour costs, there would have been no training costs, there would be discreet professional back-up. Out of the 1,067 letters sent...2 percent were returned as undeliverable, 16 written responses were received [but they were negative], and there were five telephone inquiries, of which two were positive... [They] finally decided not to participate in the program, although they did have vacancies, and they gave no logical reasons.<sup>25</sup>

In addition to recruitment, negative attitudes among employers may also affect the level of the job in which a person with a psychiatric disability is placed, the salary paid, opportunities for advancement, and the likelihood of being among the first fired in an economic downturn. Indeed, the evidence suggests that when people with psychiatric disabilities are hired it is usually at minimal compensation in low-level jobs that are subject to abrupt termination.

A number of submissions to the Inquiry raised the issue of disclosure of mental illness during employment interviews. It was often stated that when applicants with a mental illness were honest about their condition at interview, the interview suddenly went badly and they did not get the job.

They found themselves in a real dilemma as to whether to inform potential [employers of their] illnesses. On the one hand many preferred to be honest but the minute they [did] that they knew they would be seen in a negative light. If they did not tell their employer they said they would feel considerable guilt if they became ill whilst working.<sup>26</sup>

Further problems exist for those employees who choose to hide their illness from employers. The stress involved may exacerbate the likelihood of the illness recurring. In addition, by not disclosing an illness the employee is, at least initially, foregoing the possibility of an employer providing some form of 'reasonable accommodation'.<sup>27</sup>

The attitudes of employers to people with mental illness are often shared by workmates and the general community. One individual, outlining the difficulties he faced in obtaining information about 'slow worker permits'<sup>28</sup> from a union official, stated that he was told by the official to:

deliver pamphlets door-to-door to make more money. The union official did not understand that I wanted full-time employment, a skill of some sort and, most importantly, to become a taxpayer again instead of continuing as a sickness benefits beneficiary... I can understand the union's point of view in regards to exploitation. But honestly who on earth is going to employ somebody with schizophrenia...who has been out of work for five years. It is not a matter of exploitation, it is a matter of preparing a disabled person to obtain gainful employment.<sup>29</sup>

While legislation (in particular, anti-discrimination legislation) can contribute to modifying attitudes and behaviour, the most effective agent of attitudinal change for employers is the experience of employing someone affected. By hiring, orienting, placing, supervising, and interacting with such people, employers come to see them as individuals with strengths and weaknesses — rather than simply focussing on their disability.

Education strategies designed to inform employers, co-workers, unions and the general community about mental illness and the effects of medication are also an essential element in promoting more enlightened attitudes in the workplace.

### **Type of Job and Job Design**

In recent years it has become increasingly difficult to place people in open employment, due to the continuing economic downturn and the structural changes taking place in the Australian economy. The Inquiry heard evidence that the introduction of 'multi-skilling' in award restructuring has eroded the already limited employment opportunities for those people with psychiatric disabilities who cannot perform the expanded range of tasks now expected by many employers.

Clearly, the type of jobs which people with psychiatric disabilities can secure in the labour market will also be determined by their awareness of existing options, levels of support available and the extent to which modifications to job design are undertaken.

While witnesses to the Inquiry welcomed recent Federal Government funding under the *Disability Services Act 1986*,<sup>30</sup> concerns were expressed that the resources provided were clearly inadequate to meet the needs of people with psychiatric disabilities seeking employment.



## **Effects of Psychiatric Illness and Treatment on Capacity to Work**

While services generally exist for the unemployed and disabled, the very nature of mental illness negates the usefulness of these services. A person affected by mental illness may not cope with full time work but might be able to usefully complete five hours work, three days a week. Further, this might vary from week to week or even day to day. Motivation, mental state, concentration, isolation, emotional expression and coping similarly can vary. At times getting through the day will be a major chore.<sup>31</sup>

Mental illness affects different people in different degrees. Symptoms can differ, severity differs, treatment can differ, and the evidence clearly indicates that ability to work differs. Unlike many other individuals seeking employment, a high proportion of those affected by mental illness are often unable to secure and maintain employment, without some form of specialist assistance, because of the very nature of their illnesses. Submissions and witnesses to the Inquiry indicated that the effects of mental illness may restrict an individual in employment due to performance problems (for example, reduced concentration, lowered interest and blocks or interference with cognitive processes)<sup>32</sup> and/or relationship problems (for example, difficulty confronting social situations, withdrawal, poor social and stress management skills).<sup>33</sup>

Many individuals with mental illness have difficulties obtaining and retaining open employment. These difficulties stem largely from the way they have learnt to perceive themselves. Their access to employment is often hindered by confusion in role perception, anxiety about their abilities to perform, fear of social interaction and fear of relapse. If these issues remain unaddressed, employment ceases to be an option for many of these individuals.<sup>34</sup>

The episodic nature of many psychiatric illnesses can also complicate arrangements. For example, a person with a mental illness that recurs approximately every 12 months, may find it possible to participate in full-time employment most of the time without any assistance or difficulty. However, the onset of the illness may mean a brief period of hospitalisation. If this period exceeds their accrued sickness leave entitlements, the job may be lost. Unemployment in these circumstances often has drastic consequences — including loss of one's home and social networks. Many submissions to the Inquiry stressed the need for appropriate leave conditions that take account of the variable nature of many mental illnesses.

In addition to the effects of illness, medication and treatment can also have a negative impact on work capacity and participation in other activities. Side effects, including sedation, are particularly relevant in this regard.

## Access to Vocational Services

Individuals' rights to employment are violated because of the lack of services designed to address their specific needs.<sup>35</sup>

People with psychiatric disabilities have never received the same level of funding and access to vocational services as other disability groupings.<sup>36</sup> Evidence to the Inquiry indicated that although access to generic vocational services for those with disabilities exists in theory, in practice the structure and operation of these services frequently excludes individuals with mental illness.

The Inquiry heard that people with psychiatric disabilities were often either denied access to vocational services on the basis that the service providers did not have the skills, time or resources to meet their needs, or they were institutionally excluded because the guidelines for service provision set certain eligibility criteria which they could not meet.

For example, the Commonwealth Rehabilitation Service (CRS) has generally been unsuccessful in dealing with or being accessible to moderately to severely mentally ill persons.

In 1989/90 less than 7 percent of [CRS] clients had a psychiatric disability.<sup>37</sup>

One submission<sup>38</sup> to the Inquiry suggested that some staff implemented 'informal' policies that people with mental illness, regardless of severity, were classified as severely disabled and not likely to gain substantial benefit from a rehabilitation program and were therefore denied assistance. However, since the Inquiry commenced there have been some positive developments concerning access to employment services — as already noted.<sup>39</sup>

The Inquiry heard evidence in Alice Springs concerning one of the new CRS pilot psychiatric rehabilitation units referred to earlier.<sup>40</sup> This unit's objective is to redress the previous bias by CRS towards services for people with physical and intellectual disabilities, limiting the inclusion of those with a psychiatric disability to individuals whose condition had stabilised, and who were considered capable of making substantial rehabilitative gains from the programs. In practice, as the above evidence indicates, two factors had militated against this. First, the majority of people with a psychiatric disability had historically been excluded or discouraged from accessing the service; and second, selection of CRS staff had rarely included workers skilled in training those with a psychiatric disability. (Problems were experienced in recruiting qualified staff for the new vocational units, so not all pilot programs commenced operation by the proposed date.)<sup>41</sup>

The Alice Springs Unit can cater for up to 30 people, aged from 15 to 65. The pilot is to run for two years, and the Inquiry was informed 20 people had already been referred to it, 11 of whom had been accepted as suitable.<sup>42</sup> A witness described the Unit's activities in its first few months of operation.

We look at work training and work placement... We may place clients in a training placement, or we may send them to TAFE to hone up on some skills. We are looking at setting up a 'job club' to compare resumes and learn interview skills. We liaise with employers to find sympathetic employers within the town who are willing to accept our people to work in their organisation. Once they are in an organisation, we can offer support. The unit is relatively new and although we have a number of people going through programs, we have no outcomes as yet, although it is looking quite promising.<sup>43</sup>

Such specialised work rehabilitation programs for people with mental illness are long overdue. The Inquiry hopes these pilot projects will be carefully evaluated and an expansion of such services will provide psychiatric vocational assistance which is flexible, accessible and adequately resourced.

General employment services simply do not know how to respond to the ambiguous social position of people with mental illness who are independent enough not to be hospitalised but who remain socially and vocationally disabled. Such people are frequently consigned to a social 'twilight zone' of being 'better but not well' — and to vocational service systems which function on the assumption that you are either 'sick' or you are not. This approach has led to a general failure to adopt effective employment programs for people with mental illness.

Traditional disability vocational services have seldom recognised or accorded any priority to the specific needs of people with psychiatric disabilities.

Generic employment services which access people into open employment, have traditionally had little success assisting those with mental illness. These services perceive themselves as lacking the resources to address the needs of this client group, both in terms of expertise and time.<sup>44</sup>

Almost all vocational services for people with disabilities are geared for people with physical and intellectual disabilities.<sup>45</sup> Not surprisingly, this has resulted in such services focussing almost exclusively on the needs of these individuals — to the exclusion of people with psychiatric disabilities. Evidence to the Inquiry indicated that the few specialist services that do exist for people with psychiatric disabilities are overloaded and have a tendency to engage only with the least disabled applicants.

Submissions and witnesses to the Inquiry highlighted a number of problems affecting access to several existing services. These included the Commonwealth

Employment Service, the Commonwealth Rehabilitation Service, Supported Employment Programs and Employment, Training and Placement services, activity therapy centres and sheltered workshops, Skillshare programs and private training services.<sup>46</sup>

The Commonwealth Employment Service (CES) was seen as lacking an adequate understanding of the vocational needs of people with psychiatric disabilities. Individuals attempting to access CES programs felt that CES frequently placed an overly restrictive emphasis on full time employment as a goal, at the expense of other vocational options.<sup>47</sup>

The Inquiry also heard that the Commonwealth Rehabilitation Service referral process involves a series of interviews which many people with a psychiatric disability find particularly stressful. For some, the demands of rehabilitation combined with mental illness are too difficult and their symptoms return. Others stated that they needed more support and structure in establishing their goals and following through their programs. Some were unable to make use of the training options available because of their difficulty translating skills from a learning environment to a working environment. Others, however, coped well with the rehabilitation process but failed to gain employment.<sup>48</sup>

The Commonwealth Rehabilitation Service is great if only follow-on jobs could be found.<sup>49</sup>

Supported Employment Programs (SEP)<sup>50</sup> and Commonwealth Employment Training and Placement (CETAP)<sup>51</sup> services were not considered sufficiently flexible to accommodate the specific needs of people with mental illness. (CETAP assists with locating full-time employment and provides limited on-the-job training using job support officers or work trainers.) People with mental illness found it difficult to access CETAP services — due to the focus on full-time employment and the restrictions of time-limited job support.

The majority of service users have an intellectual disability and few CETAPs deal with persons with mental disorder as clients need to be work ready and able to manage and retain full time employment.<sup>52</sup>

SEP services are designed for people who have greater support needs but are still able to engage in employment with continuing support. Problems associated with these services were generally related to the limited nature and type of support offered. The Inquiry heard that SEP support was not sufficiently comprehensive to meet the specific needs of many people with mental illness.

Sheltered workshops and activity therapy centres were seen as mainly providing work for people with intellectual disabilities. Although people with psychiatric disabilities are placed in them, witnesses to the Inquiry generally considered this situation undesirable. People with psychiatric disabilities complained that the work was often monotonous and under-stimulating.<sup>53</sup>

Skillshare services were regarded as useful to individuals with less chronic disabilities, but seen as inappropriately structured to effectively assist those with chronic mental illnesses. People with psychiatric disabilities often need much more social and emotional support than is currently provided by the service. Basic skills training is insufficient in itself.<sup>54</sup> Private training services were generally considered to be too expensive and to have many of the same limitations as Skillshare.

Overall, the evidence presented to the Inquiry clearly indicated that the main reason people with mental illness experience problems accessing existing vocational services is that these services have never been structured to address their particular needs.

## Vocational Options

My terms of reference are these...that we have real training programs in rehabilitation and living skills. Rehabilitation courses which have expectations and...outcomes leading to real rehabilitation training and potential employment. They're not just like child-minding facilities, they actually lead somewhere. I think the problem in a lot of rehabilitation at the moment is that it has no direction.<sup>55</sup>

On the basis of the evidence presented, the Inquiry concluded that it is necessary to examine the entire vocational and rehabilitation service system in order to rectify gaps in services and facilities and to clearly define the specific vocational needs of people with mental illness.

The community support packages for the seriously mentally ill are just vital... Employment, rehabilitation, advocacy with employers...[or] other social agencies, I mean all these things are part of the non-specific but equally vital component of treatment.<sup>56</sup>

The development of effective vocational rehabilitation programs will not only substantially assist the recovery of people with mental illness, it will go a long way to ensuring their equal participation in the community.

## Service Design

What is necessary for good rehabilitation? A supportive, calm, stable environment where performance demands are at a minimum but where opportunities for self-esteem,

confidence-building and achievement are readily available. Stability, support and security must still be flexible enough to allow convalescence to proceed steadily through rehabilitation to maximum recovery.<sup>57</sup>

The heterogeneous needs of people with mental illness mean that a variety of services will be required. Evidence to the Inquiry indicated that a range of graduated transitional services need to be developed — between the hospital environment and the community — to provide greater access to employment opportunities and more meaningful use of non-working time.

Witnesses stressed the need for vocational rehabilitation programs to acknowledge individual participants' goals and preferences. Individual rehabilitation plans should be an integral part of each program.

A range of work programs/services need to be developed to take account of the differing effects of mental illness to ensure that people with a mental illness develop and maintain their work and social skills.<sup>58</sup>

In Ballarat, the Inquiry was told that the local CRS encourages people to define their own rehabilitation needs over a six week period.

It is a very powerful process in terms of people identifying what their priorities are and linking them up with the resources we have... The CRS on the whole has about a 25 to 30 percent success rate of returning people to work. Using this approach, so far we've had nearly 60 percent of people at the end of the process find work successfully.<sup>59</sup>

In addition to vocational skills training, the vocational rehabilitation needs of many people with psychiatric disabilities include assistance with social and interpersonal skills and support in matters like housing and finance. If they are to be effective, therefore, vocational programs must recognise the interdependence of these areas of life, and their contribution to successful rehabilitation.

Some people with mental illness suffer one or more episodes of mental illness and between episodes they are quite well. Their needs are mostly for prompt, effective treatment of their episode of illness. However, most severely mentally ill people have an illness that is lifelong, and even during periods of relative remission, they have impairments that interfere with their ability to make an unassisted stable adjustment to community life. These impairments include sensitivity to stress, difficulty with interpersonal relationships, a deficit in coping skills, inability to organise their lives and difficulty in transferring learning from one site to another. The strategy of services should be to prolong the period of relative remission as long as possible.<sup>60</sup>

Evidence presented to the Inquiry also emphasised that the potential long-term and episodic nature of much mental illness means that vocational programs must be flexibly structured. In developing programs, consideration must be

given to the fact that a person's ability to work can fluctuate. Programs should be sufficiently flexible to accommodate changes in the course of individuals' illnesses and in their personal circumstances. People with mental illness need to be able to access services when most in need. Access to support for the employee and the employer is essential in maintaining productivity and ensuring continuity of employment. Support during non-working hours is also important.

The evidence indicated that the availability of employment programs is very much dependent upon geographic location — and that psychiatrically disabled people in more isolated areas are seriously disadvantaged. Clearly, the more accessible a service is, the greater the likelihood of it being used. This applies not only to place and time:

*The more elaborate the procedures to be negotiated to gain access (eg referral or appointment systems), or the more daunting the institution, the less likely it is to be used.<sup>61</sup>*

Services should therefore be as flexible and accessible as possible (eg close to transport and other services and have realistic operating hours).

However, it is quite clear that a proportion of people with acute psychiatric disabilities are not suited to full-time competitive employment options. Their rights would be better protected if they were provided with other vocational opportunities — in some cases as a long-term replacement for such options.

*For the severely psychiatrically disabled, an employment model which incorporates flexible supported employment rather than mainstream part-time or full-time employment may be more appropriate.<sup>62</sup>*

Any serious attempt to frame policies ensuring meaningful employment for Australians with psychiatric disabilities must, therefore, include a range of options. This does not mean, however, the return to the creation of a separate long-term token workforce, relegating people with mental illness to menial jobs in a protected environment. More imaginative (but practical) approaches are essential.

### **The Clubhouse Model**

Several innovative vocational rehabilitation service models do exist. One investigated by the Chairman of the Inquiry is the 'Clubhouse program'. First developed in the US in the 1940s, it is based around transitional employment schemes. (As the name suggests, the program is centred on and operates from a 'Clubhouse' of which people affected by mental illness become members.

Clubhouses do not just run employment programs; they also assist their members in a wide range of areas including living skills and accommodation.)

Under one variant of the Clubhouse program, people with mental illness are placed in the open labour market with the employer paying award wages and providing standard conditions. The employer is guaranteed that the job will be done to an agreed standard every day. Should a Clubhouse member be unable to work on a particular day, the job is done by a trained back-up member or, if necessary, by a staff person assigned to support the placement. Jobs are usually worked on a half-time basis, so that one full-time job can serve at least two Clubhouse members. This allows the member to spend half a day at the Clubhouse (which is centrally located) for support and skills training.

Placements are transitional — usually providing employment for periods of three months to a year. When a member has completed the agreed time on a placement, he or she has the option of choosing another placement or seeking an independent job.

While some consider this model to be based on excessive optimism, the fact is it works. A recent study found that after 12 months in transitional employment, 11 percent of members moved on to independent employment, after 24 months 19 percent and after 48 months 39 percent.<sup>63</sup> A more recent American study found that transitional employment is up to 13 times more cost-effective at reintegrating people with psychiatric disabilities into the workforce than SEP programs.<sup>64</sup>

Under the Clubhouse model, inability to complete a placement is not seen as failure — but rather as recognition that further rehabilitation is needed. Instead of abandoning employment as an option, the person returns to the Clubhouse and, in supportive surroundings, works on the problem before attempting another placement.

### *Variations On a Theme*

There are variations of the Clubhouse model already operating in several countries. While the basic tenets of the model remain, individual Clubhouses adapt the model to suit local conditions. The Chairman of the Inquiry investigated the operation of Clubhouses in New York (Fountain House), Chicago (Thresholds) and San Francisco (Bayview). The Inquiry also inspected the only Clubhouse operating in Australia to date — in Melbourne (Bromham Place).



While each Clubhouse adapts its approach to the rehabilitation of people with psychiatric disabilities, a universal feature is the importance of employment in this process. Clubhouses regard work as central to rehabilitation and programs are premised on the principle that all individuals need to engage in productive activity.

### *The Fountain House — New York*

The Fountain House Clubhouse in New York<sup>65</sup> conducts three major employment programs — a Work-oriented Day program, a Transitional Employment program and an Independent Employment program.<sup>66</sup>

The Work-oriented Day program is organised around the day to day operations of the Clubhouse itself. All work done by members in this program is voluntary — as is attendance at the Clubhouse. The tasks involved in running the Clubhouse — such as reception duties, answering phones, shopping for food, preparing and serving meals, cleaning up, typing, filing, data entry, newsletter production, finance management and so on — are converted into opportunities for members of the Clubhouse to participate. Members and staff are divided into task units. No task is done only by members or only by staff and no task is seen as less important than any other. In this way, members quickly learn that they are wanted and needed and that the efficient operation of the Clubhouse depends upon them.

The Work-oriented Day program develops a range of work skills. New skills are learned and those which may have been forgotten in the course of hospitalisation and illness are rediscovered. The program enhances members' confidence and capacity to cope with the outside world.

The Transitional Employment (TE) program at Fountain House gives all Clubhouse members the opportunity of employment in a 'real job' in open employment. There are no prerequisite 'readiness' criteria for such placements. The availability of a job that is suited to the member's interests and skills (as evaluated by the member and staff together) determines the placement. Most members of Fountain House average about six months in the pre-vocational Work-oriented Day program before trying their first TE placement — but that period may be shorter or much longer depending on the individual.

Under the TE program, positions are found by Clubhouse staff and the responsibility for placing the appropriate person in the job lies with the Clubhouse (there is therefore no need for employment interviews or screening by the employer). The Clubhouse provides a guarantee to the employer of an agreed standard of performance every work-day. (It is regarded as important

for both the employer and the employee that the program is not seen as a charitable arrangement.) The employer, not the Clubhouse, issues the pay-slip. At Fountain House, most members stay in an assigned TE placement for six months.

The Independent Employment program at Fountain House assists members seeking work or those already working full time. The program is seen as the logical outcome of vocational rehabilitation at Fountain House. After several successful experiences on TE placements, many members wish to return to full time independent employment in jobs of their own. The Independent Employment program assists and supports members to secure, sustain and upgrade such employment. (For example, the program provides workshops on job seeking skills such as interview techniques and resumé writing.)

The Independent Employment program also provides members working full time with the opportunity to access all Clubhouse support services, including advocacy for employment entitlements and assistance with housing, clinical, legal, financial and personal issues. Members can also attend all evening and weekend Clubhouse programs.

#### *Thresholds — Chicago*

The Thresholds Clubhouse in Chicago adopts similar employment programs to the Fountain House Clubhouse, but with a number of important variations. Thresholds conducts a formal 'work-readiness' program to assess members' ability to work. In this program a member of the Clubhouse assumes a particular task, such as helping to prepare lunch, and over a period of time he or she is formally evaluated by Clubhouse staff. The member is assessed on capacity for work; speed or slowness; application; punctuality; and relationship with co-workers.

If the pre-vocational evaluation indicates work-readiness, the member is offered the opportunity of 'open' employment in the community. If the evaluation indicates that the member is not prepared for employment, further internal rehabilitation and living skills programs are offered.

As with the Fountain House Clubhouse, Thresholds actively seeks employment opportunities for its members. It approaches a wide variety of local businesses and employers, seeking both full and part-time jobs. Once employment opportunities have been secured, Thresholds staff provide on-the-job assistance for the Clubhouse member, for co-workers and supervisors. In recent years Thresholds has organised part-time individual placements for Clubhouse

members in positions as diverse as messengers, cashiers and librarians in law offices.

Thresholds also takes innovative approaches to work arrangements to accommodate the varying capacities and fluctuating abilities of its members. Job sharing, variable work days and the expansion or contraction of the hours of work are negotiated to ensure the success of a placement. Members who are in part-time open employment are required to maintain a relationship with the Clubhouse and to attend rehabilitation and living skills programs while not at work.

Unlike Fountain House, however, Thresholds utilises two forms of sheltered employment — in-house and out-of-house sheltered workshops.<sup>67</sup> The in-house sheltered workshops are for those members who are assessed to be unsuitable for open community employment placements, even after continuing rehabilitation and living skills programs. In these instances, Thresholds secures employment contracts that can be undertaken within the Clubhouse itself. For example, Thresholds owns a sophisticated high-speed copier and has a contract with IBM to produce computer training packages.

The out-of-house sheltered workshops provide employment placements within a discrete section of a factory or business. Members work together in the same location and Clubhouse staff provide assistance and support. These 'enclaves' provide a supportive working environment integrated with the rest of the business. For example, Thresholds provides a group of eight members to work at a supermarket chain stocking shelves and bagging goods at checkouts. Thresholds also provides a full-time job coach to supervise and support the members.

### *Bayview — San Francisco*

Similar to both Fountain House and Thresholds, the Bayview Clubhouse in San Francisco places particular emphasis on ensuring that each member feels wanted and necessary as a contributor to the program.<sup>68</sup> Bayview is intentionally set up so that it will not work without the co-operation of its members. Every function is shared by members working side by side with staff. Staff never ask members to carry out functions which they themselves do not also perform.

A fundamental tenet of Bayview is that work — especially the opportunity to aspire to and achieve meaningful open employment in the community — is a deeply generative and reintegrative force for all individuals. The entire program is premised on the principle that work must be a central element of the Clubhouse model and must pervade and inform all activities undertaken at the

Clubhouse. No opportunity is lost to convert every activity generated by the Clubhouse into a potentially productive contribution by its members. Such involvement is seen as a source of increased confidence in each person's ability to obtain gainful employment.

Bayview guarantees its members the opportunity to go to work in open community employment at regular wages in non-subsidised jobs. It considers this guarantee part of the social contract that it makes with every member. Like both Fountain House and Thresholds, Bayview Clubhouse actively searches out jobs in the community for its members and provides staff to support the placements.

### *Bromham Place — Melbourne*

The Bromham Place Clubhouse in Melbourne, which commenced operation in 1991, is structured along similar lines. Members can become involved in the club's Food Services or Clerical Unit or the Maintenance or Gardening groups. Here they can develop work skills which may lead them to employment in one of the club's job placements in the open community.

The Food Services Unit plans and prepares the Clubhouse's daily meals. Every day menus are planned and food is bought, prepared and served. The kitchens are maintained by members and financial records of all expenditure are kept. This provides direct training for employment in the cooking and catering industry. Members become familiar with equipment similar to that which is used in industrial kitchens and they develop general employment skills.

The Clubhouse Clerical Unit produces the club's newsletter and weekly bulletins. Members are involved in the writing, editing and production of the papers. They also undertake other clerical functions such as distributing mail, answering telephone inquiries, typing and filing, financial management and general administration.

For those members who wish to attempt open employment, the Clubhouse offers a TE placement program which allows members the opportunity to try working for a period of six months. Two members generally share a job and they are specially trained, selected and supported by Clubhouse staff. When members are ready for independent employment the Clubhouse assists with application forms and interviews. Support is provided to members and employers as long as is necessary.

## *Common Features of Clubhouse Models*

It is the goal of many, though not all, Clubhouse members to return to full-time independent employment. Successful experiences on several TE placements almost always reinforce this goal. Many Clubhouses support this by providing job placement services, counselling in the writing of resumé and interviewing techniques, and continuing evening and weekend support for full-time workers. All Clubhouses recognise that members need an after-hours place to come for friendship, support, counsel and encouragement — as they make their way in independent employment.

Member participation is not necessarily a smooth progression from Work-oriented Day program to independent full-time employment. There are often setbacks for individual members during this process. However, losing a full-time job, illness, re-hospitalisation and other setbacks are cushioned by the long-term and open ended nature of Clubhouse membership.

Much is written currently about the failure of deinstitutionalisation, about the need to provide some new sort of asylum away from the rigours of the community for people who have suffered severe and major mental illness. Acknowledging that there is currently no 'cure' for these often devastating conditions, the Clubhouse model holds out to its members the hope for a life of decent human dignity within the community, not banishment from it, no matter how humanely conceived.<sup>69</sup>

The Clubhouse model — in its various forms — provides an innovative support service for people affected by mental illness. One of the major reasons for its success is that it allows its members to participate in a wide variety of activities — including recreational, pre-vocational, rehabilitation, employment, education and accommodation programs. It works because it is a model which recognises the important inter-relationships between these different aspects of life in providing successful rehabilitation.

Unfortunately, the very reasons for its success means that the Clubhouse model currently falls outside the *Disability Services Act* 1986 (DSA) funding guidelines. Funding is allocated under the Disability Services Program to specific disability 'service types'. These service types must be discrete to be eligible for funding. The DSA guidelines therefore deny resources to organisations such as Clubhouses which provide more than one service type. (The guidelines also exclude disability support services that are targeted to a specific disability.)

A re-evaluation and reformulation of the DSA guidelines to recognise the important and successful role Clubhouses already play in assisting people affected by mental illness is therefore essential.

Other successful employment and rehabilitation services, such as those established by the Outer East Council for Developing Services in Mental Health, are discussed in Chapter 5 — Mental Health Services.

## **Non-Employment Options**

Evidence presented to the Inquiry clearly established that vocational rehabilitation should not always aim for full-time competitive employment. While the nature of our society and related government policies give particular emphasis to full-time employment, not all people with a psychiatric disability are able to undertake it.

Nor should paid employment — full-time or part-time — be seen as the only desirable option. Australia's human rights commitments require that people with psychiatric disabilities have equal access to a much wider range of social and cultural activities.

Australian culture, it could be argued, is built around work... There is no adequate concept of citizenship in our culture which can provide a frame of reference for those for whom work is not available as a major focal point for life. Inability to 'make it' within the work culture signals greater or lesser degrees of exclusion from citizenship itself.

Therefore, if we speak of rights for people with a mental illness, we must first speak of rights to citizenship which does not rely centrally upon work participation for its legitimacy. For those who can rejoin the workforce, a job still proves, for most, the best way to achieve a reasonable standard of material comfort and a state of personal and social identity. But what of those for whom a stable, secure and rewarding job is an improbability.

The citizen with a mental illness must have the right to establish a legitimate lifestyle around those activities which for them provide greatest meaning and satisfaction. This may include some work periods when possible. But it may also, for a significant number, need to be built around other non-work but for the individual still purposeful activities.<sup>70</sup>

Services for people with mental illness must include a range of options that cater for both vocational and non-vocational needs. People with mental illness, like all individuals in the community, need to engage in activities which are both positive and meaningful.

In addition to the issues discussed in this section, there are other important impediments to employment — such as education, training and accommodation problems — which are dealt with in greater detail elsewhere in this report.

## **Research**

There is also an urgent need for evaluation and research relating to several areas outlined in this chapter. These include assessment of the effectiveness (or otherwise) of the Clubhouse models mentioned; the types of disability which various forms of mental illness produce in a working environment (referred to briefly above); and the type of education programs that can be used effectively with employers.

1. M Mead, Executive Director, The Outer East Council for Developing Services in Mental Health Inc, Victoria. Submission, p2.
2. Dr J Lawrence, 'Discrimination in Employment Against People with Mental Illness', paper presented at Mindcare conference, addressed by the Chairman of the Inquiry, Queensland, 24.4.91, p10.
3. See for example: I Webster, 'Health Costs of Unemployment', *Mental Health in Australia* vi, No12, pp17-23; National Health Strategy, *Enough to Make You Sick*, Research Paper No1, AGPS, Canberra 1992; and Lawrence, op cit.
4. Prof G Parker, Department of Psychiatry, University of NSW. Submission, p1.
5. In 1991 the Federal Government began funding the Commonwealth Rehabilitation Service, on a trial basis, to establish 11 pilot rehabilitation units specifically designed to meet the needs of people with psychiatric disabilities. The goal of these schemes is to create 1200 new placements over a two year period. The Inquiry welcomes this positive step, but stresses that a more integrated, sustained and comprehensive response is required.
6. Commonwealth Rehabilitation Service, *Vocational Rehabilitation for People with Psychiatric Disabilities*, AGPS, Canberra 1991, p1.
7. E Long, *Employment of the Mentally Restored*, President's Committee on Employment and the Handicapped, Washington DC — Mental Illness and Employability, 1992.
8. In addition to the evidence presented to the Inquiry, recent data on the profile of people with disabilities in Australia also supports the proposition that people with psychiatric disabilities have extremely low employment participation rates.

In 1988, the Australian Bureau of Statistics (ABS) conducted a survey on disability and ageing. The methodology of the survey with regard to psychiatric disability has been criticised and it is likely that the incidence of these disabilities is under-reported.

The survey estimated that there were 2,543,000 Australians with some degree of disability (15.6 percent of the population), found that for 2,254,000 (88.2 percent of people with disabilities) their primary disability was a physical disorder; for 302,400 (11.8 percent) their primary disability was a 'mental' disorder (this term included both intellectual and psychiatric disabilities). There was a similar pattern of disability for women and men.

According to the ABS survey only 520,000 people (20.4 percent of all Australians with disabilities) were in the labour force. Of these, 456,400 (87.8 percent) were employed at the time of the survey and 63,300 (12.2 percent) were unemployed. It was also estimated that there were approximately 21,500 people with disabilities in Activity Therapy Centres and sheltered workshops.

9. C Wilson, Manager, St Kilda Community Health Centre, on behalf of St Kilda and Southport Community Health Centres, Victoria. Submission, p4.
10. See for example: P Bright, NSW. Submission, p1; Dr J Hoult, paper 'Community Psychiatry', *Institutionalisation and Community Psychiatry*, NSW. Submission, p321; Mead, op cit, pp1-3; P O'Brien, Brisbane Psychiatric Social Workers Interest Group, Queensland. Submission, pp1-6; R Trowbridge, Department of Leisure Studies, Phillip Institute of Technology, Victoria. Submission, pp1-4; Hon W Goss MLA, Premier of Queensland. Queensland Government Submission, pp29-35.
11. Lawrence, op cit, p10.



12. The ACTU and the Victorian Trades Hall Council have produced a resource kit to assist in the elimination of stress factors at work: *The Process of Stress*, Health and Safety Bulletin Nos 54 and 55 — ACTU/Victorian Trades Hall Council, May 1988. Workplaces may produce a wide range of occupational stresses. The kit cites a report in the *Journal of Occupational Medicine* (1985), that [in the US]: 'It has been estimated that at any one time, some 8-10 percent of the workforce are experiencing disabling emotional or psychological ill health; that up to 30 percent suffer from a fluctuating array of minor psychological discomforts and physical ailments; and that stress-related symptoms contribute to absenteeism, lost production, and company health care expenses costing \$50-75 billion annually' (p821).
13. See for example, Parker, op cit, p1.
14. See for example, Queensland Government Submission, op cit, p29.
15. See for example, O'Brien, op cit, p5.
16. id.
17. See for example, D Bryson-Taylor, President, The Alliance for the Mentally Ill, NSW. Submission, p5.
18. See for example, Mead, op cit, p2.
19. A number of these issues have recently been addressed, at least in part, in the Federal Government's reform of disability services.
20. See for example, T Wade, Queensland Association for Mental Health. Oral evidence, Brisbane 15.8.91, p1579.
21. Name withheld. Oral evidence, Sydney 18.6.91, p23.
22. M Shelley, *Report of the National Consultations with People with a Disability*, Disability Advisory Council of Australia, AGPS, Canberra, 1991; also M Lee and S Pascoe, 'Employer attitudes towards hiring physically handicapped people', *National Rehabilitation Digest*, v4 No3, 1980.
23. *Affirmative Action to Employ Mentally Restored People* — a joint publication of the National Institute of Mental Health and the President's Committee on Employment of the Handicapped, US Department of Health and Human Services and the US Department of Labor, DHHS Publication No. (ADM) 81-1073, 1981.
24. See for example, C Ronalds, *National Employment Initiatives for People with Disabilities*, Department of Community Services and Health, AGPS, 1990.
25. T Elligett, Chief Executive, Psychiatric Rehabilitation Association. Oral evidence, Sydney 21.6.91, p562.
26. R Wiggins, Daily Activity and Self Help Group, Victoria. Submission, p2.
27. For people with mental illness, 'reasonable accommodation' (which is explained in endnote 22 in Chapter 13 — Education and Training) may include:

**Adjusting work schedules.** Some workers with mental illness may need to go for treatment or therapy a couple of times a week. Others may feel uncomfortable in rush-hour crowds. Adjustable work schedules for them may be a 'reasonable accommodation'. In addition, an employer could utilise part-time or job sharing arrangements.

**Restructuring jobs.** Some people with mental illness may have problems with some components of their jobs. They may feel ill at ease in large open office environments where many men and women work together; excessive noise may bother them; or

excessive quiet. For them 'reasonable accommodation' may be a matter of minor modifications and not a matter of major alterations to the job itself.

**Flexible leave practices.** Sometimes people with mental illness may need extra time off for care and treatment. Flexible leave practices may ease the problem and help retain them as productive workers.

'Reasonable accommodation' is just that — reasonable. It does not apply if an employer can show that it would create an unjustifiable hardship on the business. One of the best authorities on 'reasonable accommodation' is the worker with mental illness. Consultation with the individual to ascertain their needs is obviously essential.

28. There is provision in industrial legislation for the issuing of 'slow workers permits' to aged, slow, inexperienced or infirm workers.
29. Bright, op cit, p1.
30. See Commonwealth Rehabilitation Service, *Vocational Rehabilitation for People with Psychiatric Disabilities*, op cit.
31. O'Brien, op cit, p2.
32. See for example: the Hon J Kirner, then Premier of Victoria, Victorian Government Submission, p50. Also O'Brien, op cit, p2.
33. O'Brien, op cit, p2 and Lawrence, op cit, pp2-5.
34. Mead, op cit, p2.
35. id.
36. Commonwealth Rehabilitation Service, *Vocational Rehabilitation for People with Psychiatric Disabilities*, op cit, p1. The Disability Support Program (DSP) covers a variety of services — advocacy, research, recreation, respite care, accommodation, living skills, information services, employment and print disability services. The responsibility for these services is split between the Commonwealth and State governments. The Commonwealth Government has responsibility for the employment programs of the DSP. Both the Commonwealth and the State Governments are responsible for advocacy and research. State Governments are responsible for the rest of the services under the DSP. The *1991 Census of Disability Services* (AGB Australia, 1991) found that programs for people affected by mental illness received little government funding support — just 2.2 percent of all long-term funded services and 4 percent of new services.
37. Queensland Government, op cit, p29.
38. M Galligan, Queensland. Submission, pp1-4.
39. See Commonwealth Rehabilitation Service, *Vocational Rehabilitation for People with Psychiatric Disabilities*, op cit.
40. See endnotes 5,6.
41. Suellen de la Hunt, Regional Manager, Southern Region, Commonwealth Rehabilitation Service. Oral evidence, Alice Springs 23.7.92, p207.
42. David Stradling, social worker, Alice Springs Vocational Unit for Psychiatric Rehabilitation, Commonwealth Rehabilitation Service. Oral evidence, Alice Springs 23.7.92, p208.
43. id.
44. Mead, op cit, p2.

45. This situation is also reflected in the income support measures of the Disability Support Pension. The impairment tables used to assess eligibility for the pension are based on physical disability indicators. The episodic nature of mental illness is not adequately addressed. As a result, people affected by mental illness are disadvantaged in seeking income support.
46. Many of these services are part of the Federal Government's Disability Reform Package (DRP). The DRP covers income support measures through the Disability Support Allowance and vocational and rehabilitation programs. DRP programs are the responsibility of three government departments: the Department of Health, Housing, Local Government and Community Services, the Department of Social Security and the Department of Employment, Education and Training. The activities of these three departments are coordinated through Disability Panels (the panels contain a representative from each department and develop individual plans for consumers).
47. See for example, O'Brien, op cit, p4.
48. id.
49. J Hodgess, Association of Relatives and Friends of the Mentally Ill, NSW. Submission, p1.
50. Supported employment services are defined as services to support the paid employment of persons with disabilities, being persons:
  - (a) for whom competitive employment at or above the relevant award wage is unlikely; and
  - (b) who, because of their disabilities, need substantial ongoing support to obtain or retain paid employment.

The then Department of Community Services and Health, in its submission to the 1989 Senate Standing Committee on Community Affairs Inquiry into the Employment of the Disabled, stated: 'Supported employment services... are intended to provide meaningful, paid employment for people with disabilities who would not be able to perform paid work in open employment unless they had ongoing support... Such services should promote independence and integration into the community.'

The 1990 Report of the Labour and Disability Workforce Consultancy, op cit, states that some typical models of supported employment include: 'enclaves, specialised businesses, mobile work crews and individual supported jobs'.

51. Competitive employment training and placement services, defined as services to assist persons with disabilities to obtain and retain paid employment in the workforce, include:
  - (a) services to increase the independence, productivity and integration of persons with disabilities in the workplace;
  - (b) employment preparation, and employment and vocational training services; and
  - (c) services to assist the transition of persons with disabilities from special education, or employment in supported work settings, to paid employment in the workforce;

The then Department of Community Services and Health, in its submission to the 1989 Senate Standing Committee on Community Affairs Inquiry into the Employment of the Disabled, stated that competitive employment training and placement services 'assist people, who, because of their disability, may require access to training, placement and time-limited support to obtain and retain award wage paying work in the general labour market. In this service type, service providers will provide training and support for a

limited period. Support and training may be intensive initially, then diminish as the employee becomes proficient in the job. When the person can perform the job without ongoing support or assistance, agency involvement is reduced to ongoing monitoring or contact with the employee. Training and support can be re-introduced if necessary, for example if the nature of the job changes.'

52. Queensland Government submission, op cit, p30.
53. The 1990 Report of the Labour and Disability Workforce Consultancy, op cit, stated that there were 269 sheltered workshops funded under the Disability Services Act 1986, where approximately 11,000 people with disabilities were employed. Sheltered workshops and Activity Therapy Centres (ATC) have been criticised in the past for:
- \* paying 'allowances' at a very low rate and not paying wages;
  - \* deducting an excessive amount from each worker's social security payments for board;
  - \* failing to respect the common law rights of employees;
  - \* failing to enhance the skills and self-reliance of workers and providing only boring, repetitious work;
  - \* improperly restricting the freedom of workers; and
  - \* denying workers the right to organise industrially or discouraging them from exercising that right.

These problems stem, in the main, from the traditional perception of workshops and ATCs as services to people with disabilities rather than as employers. The traditional format of sheltered workshops and ATCs often fails to respect the right of people with disabilities to develop their skills to the maximum, to engage in a useful, productive and remunerative occupation, to economic security, and to protection against treatment that is discriminatory. However, it is clear that basic principles of human rights law require that improved alternatives be introduced and adequately funded — before these more traditional responses are abandoned.

54. O'Brien, op cit, p4.
55. J Meagher. Oral evidence, Sydney 17.6.91, p104.
56. Prof G Andrews. Oral evidence, Sydney 17.6.91, p44.
57. Lawrence, op cit, p9.
58. Hout, op cit, p321.
59. P Humphreys, social worker, Commonwealth Rehabilitation Service, Ballarat. Oral evidence, Ballarat 11.4.91, p559.
60. Hout, op cit, p321.
61. id.
62. Queensland Government, op cit, p29.
63. T J Malamud, *Evaluation of a Clubhouse Model: Community-based Psychiatric Rehabilitation*, Fountain House, New York, Mimeograph, 1985.
64. Prof J Noble, University of New York (Buffalo) 1991.
65. Fountain House is one of the largest Clubhouse programs — serving a total of over 2000 members. 350 members attend each day.
66. R Propst, (Director of Education at the Van Ameringen Center for Education and Research, Fountain House, New York) 'The Clubhouse Model and the World of Work', *The Lines* vV No2, TIE Inc, 1988.
67. This is an unusual arrangement. The *Standards for Clubhouse Programs* actually proscribe the provision of employment through sheltered workshops (Standard 19).

68. The Bayview Program includes individuals from the Mexican, Vietnamese, Chinese, Spanish and Greek communities.
69. R Propst, op cit, p2.
70. Trowbridge, op cit, pp3-4.

## Chapter 13

# EDUCATION AND TRAINING

A right to education?... [It's] virtually non-existent.<sup>1</sup>

Our education system plays a critical role in assisting individuals to achieve their maximum potential in society. While a relatively small number of witnesses and submissions focussed specifically on this issue, the evidence which was presented to the Inquiry underlined the importance of education in any effective system of care for people with mental illness. In addition to the acquisition of knowledge and skills, education can assist those affected by mental illness to gain greater insight into their problems and consequently, control over their lives.

People with psychiatric disabilities clearly have a right to an education.<sup>2</sup> In many cases, however, special educational programs and services are required to assist them to achieve their potential. Evidence to the Inquiry indicated that many individuals with psychiatric disabilities are unable to participate in existing education and training programs.<sup>3</sup> Consequently, they are denied the opportunities that education and training can offer.

## Barriers to Education and Training

### Effects of Psychiatric Illness and Medication

I have...started various courses. Perhaps the courses I enrolled in were either too hard or far too easy. In any event my illness prevented me from finishing the harder courses...<sup>4</sup>

A number of witnesses emphasised that the effects of illness and medication may result in lower levels of educational achievement or weaknesses in key curriculum areas, study skills or communication skills.<sup>5</sup> Effective use of libraries, note-taking skills, analysis of material and assignment writing may also be affected.

Educational performance may also be impaired by factors such as lack of confidence and poor self esteem. These traits are often more pronounced in people who have experienced negative stereotyping, prejudice or neglect. Many individuals affected by mental illness have had such experiences — which reduce their willingness to interact with other students and teachers.

The majority of Australians affected by mental illness have never had the opportunity to pursue long term educational goals in a positive environment. Indeed, most have had to contend with serious disruption of their family lives, breakdown of personal relationships and financial hardships — as well as the other effects of their illness.

Firstly, there is the shattering effect that such an illness can have on one's own concept of self, one's identity, of being a person who is the master of one's destiny, an autonomous being in command of one's life. To experience an episode of distorted experience over which one has no control and for which one has not been prepared, strikes at the very core of one's identity and particularly at self esteem, self confidence and self respect... An episode of psychosis very often also has severely disruptive effects on the individual's personal, family and interpersonal relationships and financial, social and personal circumstances. Restoration of the individual's life to one approaching its pre-existing norm, may take time and be demanding in its own right.<sup>6</sup>

Many mental illnesses have their onset in adolescence and childhood — indeed the Inquiry was told that the median age of onset for several major illnesses is 16 years.<sup>7</sup> Such illness during adolescence frequently disrupts education and interrupts social development in ways which can drastically disadvantage an individual in later life.

Typically, serious mental illnesses manifest between the ages of 16 and 25 years. The development of mental illness in these crucial years can interfere with successful schooling, completing a trade or embarking on a career. Periods of relapse and admission to hospital can significantly disrupt the development of work skills, qualifications or creditable work histories.<sup>8</sup>

The President of the Australian Society of Adolescent Psychiatry told the Inquiry:

The peak age of onset for schizophrenia is in late adolescence and young adulthood... We estimate, for example, that in NSW there will be 1000 new cases of schizophrenia per year, and most of those will be adolescents. In NSW in 1986 there were 682 admissions to psychiatric hospitals of adolescents. In the 12-16 year group, 130 admissions; in the 16-19 group, 552.<sup>9</sup>

Evidence presented to the Inquiry indicated that once their education is disrupted, many young people with mental illness find it difficult to return to secondary or tertiary education. In addition, many older individuals lack the pre-requisite knowledge or 'starter' qualifications which permit them access to further education.

## Access to Education and Training Services

While support services for people with other kinds of disabilities have been set up in TAFE colleges in NSW and some universities, they have generally excluded students and staff who have disabilities caused by episodes of serious mental illness.<sup>10</sup>

### *The School System*

Approximately 15 percent of children have some form of emotional or behavioural problem during childhood which requires assistance and between 1 percent and 2 percent of children have psychiatric disorders of sufficient severity to warrant specialist services.<sup>11</sup>

Securing primary and secondary education for children with psychiatric disabilities can be difficult, especially given the lack of appropriately trained teachers and support systems. Witnesses to the Inquiry emphasised the problems associated with 'mainstreaming' children with psychiatric disabilities within the general education system without providing adequate professional or material resources to address their educational needs.<sup>12</sup>

Evidence to the Inquiry also indicated that psychiatric disabilities in childhood are often not recognised, ignored or disregarded.<sup>13</sup> The Inquiry heard that this is largely due to inadequate teacher training and the lack of specialised counselling services to assist such children and their families.

A couple of group members had become ill at a young age and felt they had been discriminated against whilst at school. They felt it was mainly related to ignorance and lack of understanding on behalf of students and teachers. They were often taunted and ostracised due to their behaviour.<sup>14</sup>

Schools should be a major focus for identifying children with learning difficulties and emotional problems associated with mental illness. In fact, emotional or behavioural problems are often most apparent at school. Children do not learn as they should, do not make friends, or do not behave appropriately. However, early intervention requires intensive training to enable teachers to identify, understand and work with these children.

Evidence to the Inquiry also highlighted the lack of services for pre-school children with psychiatric disabilities and the inadequate educational opportunities for children confined in hospitals.<sup>15</sup> Most inpatient services for children and adolescents with mental illness have no education facilities at all.



## *Higher Education and Training*

Several submissions identified the paucity of resources allocated to special education needs in the tertiary sector as the greatest problem affecting the integration of people with psychiatric disabilities into the higher education system.<sup>16</sup>

Evidence was also given that inflexibility by the Department of Employment, Education and Training and the Commonwealth Rehabilitation Service in the provision of financial support for those affected by mental illness undertaking tertiary study was a substantial barrier to participation in education and training.

Some mentally ill people may need to take time off during their courses, or may elect to take a particular course of study over a longer than usual period of time. Funding agencies are not usually tolerant of such behaviour, which may indeed be sensible and responsible considering that particular person's disability.<sup>17</sup>

Evidence presented indicated a general lack of support for the thousands of tertiary students affected by mental illness. The Inquiry was told that many lecturers and student counsellors had confused and inaccurate notions about psychiatric disability and little understanding of the problems individuals faced in coping with episodes of mental illness and the side effects of medication.<sup>18</sup>

I did really well in high school and my first year of university. Then I got really depressed and almost failed second year. I managed to scrape through the last year of my course but my self confidence was really low. There was a student counsellor but she didn't seem to know anything about the illness or the drugs I had to take. I got my doctor once to write me a medical certificate when I couldn't sit for an exam and I think that actually created more problems for me — they all knew at the college I'd had a breakdown and I felt really humiliated that they knew.<sup>19</sup>

Ignorance about mental illness often means that educational and training institutions make no effort to accommodate the needs of students who are affected. Episodes of illness are particularly common in periods of high stress such as exam times. Counselling and teaching services need to be better informed and appropriate arrangements made for students to be able to resume their studies when well — or to complete the requirements of their course in appropriate but less stressful ways.

In my final year I had a 'breakdown'. I found it difficult to convince the Department that (a) I was suffering from an exacerbation of my illness, (b) mental illness really did exist, and (c) I needed them to make some tolerable adjustments... (for example, giving extensions on assignments and relaxing attendance requirements).<sup>20</sup>

If equity in education is to be more than mere rhetoric, educational and training institutions must provide some form of reasonable accommodation to meet the needs of students and potential students affected by mental illness.<sup>21</sup> Reasonable accommodation in educational settings may mean changes, for example, to the instructional process, extra time for examinations, tape recording of classes, the provision of bridging courses and study skills programs.

Some forms of mental illness make consistent levels of concentration and/or performance difficult. Flexibility in course structure and assessment may assist in reducing stress levels.<sup>22</sup>

The Inquiry was told that the Higher Education Contribution Scheme (HECS) payments and course fees in tertiary education do not facilitate access for the vast majority of individuals with psychiatric disabilities.<sup>23</sup> Since these people often take on tertiary study at a 'mature age' and since many also take longer than usual to complete their degrees, the cost to them may be prohibitive.

Because people with psychiatric disabilities already carry a large emotional and financial burden [due to their illnesses], the prospective costs of tertiary education may deter many...<sup>24</sup>

The Inquiry received a number of submissions identifying the difficulties faced by people with psychiatric disabilities both in pursuing higher education and in attaining vocational training. Some suggested that people with psychiatric disabilities have been pushed into low skilled employment because of the inaccessibility of higher education, the insufficient number and variety of programs and inadequate funding for support services. These submissions, together with our own research, indicate the importance of an increased focus on the gap between education and employment.

Education provides access to employment and employment is the single greatest factor mitigating against poverty and marginality, both of which the mentally ill suffer from profusely.<sup>25</sup>

Employment opportunities can be expanded by education and training — both on and off the job. People with psychiatric disabilities may be further disadvantaged in obtaining or advancing in employment by poor educational qualifications or vocational training. The Social Security Review (1988)<sup>26</sup> noted that a high proportion (62 percent) of people with disabilities<sup>27</sup> had no post-school qualifications. (The issues surrounding vocational training for people with a psychiatric disability are addressed in more detail in the previous chapter.)

The evidence presented to the Inquiry also indicated that many educational and training institutions appear to be uncertain or undecided about their role and

responsibilities in providing education and training for people with mental illness. This is reflected in the lack of planning and support services necessary for a coordinated approach to meet their educational needs.

At present no university appears to include mental illness as part of a disability support program and some universities have stated that they do not wish to include mental illness as part of their disability support program. Students having a breakdown in health are often not given help or advised what their options are.<sup>28</sup>

Appropriate support services for people with mental illness are required urgently. They should preferably be incorporated into existing organisational structures (services which are add-ons or temporary are seldom effective) and must be provided with appropriate resources.

## **Education and Training Program Design**

The concept of 'the least restrictive environment' should be the guiding principle in determining the type of special educational programs and services which people with mental illness receive. Educational programs for them should be an integral part of education service delivery. This means that a range of services must be adapted or developed and implemented to assist those affected by mental illness.

However, the initial requirement is to clearly define the educational and training needs of people with mental illness over the full educational continuum — ranging from pre-school needs to tertiary and vocational studies — and to examine the educational and training system in order to identify deficiencies and problems with service delivery. The development of an effective and responsive education and training system will help people with mental illness to exercise their rights and realise their potential in society.

It is recognised that the way programs are delivered will affect [the] involvement of students. Research is required to examine alternative methods of curriculum delivery, accreditation and economic implications.<sup>29</sup>

The Mayer Committee<sup>30</sup> was established to develop statements of employment-related 'key competencies' for inclusion in all postcompulsory education and training programs.<sup>31</sup> These key competencies define essential learning for all young people and provide them with better preparation for initial employment and a foundation for their continuing vocational education and training. (That is, the adoption of employment-related competencies should lead to closer links between school-based learning, work experience and part-time work.)

The Committee recognised that in the development of key competencies there is a need to take account of the experiences and needs of different groups of young people.<sup>32</sup>

Witnesses and submissions to the Inquiry<sup>33</sup> stressed that individuals with mental illness have the right to appropriate educational programs that prepare them to live as independently as possible. Educators have the responsibility to provide programs that will enable people with mental illness to exercise that right.

Programs most in demand by this client group (adults with mental illness) are adult basic education and personal development programs.<sup>34</sup>

Where possible, individual education and service delivery needs should be accommodated.

Flexible arrangements for the resumption of study or the completion of course work should be made for people affected by mental illness.<sup>35</sup>

Educational support services for those affected by mental illness should not be seen as a drain on resources. Indeed, appropriate provision for the inclusion of people who have or have had psychiatric disabilities is a basic human rights issue and should constitute one of the prerequisites for certain institutions' accreditation as places of learning. The cost of providing appropriate education and training services will be significant. However, the long term social and economic benefits to the community will be considerable.

1. D Cheetham, consumer. Oral evidence, Brisbane 16.8.91, p1715.
2. See Chapter 2 for the human rights provisions prescribing the right to education.
3. For example: Professor B Tonge, Director of the Monash University Centre for Developmental Psychiatry, President of the Australian Society of Adolescent Psychiatry and representing the Faculty of Child Psychiatry of the Royal Australian and New Zealand College of Psychiatrists. Oral evidence, Melbourne 9.4.91, p235.
4. P Bright, consumer, NSW. Submission, p1.
5. Eg M Smith, Depressive and Manic Depressive Association of NSW. Submission, p4.
6. Dr J Lawrence, Queensland. Submission, p8.
7. R Kosky, H Eshkevari and G Kneebone (eds), *'Breaking Out: New Challenges in Adolescent Mental Health'*, Report by the National Health and Medical Research Council, 1992. Also, A Greener, social worker and consumer, NSW. Submission, p11.
8. P O'Brien, Brisbane Psychiatric Social Workers Interest Group, Queensland. Submission p2.
9. Tonge, op cit, p238.
10. Smith, op cit, p4.
11. Tonge, op cit, p235. The incidence of psychiatric and other disorders among children and adolescents is addressed in more detail in Chapter 20 of this Report.
12. C Flynn, Policy/Administrative Director, Mental Health Coordinating Council, NSW. Submission, p16.
13. Smith, op cit, p5.
14. R Wiggins, Daily Activity and Self Help Group, Victoria. Submission, p2.
15. Tonge, op cit, p237. See also Chapter 8 — Inpatient Care and Treatment.
16. See generally: Greener, op cit.
17. *ibid*, p11.
18. Flynn, op cit, p16.
19. Smith, op cit, p4.
20. Greener, op cit.
21. Existing anti-discrimination law in Australia dealing with mental illness (including the Federal *Disability Discrimination Act 1992*) uses the concepts of 'reasonable accommodation' and 'unjustifiable hardship'. This recognises that ensuring equal treatment in practice for people with disabilities in many situations requires some form of reasonable accommodation by other parties (eg education and training institutions). This accommodation may include, in different circumstances, modification to premises, practices or course design. In many cases this may be straightforward and inexpensive. It is recognised, however, that in other cases substantial costs or other significant consequences may be involved that would constitute an unjustifiable hardship for the educational institution. In considering whether there could be any unjustifiable hardship, account must be taken of all the relevant circumstances of a particular case — including the nature of the benefit or detriment likely to accrue or be suffered by all persons concerned and the financial circumstances and the estimated amount of expenditure required by the party claiming unjustifiable hardship.

In relation to education, the 1992 Federal Act (s.22) provides that:

- (1) It is unlawful for an educational authority to discriminate against a person on the ground of the person's disability or a disability of any of the other person's relatives or associates:
  - (a) by refusing or failing to accept the person's application for admission as a student; or

- (b) in the terms or conditions on which it is prepared to admit the person as a student.
- (2) It is unlawful for an educational authority to discriminate against a student on the ground of the student's disability or a disability of any of the student's relatives or associates:
- (a) by denying the student access, or limiting the student's access, to any benefit provided by the educational authority; or
- (b) by expelling the student; or
- (c) by subjecting the student to any other detriment.
- (3) This section does not render it unlawful to discriminate against a person on the ground of the person's disability in respect of admission to an educational institution established wholly or primarily for students who have a particular disability where the person does not have that particular disability.
- (4) This section does not render it unlawful to refuse or fail to accept a person's application for admission as a student at an educational institution where the person, if admitted as a student by the educational authority, would require services or facilities that are not required by students who do not have a disability and the provision of which would impose unjustifiable hardship on the educational authority.
22. Hon J Kirner, then Premier of Victoria, Victorian Government Submission, p50.
23. Cheetham, op cit, p1715.
24. Greener, op cit, p11.
25. id.
26. Social Security Review, Issues Paper No5, 'Towards enabling policies: income support for people with disabilities', AGPS, Canberra 1988.
27. At the time of the review, people with disabilities were defined as 'invalid pensioners' under the 1988 Department of Social Security classifications.
28. Smith, op cit, p5.
29. Victorian Government Submission, p49.
30. In the training sector, Commonwealth and State Ministers established a Vocational Education, Employment and Training Advisory Committee to implement a nationally consistent framework for training programs. This framework is based on the progressive introduction of a competency-based approach to vocational education and training linked to award restructuring through the National Training Program. The Mayer Committee was established in 1991 by the Australian Education Council and the relevant Ministers to undertake work on employment-related key competencies.
31. 'Employment-related competence' refers to that generic competence which is required to undertake a wide range of occupations and industries. Statements of employment-related competence are developed through analysis of the kinds of work people do and how work is organised at entry levels within industry.
32. The Mayer Committee, *Employment-Related Key Competencies for Postcompulsory Education and Training: A Discussion Paper*, Ministry of Education and Training, Melbourne 1992, p21.
33. Eg D Bryson-Taylor, President, The Alliance for the Mentally Ill, NSW. Submission, p5.
34. Victorian Government Submission, p49.
35. Flynn, op cit, p16.

## Chapter 14

### **DISCRIMINATION: THE PERSONAL EXPERIENCE OF MENTAL ILLNESS**

How can I help you step inside my shoes, and the shoes of thousands of other mentally ill people?<sup>1</sup>

The worst thing was people I thought were my friends didn't talk to me after I came out of hospital. I don't know whether they thought I was still mentally ill or whether it was contagious or something, but it really hurt that they didn't seem to want to know me anymore.<sup>2</sup>

This report is primarily concerned with the reality of living with mental illness and psychiatric disability. The destructive effects of discrimination and stigma are documented in many chapters.

However, a substantial number of oral and written submissions were not just about the overt effects of discrimination and stigma; they included intensely personal and emotional accounts of the effects on the individual. These accounts were reinforced, in hearings and forums, by witnesses who provided powerful and moving descriptions of the trauma, erosion of dignity and denial of rights experienced by Australians with a psychiatric disability.

One must appear saner than the sane and...one must frequently encounter attitudes that the psychiatrically disabled cannot feel real emotions, love or care — are selfish, irresponsible and untrustworthy, or their various equivalents in legal, professional or bureaucratic terminologies. The only emotion we are ever attributed is anger...and anger is, of course, never rational in its origins and is always symptomatic of our condition — not a reaction or insight into slight, stigma, patronisation or discrimination, or the sense of overwhelming frustration we so often feel when the reality of our grievances are denied.<sup>3</sup>

I was surprised how much my internalisation of stigma and prejudice still limited my thoughts on the issues surrounding basic human rights.<sup>4</sup>

Of all the issues raised, the loudest and clearest messages from those directly affected were:

- the desperate need for understanding;
- the need to be able to speak openly and to be heard;

- the longing for acceptance by others of the mystery and the unpredictability of their illness, without constantly having to defend and explain to those who have little interest in understanding; and
- the desire to be equal with others and to have basic human rights respected.

These are, clearly, reasonable expectations. But the evidence indicated that they are not being met by the general community, nor by some professionals charged with caring for the individuals concerned.

And you wouldn't believe how many professional people don't understand the illness...the community has no hope if we are not able to communicate exactly what...people go through.<sup>5</sup>

The experience of mental illness is highly individualised, with people affected for varying lengths of time and suffering different degrees of disability.

To me a mental illness is a biochemical vulnerability, if you like, which means that under stress I become ill and I will probably need some extended care and I will probably have to go to hospital. It is disabling because sometimes I don't function, sometimes the medication makes it difficult for me to function and I don't really care how the services look after me as long as I am competently looked after and I think this is an issue that really needs to be discussed a lot more.<sup>6</sup>

Individuals also develop symptoms at different times in their lives, and their ability to cope depends, in part, on the severity of the episode, their insight into the illness, the support of family and friends, securing appropriate treatment in a timely fashion, their understanding of the services available and their ability to gain access to them.

Regardless of when someone has their first episode of mental illness the effect on their lives is dramatic. For some, one episode is all they experience — others will develop symptoms intermittently (some for the rest of their lives).

However, the initial advice from professionals is sometimes conveyed insensitively.

I don't think we can underestimate the damage we can do to people when someone with a lot of power says to them, 'you have this for the rest of your life'. I think it is one of the most disabling approaches that I can possibly imagine.<sup>7</sup>

Some individuals have been aware of being 'different' from those around them since their childhood.



If you ask people who suffer from mental illness about their childhoods most of them will say that in hindsight they can remember and recognise certain things about them that marked them out as being different from other people...before we experienced our first major episode of mental illness. These symptoms interfered greatly with education, employment, recreation and one's social life.<sup>8</sup>

And for many, the first episode of mental illness comes at a critical developmental stage, particularly in adolescence or early adulthood when they are challenging themselves and those around them in the search for independence.

The first episode of mental illness often disrupts secondary schooling, tertiary studies, our first employment experiences. It can disrupt dating and the formation of adult relationships and networks. It disrupts childbearing and child rearing.

Now these are incredibly important stages in anyone's life and they are difficult for most people. But if you compound that difficulty with having a mental illness that is especially problematical and uncontrolled, especially in the early episodes, those life stages become impossible obstacles to the full enjoyment of human life...I lost my late teens and I lost my thirties to mental illness. During my first decade of adulthood I spent about 70 percent of my life in psychiatric hospitals.<sup>9</sup>

## **What it Feels Like to be Mentally Ill**

As outlined in other chapters of this report, the physical and psychological symptoms of mental illness are disruptive and isolating.

You become withdrawn, and thus you quickly lose all social interest. All the time this is happening, it appears to be getting worse and worse... You begin to feel there is no point in living, in being part of the social and political scene. At its very worst, the depression is so extreme that it is physically painful to think... You feel worthless, listless, numb, fearful, uncaring, angry, confused, hateful, morose and anguished.<sup>10</sup>

For some, the experience of being ill is a dark and disturbing one. One person described an episode of endogenous depression:

Your thoughts start to get darker and increasingly negative. Regardless of what is going on around you, this black veil continues to descend across your line of vision. Your brain feels like it is carrying a lead weight. You begin to have a sense of futility. You are bored and apathy-stricken.<sup>11</sup>

For others, the experience has liberating aspects:

... I have danced glowing around gum trees [and] played piano concertos with joy. There have been lions and dragons and unicorns. I have walked with God through fields of colour and light surrounded by jewelled butterflies with birds free-wheeling above me and daisies at my feet.<sup>12</sup>

The way in which mental illness affects individuals and their relationships with other people and society at large means that those who are not ill are often suspicious and fearful of the mentally ill — because they have no insight into their condition.

To be understood, strengthened and helped in [the] community can be a daunting task for a mentally ill person. Confusion, embarrassment, strange behaviour and sensitivity to odours can stimulate weird or familiar memories which create tremendous problems for a mentally ill person.<sup>13</sup>

They lose insight into their condition, and as in my example, I was wandering the streets, yelling out, and someone grabbed hold of me and asked if something was wrong?... But the thing is that a lot of people who are mentally ill are not violent; they're very, very scared, right? They're very, very, frail, but they're frustrated, and they don't know which way to go.<sup>14</sup>

The discrepancy between the experiences and behaviour associated with mental illness and the community's standard of acceptable behaviour was one of the issues repeatedly mentioned by consumers.

No one perceives the value of differentness...if Van Gogh was in Australia he would be behaviour-modified out of painting; if Virginia Woolf was writing she would be locked up.<sup>15</sup>

Mentally ill people often have such intense experiences of what we call the supernatural that when trying to understand these experiences they begin to ignore the physical and emotional situations that the community are more concerned with, safer with and more tolerant of. [They] often lose touch with society's more mundane expectations both of itself and of others. So mentally ill people won't see that society can't share their vantage.<sup>16</sup>

Regardless of the cause, the reality for those affected is frequently frightening. But there is little appreciation of how difficult it is to live under such duress, by those fortunate enough to be symptom free.

You can't have a privileged or quality life. Life for me is a survival and not a pleasurable thing.<sup>17</sup>

Others feel their life is controlled by voices and radio waves:

The electronic media has invaded my privacy and I demand they stop persecuting me. They have no right to monitor me.<sup>18</sup>

Over time, many learn to recognise the early warning signs and prepare for the symptoms. For some this means they gain a degree of control over their lives as they develop an understanding of their illness and begin to negotiate our complex mental health system — which many consumers perceive as largely user unfriendly.

When one is ill, one needs help to cope and help in asserting one's rights; and apart from family and friends, help is difficult or impossible to find. I am lucky in having helpful family and friends, but many people who are ill have no one to help them.<sup>19</sup>

For others this feeling of control is extremely fragile. They live in fear that all they have achieved, both professionally and personally, between episodes of illness will be put at risk if, or when, the symptoms start again.

During this three month period I did horrendous damage to my marriage, my ten year old daughter, my family business and my local community standing.<sup>20</sup>

Anything I had done, any achievements, hopes or aspirations were as if I had never existed, because I was no longer part of the mainstream. I had gone.<sup>21</sup>

Those who have experienced devastating episodes often fear they will not survive, or don't want to survive, such turmoil and blackness again.

You're constantly living on the edge of a precipice. You don't really know what's down there in the murky depths. You've fallen off the top many times, and you're scared stiff. Each time it's different, so you never get used to it.<sup>22</sup>

## **Stigmatisation**

Coming to terms with the illness and the associated disability is often exacerbated by the effects of stigma:

The horrendous consequences of my illness have been [a result of] public attitudes of ignorance, fear, discrimination and neglect and professional indifference.<sup>23</sup>

Indeed, many felt that one of the most debilitating aspects of being mentally ill was not the illness itself, but the social stigma it attracts. It erodes confidence, damages self esteem, and contributes to an overwhelming sense of isolation and fear.

While discussion of the symptoms and treatment of physical illness is commonly accepted in our society, the same is not true of psychiatric disorders. Evidence to the Inquiry clearly established that a major factor shaping the way in which mental illness is perceived and treated is the stigma still almost invariably associated with it. This was a major issue of concern identified by all consumers giving evidence to the Inquiry. For those who experience mental illness, the lack of acceptance and understanding of psychiatric disability is itself an abuse of human rights.

There is a stigma associated with mental illness. It leads to some strange behaviour and creates difficulties in living in peace and harmony with oneself and with others... Lack of understanding of what is happening to a mentally ill person can make for difficult

situations. Many people prefer to avoid relationships with others whose behaviour is not seen as 'normal'. This is not good for the mentally ill person. People need social interaction to improve health.<sup>24</sup>

This attitude devalues me as a person and it devalues all the suffering my illness has caused me. I find that I am blamed for being ill, and all the resultant problems, I am told, are all my fault.<sup>25</sup>

**The stigma and suspicion directed at people affected by mental illness is a major barrier to their full and equal enjoyment of life. It creates fear and isolation when people are most in need of tolerance and understanding.**

- Suffering from a mental illness is a terrible experience and it is made worse in that people are not respected as human beings... My illness is harrowing and the misunderstanding I constantly meet makes it difficult to maintain my self esteem.<sup>26</sup>
- We are unwanted and neglected. People say 'They are best left in hospital where they belong': 'They make me nervous': 'They're not like us': 'What if they hurt my children'... You want to be loved when you are sick.<sup>27</sup>
- You tend to get the attitude that you are a vegetable and incapable, and get treated like a child — pushed around instead of being treated like a human being...because you are a bit slowed down by medication etc and not so capable of looking after yourself..<sup>28</sup>

**For many, public reaction to their illness means discrimination and severely curtailed opportunities because they do not conform with what are considered 'normal' codes of behaviour.**

As a psychiatrically disabled person, too well I know the limitations I experience because of my disability, but my heart is beating like thunder to think of the endless other limitations that daily I endure not because of my disability but because of society's fear of the label 'schizophrenic'.<sup>29</sup>

Although society is not to blame for the client's illness, society's fear and ignorance of such problems does often perpetuate and amplify them.<sup>30</sup>

**The stigmatisation and marginalisation suffered by the individual is often allied to the use of psychiatric labels:**

- One of the worst things that can be done is to have a psychiatric label put on you...because it discredits you for the rest of your life. And people use that to discredit what you want to say, when you want to complain about abuses in psychiatric hospitals...and the abuses in the hospitals today.<sup>31</sup>
- It is important to note that my illness is episodic, but the label is continuous. So, the minute your mental illness is perceived you vanish. All they see is that.<sup>32</sup>

- There is also the ongoing pain of social stigma when a label has been applied which affects housing, employment, social life, everything. Couple this with the helplessness of illness and paternalistic treatment and it seems only logical and quite sane that many mental patients resort to suicide to get off the treadmill.<sup>33</sup>

Many witnesses recounted the loss of their 'identity' once a diagnosis had been made. They felt that society saw only their label, and with this they ceased to have the same needs, emotions and rights to make decisions about their lives.

- These needs include the right to a reasonable quality of life to be treated with respect, understanding and friendship — as well as treatment for (medical) needs.<sup>34</sup>
- Those labelled mentally ill or mentally disturbed are deemed to be incapable of making rational decisions for their own welfare.<sup>35</sup>
- One's sexuality is not considered to be important.<sup>36</sup>

Criticisms were also made of the manner in which all people with a mental illness are grouped together — regardless of the substantial differences in their symptoms and their needs.

...when you are a psychiatric patient you are lumped all in together. Everybody with every disorder is kind of put in the same ward. It's very difficult to cope with your own feelings that are going on in your own head and trying to sort of comprehend what is happening to you, let alone trying to comprehend what is happening to 20 different other people, all of whom may be suffering maybe from 20 different other kinds of disorders.<sup>37</sup>

## Inequality

Why haven't we got the right to say this is the most neglected, forgotten illness and nobody is taking responsibility for it.<sup>38</sup>

But I felt, at last, that I had won the right others not so affected took for granted and frequently denied me. Beyond the right to be angry about injustice was the right to a full range of feelings that were appropriate to the reality of my life.<sup>39</sup>

It is clear from the evidence that many thousands of Australians affected by mental illness must still struggle daily to have their rights respected.

Ultimately human rights are not about words on paper or ideas one talks about — real human rights for the psychiatrically disabled are about optimum care and access to services in illness, and ensuring that in recovery your diagnosis does not deny you access to aspects of society others can fully partake of...<sup>40</sup>

Quite often they don't get what they want, they get what other people think they want.<sup>41</sup>

Evidence concerning widespread and often systemic failure to respect human rights is documented throughout this report. Much of it concerns the failure to respect the individual's rights in hospital.

Hospital life is frustrating and humiliating. No real attempt is made to restore one's self respect before one is released from hospital into a world where one is devalued and regarded with suspicion.<sup>42</sup>

The process itself of being forcibly detained is distressing but to be upset by it or to exhibit anger or despair or agitation is to prove oneself ill or disturbed. The person in difficulty has to muster, by some superhuman means, the ability while so distressed to present a totally rational and articulate plea to those who are trained in such things while, in fact, in need of a stress-free and nurturing environment in which to rest and heal.<sup>43</sup>

## Marginalisation

Another significant theme emerging from many submissions was the extent to which people with a psychiatric disability feel marginalised from society and excluded from basic issues which affect their lives.

One needs help to find the way through the medical system. Getting adequate and supportive professional help seems to be a matter of chance or persistence. It is difficult to be persistent when you are ill, even if someone is encouraging you... I was very disappointed that my doctors and the hospital did not give me more information about my illness and the availability of help... When one is ill, one needs information — but it must be offered. The sick person cannot press for the information.<sup>44</sup>

Consumers experience immense difficulties in asserting their right to be accepted and to find the support and opportunities to simply share in community life.

Consumers today still do not have a guaranteed platform from which to speak, but rather we stand on a web spun from our own efforts, tethered to those within the system who believe in us and our rights. We sometimes feel that to vibrate the web too much is to be shaken from it, but now there are always more consumers ready to speak out for the changes they need to ensure that their dignity and their rights to adequate care and services are maintained.<sup>45</sup>

Many witnesses appealed for appropriate public recognition of their rights.

[We want] the right to speak and represent ourselves directly, because I firmly believe they are still essential for future generations of the psychiatrically disabled to achieve their full potential within society.<sup>46</sup>

Clearly, many barriers prevent people with psychiatric disabilities from participating in the advocacy and decision-making processes which directly affect them.

Historically we have been, for the most part a silent minority group...falsely shamed into silence and frequently intimidated — and I mean intimidated here — from seeking representation.

At best...we have encountered a forest of patronising attitudes and paternalism...at the same time denying us the dignity and the right to represent ourselves.

To speak for ourselves, [is] a basic human right. That it would be too stressing used to be the most common rationalisation for our exclusion from the debates that affected our lives. Repression, misinterpretation and reinterpretation of one's reality is stressful.

Some of these forums that purport to have our interests at heart still actively in their charters or constitutions discriminate against us.<sup>47</sup>

However, it is significant that despite these difficulties, many consumers were prepared to share their experiences with the Inquiry — in the hope that others with mental illness and the community at large would better appreciate their human rights and needs.

There are many more survivors out there who have the qualifications of 'consumer' but are not being able to use those qualifications in any way, manner or form. I think these qualifications, to call oneself a consumer of psychiatric services, are the hardest earned qualifications that any person could attain. It is the hardest of all qualifications I have ever had. It is the one I fight every day — every moment of every day — to retain and I think anyone who is a consumer of psychiatric services knows what I'm saying.<sup>48</sup>

As this evidence indicates, one of the fundamental difficulties experienced by people with mental illness is the degree to which they must depend on those around them. Others discussed the effect the illness has had on their family relationships.

I still have a bit of a problem with the fact that my parents would not accept me when I left hospital... I left home and then I had my breakdown and they wouldn't accept me back.<sup>49</sup>

Several consumers expressed their frustration and anger at not being able to function as fully independent adults because of the nature of their disability.

Our right to the pursuit of wealth and happiness is circumscribed in this society as are our job prospects and opportunities. We are at present forced into the dual health and wealth crisis of acceptance of an episodic illness, and poverty, imposed by prejudice and unfair social response to our illness.<sup>50</sup>

A consumer consultation undertaken by the Victorian Mental Illness Awareness Council found that many consumers identified the need to feel more involved in and responsible for their own lives.<sup>51</sup> These sentiments were echoed in evidence to the Inquiry.

Consumers want to be more involved in managing their own illness and to participate in decisions about their lives. They do not want to be ignored and their views invalidated because they are sometimes mentally ill. International charters support their rights to this participation and both national and state policies endorse the principle of participation. It is obvious from this consultation that most people with mental illness have not experienced this principle in practice.<sup>52</sup>

## Discrimination

There has been systematic discrimination against the mentally ill in terms of communal stigma which is reflected in the services. There is ample evidence that they are stigmatised more than other groups with disability... They are [treated as being] the bottom of the heap in the pecking order.<sup>53</sup>

It takes more than living skills and assertiveness training to acquire access to services and your potential if society as a whole does not believe in your value...[and] harder still if those services never existed.<sup>54</sup>

**The Inquiry repeatedly heard evidence of discrimination against people affected by mental illness in a wide range of areas.**

We're called consumers, but when we go to look for services for consumers — what services are there provided for us to consume?<sup>55</sup>

There are difficulties in terms of 'labelling'. It is civil law for people to enter into contracts, but many private contracts specify that a person who is made an involuntary patient ceases to have rights under particular legislation or agreements. I believe that is still very widespread. It was, in fact, a shorthand attempt to deal with the issue of competence.<sup>56</sup>

There were also occasional stories of success in combating discrimination. For example, the President of the National Association for Mental Health told the Inquiry that the Civil Aviation Authority had, until recently, a number of 'bizarre' restrictions on people with a mental illness travelling on aircraft: the authorities must be informed; no two people with mental illness may travel on the same aircraft; anyone at risk of being violent must be restrained on a stretcher and accompanied by two attendants, including a trained psychiatric nurse; there must be a net or other barrier between them and the flight-deck; and therapeutic oxygen must be available. As the witness remarked, 'One wonders whether psychiatry has been missing something for years!'<sup>57</sup> He described action taken by his Association:

If you look at the back of your airline tickets when next you are flying, just have a read and see what it says — it will shock you... We received a letter from the Managing Director of Australian Airlines within the month, saying he fully supported our contentions and that he had instructed his legal department to re-write the provisions.<sup>58</sup>



However, the Inquiry heard many other examples of unwarranted discrimination against people affected by mental illness, in addition to those chronicled in earlier chapters of this report. These included ineligibility for membership of Boards and Tribunals at one end of the spectrum and inappropriate questions on standard form documents at the other. In many cases no attempt was made to specify evidence of 'functional impairment' as the sole relevant criterion for exclusion — or, conversely, to require proof of 'competence' in order to take up or continue the activity or receive the relevant benefit.

I was told that I wasn't stable enough [to go to university]... Well to be fair, at the time I probably manifested as not being stable enough, because everything in my life to date was about failure. My whole identity was about being a mentally ill person. I had none of the social skills that I've gained through my education and through my employment.<sup>59</sup>

## **Discrimination in Financial Life**

Evidence was also received concerning two particular areas in which people affected by mental illness encounter unjustified discrimination: insurance and superannuation.

### *Discrimination in Insurance*

The Inquiry was told that insurance companies frequently impose loadings, or even exclusions, on people who have (or have had) a mental illness. Witnesses considered these loadings and associated conditions were out of keeping with the true risk which their state of health implied. In particular, they considered that insurers took insufficient or no account of the type of illness, its severity, its prognosis, or its consequences for longevity or for income-earning capacity:

I inquired of my usual insurance company about the cost of insurance for schizophrenia sufferers. I was told that there is a 100 percent loading on all types of insurance to cover people who have had at least one acute episode in their lives requiring hospitalisation. If the policy is taken up, the insurer has the right to refuse [cover] if there has been an acute episode in the preceding 12 months. This means that, compared to other non-loaded consumers, a \$50,000 policy would cost double the premium charged [for a non-mentally ill policy holder], or alternatively, the value of the policy would be halved... Penalties can be imposed or a policy voided if information [about the illness] is withheld.<sup>60</sup>

The Inquiry also heard allegations of insurers failing, without explanation, to take account of specialist medical opinion in rejecting applicants:

I am aware of one person who had been working for the same organisation for five years and decided to apply for income protection. She had previous episodes of depression. She included a letter from her doctor with the application, which was rejected.<sup>61</sup>

In this context the Inquiry noted the submission of the Life Insurance Federation of Australia (LIFA):

LIFA wishes to emphasise as strongly as possible that insurers are concerned to treat mental illness, for the purposes of underwriting, in the same manner as they would treat any physical illness.

Nevertheless, the question must be asked whether, in the light of contemporary expert medical opinion, and the well established success rates of treatment for mental illness, the insurance industry remains unjustifiably cautious — to the point of discrimination in its assessments of risk in this area. (Issues relating to health insurance for people affected by mental illness are also addressed in Chapter 5 — Mental Health Services.)

### *Discrimination in Superannuation*

A clear case of discrimination against people affected by mental illness exists in certain employer-sponsored superannuation arrangements:

I personally have lied about superannuation, and this is the dilemma that people like me face. We have severe episodes of mental illness, we recover to the extent that we can actually get jobs, we are able to fudge our CVs a bit...but superannuation really is an issue for a lot of people. The medical form for superannuation is outdated... The particular part on the form asks 'Have you ever suffered from depression?' It is a very widespread disorder and there is a vast difference from a mild depression...to the severe kind of depression that may last a couple of years. The form doesn't really reflect the prognosis for depression — initially it was quite debilitating...[but] now the medication I take works fairly quickly when I get that kind of depression and I don't even take a day off work.<sup>62</sup>

This type of discrimination is particularly insidious because it is structural. Eligibility for insurance (or its equivalent) is being used to exclude people from a very significant financial benefit irrelevant to insurance, viz, superannuation. Access is being denied to the financial support that employer-sponsored schemes provide, which is the principal attraction of superannuation.

Clearly, such discrimination is impossible to justify — especially when many schemes do not have this defect, but treat insurance issues separately from the right to be a member of the employer's superannuation scheme and to receive benefits for retirement purposes accordingly.

Another consumer, who had had superannuation, but lost it told the Inquiry:

I was suffering from my illness for two years before I was treated for it. During this period, I did some bizarre acts, including resigning from my job when my sick leave ran out. I have tried, unsuccessfully for five years to obtain the superannuation benefits that would have been mine if I had suffered from an ordinary illness... A recent court decision

has left the way open for me to take the case to court — if only I could find a medical referee would [verify what I say].<sup>63</sup>

The case suggests that the exercise of trustee discretions can be applied in a discriminatory manner. (In the absence of mental illness, it seems clear that the employee here would not have resigned, and lost superannuation entitlements on account of that act.)

Discrimination also clearly occurs when an employer accepts a resignation from a person affected by mental illness, when other options (such as invalidity) would be pursued in the event of physical illness.

Evidence to the Inquiry indicated that when individuals have suffered a mental illness, claims for superannuation entitlement are seldom pursued. This is either because claimants do not feel confident enough to pursue powerful trustees, or because they wish to avoid publicising their mental illness, or both.

### **Discrimination in Provision of Professional Services**

This is a very delicate issue. It is difficult in this State to find sufficient people to fulfil the tasks of Medical Officers in many of our psychiatric hospitals, and what happens is that people with overseas medical qualifications which are not recognised in Victoria are given provisional registration to work in psychiatric hospitals until they can pass the necessary examinations to obtain local qualifications.<sup>64</sup>

Earlier chapters of this report describe discrimination practices against those affected by mental illness in psychiatric facilities and other institutions.

The Inquiry was also informed that in at least one State, Victoria, it has been the practice to recruit to psychiatric hospitals overseas trained doctors who did not hold a current practising certificate. The apparent justification for this practice was that there were not enough Australian-trained psychiatrists available or willing to work in public hospitals.<sup>65</sup>

While sympathetic to the considerable difficulties faced by doctors from overseas in finding employment in Australia, the Inquiry considers that a person hospitalised with a mental illness has the right to be treated by clinicians whose qualifications have been assessed and approved by the competent Australian authorities — whether those doctors have received their training in Australia or elsewhere. If this practice still exists it clearly constitutes discrimination and must cease.

## **Conclusion**

Consumers presenting evidence to the Inquiry eloquently, and movingly, established that mental illness is an enormous burden for many Australians. That burden, however, becomes overwhelming when stigmatisation and discrimination are the daily lot of those who bear it. There is no excuse for such breaches of human rights: but it is clear that such breaches are often based on fear and ignorance. That is something our community can and must address.

1. Anne Greener, consumer. Oral evidence, Sydney 20.6.91, pp519-520.
2. Meg Smith, Depressive and Manic Depressive Association of NSW. Submission, p5.
3. Simon Champ, Schizophrenia Fellowship. Oral evidence, Sydney 18.6.91, p217.
4. Simon Champ, consumer. Submission, p1.
5. Win Leslie, carer. Oral evidence, Ballarat 11.4.91, p623.
6. Meg Smith, Depressive and Manic Depressive Association of NSW. Oral evidence, Sydney 17.6.91, p90.
7. Peter Humphries, social worker. Oral evidence, Ballarat 11.4.91, p561.
8. Greener, op cit, p519.
9. id.
10. Written by Jason, who committed suicide aged 20. Information made available to the Inquiry by his mother.
11. Name withheld, consumer. Canberra Issues Forum, 18.3.92.
12. Fran Gillespie, consumer. Oral evidence, Devonport 13.11.91, p307.
13. Doug McIver, consumer, ACT. Submission, pp2,3.
14. D Cheetham, consumer. Oral evidence, Brisbane 16.8.91, p1699.
15. Gillespie, op cit, p307.
16. Penelope Douglas, consumer, NSW. Submission, p2.
17. R Bailey, consumer, NSW. Submission, p2
18. Name withheld. Information provided to Inquiry.
19. Name withheld, consumer, NSW. Submission No239, p1.
20. M Graden, consumer, NSW. Submission, p1.
21. J Meagher, consumer, NSW. Information provided to Inquiry.
22. Name withheld, Canberra Issues Forum, 18.3.92.
23. Gillespie, op cit, p307.
24. McIver, op cit, pp2-3.
25. Name withheld. Submission No239, p7.
26. Name withheld. Submission No239, pp4-5.
27. B Rainey, consumer, NSW. Submission, p3.
28. Name withheld, consumer. Oral evidence, Melbourne 10.4.91, p451.
29. Champ, op cit (submission), p2.
30. Douglas, op cit, p1.
31. B Hart, Chelmsford Action Group. Oral evidence, Sydney 19.6.91, p35.
32. Gillespie, op cit, p302.
33. Dr C McLeod, PALA. Oral evidence, Sydney 21.6.91, p622.
34. Name withheld, consumer, NSW. Submission No334, p2.
35. Name withheld, consumer. Oral evidence, Canberra 21.7.92.
36. Name withheld, consumer, NSW. Submission No239, p5.
37. Smith, op cit, (oral evidence), p89.
38. Leslie, op cit, p623.

39. Champ, op cit, p6.
40. ibid, p12.
41. Humphreys, op cit, p555.
42. Name withheld, consumer, NSW. Submission No239, p4.
43. McLeod, op cit, p618.
44. Name withheld, consumer, NSW. Submission No239, pp2,4.
45. Champ, op cit (submission), p4.
46. id.
47. ibid, p3.
48. J Meagher, consumer. Oral evidence, Sydney 17.6.91, p126.
49. Name withheld, consumer. Oral evidence, Melbourne 10.4.91, p451.
50. Name withheld, consumer. Oral evidence Brisbane. 14.8.91, p1492.
51. Victorian Mental Illness Awareness Council, *Listen to our Voices*. Project Focus: Consumer Consultation Report, Melbourne 1993. Information made available to the Inquiry, p11.
52. ibid, p33.
53. Dr A Rosen, psychiatrist, Northern Sydney Area Mental Health Service. Oral evidence, Sydney 19.6.91, pp370-1.
54. Champ, op cit, p5.
55. Leslie, op cit, p623.
57. Tony Lawson, President and Board Member, Guardianship Board of Victoria. Oral evidence, Melbourne 9.4.91, p207.
57. Rick Redom, President, National Association for Mental Health. Oral evidence, Hobart 12.11.91, p200; and Giles Yates, Centre for Human Bioethics, Victoria, pp1-9. Paper provided to the Inquiry giving an analysis of the Civil Aviation Orders.
58. id.
59. Greener, op cit, p522.
60. Name withheld, South Australia. Submission No753.
61. Smith, op cit, p92.
62. ibid, p91.
63. John Caldwell, consumer, Vic. Submission, p1.
64. N Rees, President, Mental Health Review Tribunal, Victoria. Oral evidence Melbourne 8.4.91
65. Concern about the fact that too few psychiatrists are choosing to enter the public health system was expressed by a number of representatives of the Royal Australian and New Zealand College of Psychiatrists who gave evidence to the Inquiry. Eg Dr David Lord, representative, RANZCP, Western Australian Branch, and consultant psychiatrist, Fremantle Hospital, Perth. Oral evidence, Perth 11.2.92, p138; and Dr William Bor, representative, RANZCP, Queensland Branch, and Child, Adolescent and Family psychiatrist in private practice. Oral evidence, Brisbane 15.8.92, p1603.

## Chapter 15

# CARERS: THE EXPERIENCE OF FAMILY MEMBERS

### Introduction

Carers, as a group, work 24 hours a day, seven days a week, 365 days of the year. They do not get shift allowances... they do not get recreational leave, and they certainly do not get long-service leave. They have got a huge responsibility... and there have not been appropriate resources applied to their support. There have been substantial savings made by state governments from closing down institutions of various sorts... and the money has gone up in smoke.<sup>1</sup>

The pain and stress associated with caring for a child, partner or parent who has a mental illness is a cost to the community which can no longer be ignored. Watching a loved one succumb to the ravages of mental illness is devastating, and the struggle to obtain professional advice and appropriate treatment is in itself exhausting and often traumatic.

Like hundreds, perhaps thousands of families of the mentally ill, my husband and I stumbled about in the dark, unable to effectively help our daughter and alone with our pain.<sup>2</sup>

The task of providing continuing and continuous support and care at home often extends over many years — and the stresses associated with providing that care are compounded by what families perceive as an almost total lack of understanding, recognition or support from government agencies, health care professionals and the community at large. Needs most consistently identified in evidence to the Inquiry included a desperate lack of respite and domiciliary care, counselling and family therapy, better recognition of and sensitivity to relatives in the primary carer role, and more information and consultation — carers want to be heard by clinicians, not dismissed.

With the shift to community care, the burden borne by thousands of families of those affected by mental illness has intensified — in some cases beyond endurance.

Alliance for the Mentally Ill...speaks also for the rights of the families who act as primary caregivers, often by default as there are no other alternatives and the 'system' fails to provide the support and relief needed. Only recently has there been some recognition of the 'Burden of Care' and the costs, economic, physical and social, which are the result of deinstitutionalisation.<sup>3</sup>

The parents, spouses and children of people with mental illness rarely have any specialist training or education in dealing with chronic mental illness, little or no knowledge of the side-effects of psychotropic drugs, and no knowledge of how to calm or counsel a suicidal or potentially violent person. Carers are crying out for this basic information — frequently denied them on the basis of doctor-patient confidentiality.

Many submissions criticised the lack of credibility — or even basic courtesy — accorded to relatives, and doctors' refusals to hear or take seriously a relative's account of behavioural symptoms and history. This causes great difficulty and distress where a carer is battling to obtain appropriate treatment for their loved one, and the patient presents well to the assessing psychiatrist, but is psychotic at home. On the other hand, where doctors do attend to what a relative has said in this regard, they sometimes proceed to recount this information to the patient. This can damage an already fragile relationship, undermining the trust which is a vital element in every patient-carer bond.

These situations pose ethical dilemmas which, while complex, demand urgent attention. A simplistic and inflexible approach to the issue of confidentiality denies and devalues the role of home carers as front-line members of any treatment team.

Individual carers and representatives of support groups such as ARAFMI repeatedly presented evidence of the impact which a role as full-time carer has upon the relationship with the patient, on other family and social relationships, and on home life, career and family finances. Withdrawal, isolation, depression and physical and emotional exhaustion frequently follow from the stresses of coping with mental illness in the family. And, not surprisingly, excessive family burden and stress associated with care will influence the outcomes for people with serious psychiatric disorders.<sup>4</sup>

The burden of care is particularly high where the consumer lives at home. Many of the issues associated with caring for consumers who are still living with their families have been addressed in Chapter 10 — Accommodation.

While many submissions criticised medical staff and other service providers, carers expressed great admiration for those health professionals who did consult with relatives, kept them informed, provided support and treated the family and consumer with dignity and respect. Unfortunately, such individuals were hard to find. For some carers, resort to the private sector, often at great expense, provided the only sustainable solution.<sup>5</sup>



## Lack of Information

How dare the doctors hide the facts from parents and patients? It was our right to know that which was to affect our lives so much. How dare they fail to explain how important the medication is, exactly what it is intended to do and what can happen if the person with schizophrenia does not take it.<sup>6</sup>

In the initial stages of a person's illness, family members may be confronted by disturbed behaviour, odd statements, depression or anxiety. Many carers described their sense of growing frustration in efforts to gain help or information, particularly from GPs.

My Sydney GP... told me when my daughter was psychotic and I could not get her scheduled, to forget her. She said I had three other children, let [this daughter] go, and get on with my life... This doctor felt that her troubles were drug-induced, and wanted nothing to do with it. My angry answer to this is: do GPs only treat the good ones?<sup>7</sup>

Many witnesses reported that the first glimmer of understanding and efforts at explanation came from contact with ARAFMI, the Schizophrenia Fellowship, or other support and self-help organisations for relatives and friends of people with mental illness.<sup>8</sup> Where carers had been fortunate enough to discover these organisations, it had usually been by chance:

It was a newspaper article about the Schizophrenia Fellowship that allowed me to establish contact, receive endlessly helpful advice, access to reading material and encouragement to join ARAFMI. None of the doctors, nor the two hospitals... had suggested it.<sup>9</sup>

However, while these groups can provide invaluable support and general information, carers felt strongly that they have a right to information direct from treating doctors about the nature of the illness, the symptoms, and how to cope with a person who is experiencing a period of severe mental illness. (See also Chapter 8 — Inpatient Care and Treatment.)

The duty of confidentiality to the patient is a reason sometimes advanced for failure to disclose information about matters as fundamental as side-effects of particular medication, the likely result of an outpatient's failure to take his or her tablets — and even statements made whilst in hospital about an intention to commit suicide. The consequences of withholding such information from parents or spouses responsible for day-to-day care can be fatal,<sup>10</sup> and at the very least cause distress:

For 25 years my mother has been treated for manic-depressive illness. In that time, my father had one psychiatrist talk to him, and my sister and I have had none. My mother has had a severe reaction to the drugs used over Christmas. She was in a semi-coma which

is directly attributable to the drugs given. However, I still have not heard from the psychiatrist.<sup>11</sup>

**Another carer described a frightening experience with her son:**

On one occasion he was given some tablets and allowed to come home for the weekend [from Morisset hospital]. During the weekend, he became paralysed. He couldn't even open his jaw, he couldn't speak, and at first you get so confused... I thought, he is putting on an act. So finally, after 24 hours of this, I realised it wasn't an act. We... took him to the community health services and they were shocked when they saw him.<sup>12</sup>

If this mother had been warned about this possible side-effect, she could have reacted sooner, avoiding unnecessary distress and 24 hours of suffering for her son. The policy of allowing home visits is clearly a good one — provided the carer is given appropriate information in advance about the patient's behaviour and progress, medication to be taken, possible side effects and how to access help, should a crisis develop.

Lack of information can impact upon the whole family. Without adequate professional advice about the illness, carers cannot explain to the children or young siblings of an ill person the nature of behavioural and physical symptoms and the effects of medication. Fear and enduring resentment may result, as the Inquiry heard from a young man whose mother has a manic-depressive illness:

One thing which severely affected my upbringing were certain by-products of the drugs. These included 'zombie' like states and the 'Parkinsonian' effects of uncontrolled limb movement, especially legs... Lack of information and understanding caused a major trauma in my life... [They] affected us both.<sup>13</sup>

## **Difficulty in Obtaining Treatment for a Relative**

Carers... know the medical history. They can detect subtle differences and changes that would not be apparent to outsiders. They know the [person's] skills, capabilities, hopes and dreams and, most of all, they love the person. What a lot of pluses that would otherwise be unused.<sup>14</sup>

Carers find it very difficult to understand why so little credibility is given to the background information they can provide, particularly in relation to early warning signs of illness, which are often quite easily recognised within the context of daily family interaction.<sup>15</sup> Gaining admission to hospital is especially difficult for someone who has insufficient insight into his or her condition to accept treatment voluntarily. Lack of insight is a particular problem with schizophrenia, with some estimates indicating that nearly 40 percent of consumers deny they are ill or need treatment.<sup>16</sup>

One mother described her desperation as she watched her son, who had already been diagnosed as having brain damage and schizophrenia, becoming more and more confused and violent. His refusals to eat and sleep were gradually reducing him to 'a mere skeleton,' while her pleas for his hospitalisation were ignored:

*The doctor took no notice of what I said. In his opinion Peter was quite alright... you couldn't possibly imagine how completely devastating it was... all my begging for help just fell on deaf ears... In my opinion this type of treatment destroyed the basic human rights of the individual to receive reasonable medical attention.<sup>17</sup>*

This mother was subsequently told by a nurse that, for the doctor to take notice of her son's condition, 'You'll have to jump up and down a lot more.'<sup>18</sup> While carers generally understand the principle of protecting the liberty and rights of the individual against inappropriate hospitalisation, many are outraged by what frequently amounts to a cruel denial of the treatment which could ease the suffering of all concerned. As one carer explained:

*Families are not wanting to 'put their relative away'; they want specialised help over the stormy period and to achieve a quick recovery.<sup>19</sup>*

Even where the relative has a history of mental illness and previous treatment, and family members observe behaviour patterns indicating that relapse is imminent, early intervention by professionals is, according to many witnesses, uncommon. Deterioration must be extreme before anything can be done, which has significant consequences both for consumers and carers in the long term.

*It is an injustice to the sufferer's family and the community. It is damaging to the welfare of the sufferer who need not have been allowed to deteriorate so badly, to wreck their life chances with employment, financial status, health and the loss of support of friends and carers.<sup>20</sup>*

## **Legal Procedures**

In both written and oral submissions carers repeatedly emphasised their need for clear information about legal provisions, guardianship hearings, and procedures relating to involuntary treatment.

*There was a lot of confusion in my mind about the difference between the hospital order, which gives the medical staff the right to give any treatment they choose without the consent of the patient, and the order giving management of the patient's affairs to the Protective Office.<sup>21</sup>*

Families already experiencing the inherent trauma of seeking involuntary treatment for a loved one need support and advice in traversing the legal minefield. When a treatment or guardianship order is made, it is vital that the primary carer be advised of matters such as when and how a patient (or family member) may lodge an appeal, when the order will otherwise expire and whether, upon expiry of the order, the patient will be discharged automatically. This information should be provided to families in written form, and explained in a clear and sensitive way. The evidence demonstrated beyond question that this frequently does not happen.

One carer described the lack of reasonable notification provided by the hospital where her mother was an inpatient, when the treating doctor made an application to the court to administer ECT:

The telephone call telling me my mother was going to be put under the court order came the day before. It was fortunate that I have an answering machine and arrived home in time to receive the message and ring the hospital back during... working hours. It could easily have happened that I did not know my mother had been placed under this order until after the event. This must happen to relatives in many cases.<sup>22</sup>

Family members with responsibility for care of the patient outside the hospital stressed that they should be notified of any court application, appeal or review hearing in time to arrange attendance and representation.

Occasionally, the frustrations associated with navigating the maze of legal and medical procedures become too much, and families withdraw support, feeling they can do no more to help:

We do know of cases where [families] have applied for the role of guardian and they have been denied that role, and that the person affected has been without any provision made to ensure their welfare, access to shelter, food and support. Very often the relative in that case washes their hands of responsibility for that person, because they feel there's nothing more that they can do.<sup>23</sup>

## **Consultation between Family and Professionals**

We would like to reinforce the need for a therapeutic alliance between the professionals and the families, in order to ensure optimal outcomes for the patients.<sup>24</sup>

Including the carer in the therapeutic team has the added advantage of making available to the team the carer's detailed knowledge of the patient's background.<sup>25</sup>

Recognition as part of the caring team is denied by many doctors' reluctance, and in some cases, refusal, to consult with carers at various stages of treatment. There is some professional recognition of the problem:

If psychiatry pays attention to families and incorporates them into treatment, things become better. But we don't always listen to families as much as we should.<sup>26</sup>

Indeed, some studies of community psychiatric services have positively recommended consultation and joint decision making with primary carers in patient management, as well as education and skills-based family training and therapy.<sup>27</sup> Nevertheless, the evidence received from carers during the course of the inquiry clearly established that the practice of these principles remains the exception rather than the rule — at every stage of the treatment and rehabilitation process.

The Inquiry heard that when carers do manage to secure treatment for an acutely ill relative by admission to hospital, they are frequently excluded from any consultation thereafter. Parents and spouses are left uninformed about almost every aspect of the patient's welfare, even transferral to another hospital:

We asked to be alerted and informed [so] that maybe we could look at other alternatives for our son, if the situation got to the point in which they found it too difficult to cope at Dax House. Instead of that, they transported him to Lakeside...transgressing any rights that he had to contact his family or to look at alternatives... We had no possibility of becoming involved, even though we had been the carers for many years before that.<sup>28</sup>

The Inquiry heard that even in extreme circumstances, when an inpatient had a major seizure or attempted to commit suicide, hospitals sometimes failed to notify the primary carers.<sup>29</sup>

Some hospitals fail to provide information about matters as basic as a change in visiting conditions. Certainly, it is for medical staff to make judgments about the visiting arrangements best suited to the patient, but it is simply cruel to leave family uninformed, thereby heightening uncertainty and distress.

We would telephone the centre to go out and see our daughter and get there and have difficulties because somebody had not put a note on her file, or she had been put in some sort of solitary confinement.<sup>30</sup>

The Inquiry also heard criticism of actual visiting conditions, for their lack of sensitivity to the needs of family and patients:

Patients and visiting families feel imprisoned both by the lack of privacy and the surveillance from the nurses station.<sup>31</sup>

Relatives' concerns about the need for information apply particularly when a consumer is discharged from hospital, directly into the care of family members at home:

Too often the family or carer was left in the dark, expected to pick up the pieces after the sick family member returned from hospital, with little or no idea if support was available or where it was to come from... Carers [need] to have information so that they can 'continue to believe in' the mentally ill person.<sup>32</sup>

This would include information about rehabilitation plans, medication and a contact person should an emergency arise. Without this information, families are often at a loss as to how to play a constructive role in the rehabilitation of their relative.<sup>33</sup>

In some cases, individuals have been sent home without anyone at all being notified — sometimes with tragic results:

In addition there was someone who was not followed up properly when they left hospital and the outcome... was that the person suicided. They went home; there was no one in the house; they went into the bathroom and cut their wrists and suicided.<sup>34</sup>

In many cases consumers are released from hospital into the care of a relative. (See Chapter 8 — Inpatient Care and Treatment.) But as the director of ARAFMI in Western Australia told the Inquiry, it is often the case that little or no follow-up care or contact with professionals is offered — either by way of liaison with the hospital or with a community health care team. Families are often left asking themselves 'OK, I have got this person back, what the heck do I do with him?'<sup>35</sup> This is not an expression of a lack of concern for the ill person, but rather a typical expression of frustration at lacking the knowledge and skills to be able to effectively 'cope and care' when a patient is discharged.<sup>36</sup> As one weary and frustrated carer declared:

A psychiatrist has eight years of training and practical experience. A psychiatric nurse has five years training plus experience. I received ten minutes training, and it took me seven years to find out what my wife suffered from...and I have to care for her 95 percent of the time.<sup>37</sup>

Carers and support groups such as ARAFMI and the Schizophrenia Fellowship strongly advocate comprehensive community mental health care strategies which should address the housing, social, recreational, employment and financial aspects of consumers' reintegration into the community. (See also Chapter 9 — Community Care and Treatment.) Where services do exist to help bridge the gap between hospital and rehabilitation in the community, the Inquiry heard

disturbing evidence of a lack of appropriate liaison or consultation with the primary carers and the service providers.<sup>38</sup> One carer related details of the discharge of her 16 year old daughter from hospital into a group home, organised by the hospital social worker:

A social worker we had never met organised for [our daughter] to receive a homeless youth allowance, and found a bed for her in a group home run by an organisation which caters for street children. When I protested the placement, I was curtly advised that it was hard to find a place which [she] could afford... I find that appalling. [Our daughter] didn't need a social security pension; she came from a home where we were quite able financially to take care of her... We weren't even given a say in this; they organised it without our knowledge.<sup>39</sup>

Aside from practical assistance and consultation with service providers, carers seek training to assist their relative in recovery and reintegration into the normal patterns of daily life and family interaction.

Many relatives have commented that they are left feeling incompetent and ignorant, with little if any...insight into how to manage the change back into the family environment.<sup>40</sup>

As well as needing to know how to cope with situations or crises that may arise, carers seek advice about rebuilding an appropriate relationship. For example, the Inquiry heard that many parents consciously 'work very hard not to be authoritarian,'<sup>41</sup> yet may be faced with a son or daughter who refuses to take their prescribed medication, and remains very ill. Guidance is needed on strategies to deal with such situations, while avoiding conflict which could set back recovery. Lack of such information means the home environment may actually undermine the doctor's therapy through ignorance or misunderstanding.<sup>42</sup> (See also the section dealing with family therapy, below.)

Carers must be informed about strategies in case of significant deterioration in the health of their relative. Information is needed:

to describe the early warning signs of relapse and to show how best to get and give help and support to try to prevent relapse; to show how to structure lifestyles to minimise the adverse circumstances where relapse occurs; to describe (i) the services available; (ii) skills for working with the professionals.<sup>43</sup>

Family members also repeatedly emphasised the need for 24-hour crisis teams in the community, or at the very least a contact person who can be called if a crisis situation develops.<sup>44</sup>

# Attitudes of Professionals

## Complaints by Carers

Families/carers...rarely complain about their difficulties. The reticence on their part to complain could be tied up with...unfavourable responses on the part of professionals when they have sought help in the past.<sup>45</sup>

Families are so grateful for any help they get that they are unable to demand the best. They feel that they should be happy with what they get and do not demand what I feel is probably their right.<sup>46</sup>

The Inquiry was often informed that one of the many reasons for families' failure or reluctance to complain about inappropriate care is the negative response to any attempt to question the treatment of a relative. Evidence indicated that some doctors simply respond with rudeness, or label the family member's query or input as interfering, meddling, or over-anxious.<sup>47</sup>

When I tried to regain control of Mum's recovery for her, I found it almost impossible. I not only received clear signals to 'butt out', but was warned that the psychiatrist could over-ride my objections. Even when specific requests to refrain from tranquillisers were given to the medical doctors because of known side-effects... I was told by one doctor that they were readministered. The effect on me can be described as powerlessness.<sup>48</sup>

The sense of powerlessness experienced by this carer, who described the psychiatrists as 'godlike' in their control of the situation, was often echoed by other carers. Compounding some doctors' tendency to withhold information and consultation, is the even more worrying possibility that, if a carer complains too loudly, hard-won support and treatment for the ill relative may be withdrawn altogether. When asked why they didn't complain about archaic ward conditions, parents of a person who was resident at Lakeside hospital in Victoria responded:

We wouldn't have got anywhere. We...would have been asked to take our son out of the situation.<sup>49</sup>

The Inquiry heard evidence that some doctors can and do play upon this fear of withdrawal of service:

When the family carer complained that many of [her son's] behavioural problems might be due to unthinking management, she was told by a very senior psychiatrist 'We can always discharge him to your care if you don't like what we do.' The lady and her husband are both in their late sixties, both in poor health and she had once been hospitalised by a savage attack by her son. The psychiatrist was well aware of this, but was obviously stung by the worries of a caring mother, to make such a threat.<sup>50</sup>



Whether or not such veiled threats would ever be implemented, they are nevertheless an effective means of silencing complainants. Even more disturbing were instances recounted to the Inquiry (some of which have since been investigated) in which complaints by carers resulted in a backlash against a particular patient.

*At the time, there was no communication, or very little communication, between families and patients. We complained about this... I wrote to the hospital board and complained and the next day — they had group therapies — it was brought up that I had complained and my son was ridiculed in the group.<sup>51</sup>*

As one carer stated, it is sad that members of the medical profession seem to look upon concerned parents as the 'enemy', thereby precluding 'all of us getting together to help the patient.'<sup>52</sup> Another carer from Victoria spoke generally of the attitudes she had encountered in numerous State and Commonwealth Government agencies when seeking greater accountability for conditions and policies in public psychiatric facilities.

*If we query anything, we're actually told: 'Well, that's just bad luck, because those patients are mentally ill, therefore they don't know any better, and because it's a state free service they haven't got any right to have an improvement of services.'<sup>53</sup>*

Some early studies of the difficulties faced by carers, undertaken in the 1950s, revealed that psychiatrists tended to form certain views about wives caring for spouses with a mental illness:

*Psychiatrists...saw a 'good wife' as one who had insight into her husband's condition, leaves the doctors alone, co-operates with the hospital's plans for the patient. A 'bad wife' was someone who exhibits signs of emotional distress, tries to thwart the hospital and takes up a great deal of the doctor's time.<sup>54</sup>*

Overall, evidence presented to the inquiry indicated that for too many psychiatrists, such attitudes still prevail — in relation not only to wives but to carers generally.

### **Insensitivity to the Needs of Carers.**

*Lack of consideration for the state of shock, grief, anxiety and sheer terror and exhaustion is experienced by sufferers and carers.<sup>55</sup>*

Witnesses frequently expressed distress at the apparent lack of understanding of their situation on the part of medical staff, and also magistrates, lawyers and other professionals they encountered in their role as carers.<sup>56</sup> (This insensitivi-

ty or ignorance has also been observed by mental health professionals and others who have conducted in-depth studies of the burden of care.)<sup>57</sup>

Professionals acknowledge that medical staff may need support and understanding when a client with whom they have worked closely commits suicide.<sup>58</sup> Yet the Inquiry heard no evidence of any particular counselling or support offered to relatives, who are generally traumatised, and often guilt-ridden, after such tragedies. Far from receiving support, one couple gave evidence of being virtually ignored by staff after their daughter committed suicide in the grounds of Graylands hospital, Perth:

Our family has received only one written communication from Graylands since my daughter's tragic death. This was a letter listing the items [she] left behind in Graylands. In the absence of any word of regret or sympathy from Graylands hospital, we felt pain on receipt of an itemised account of my daughter's belongings. It seemed to us in our grief that a lack of respect was shown to our daughter and a lack of compassion shown towards our family.<sup>59</sup>

## **Blame**

Feelings of guilt and self-doubt are common among carers, especially parents — not only in the event of suicide, but throughout the illness — and particularly when a diagnosis is first made. The Inquiry heard that GPs, nursing staff and even psychiatrists, far from reassuring parents and counselling against self-blame, sometimes cause or contribute to these feelings. While the approach in psychiatry of blaming the family environment or bad parenting for mental illness is outmoded,<sup>60</sup> this message clearly has not yet reached all doctors:

[My daughter's] first acknowledged psychological problems...were diagnosed at 11. This was definitely attributed to mother/daughter problems and sibling rivalry... For years I honestly believed this, almost turning myself inside out to do the right thing.<sup>61</sup>

We were made to feel as if we were responsible for what had happened to our daughter.<sup>62</sup>

Carers also gave evidence of professional insensitivity to the consumer's sense of betrayal and the family's sense of guilt when involuntary treatment is obtained.<sup>63</sup> It is not easy to make the decision to seek involuntary treatment for a loved one. Many family members

face constant personal torment as to whether or not they are 'doing the right thing' by enforced hospitalisation and medication. These dilemmas add to [family members'] bewilderment, fear, repressed anger, grief and depression.<sup>64</sup>

Yet relatives still face suspicion and even hostility on the part of legal and medical professionals with whom they must deal in securing the treatment and welfare of the ill person.<sup>65</sup>

On arrival...to admit our son, then aged 22 years, we were asked in his presence by the registrar, 'why have you brought your son here to be locked up for three days?' I replied that we had not brought our son to be locked up, but had brought him there for treatment because he was ill. [The registrar] repeated, 'no, you have brought him here to be locked up...'[and] continued to harass us with questions as to why we had brought our son to hospital and to repeat himself about our son being locked up.<sup>66</sup>

Being forced to field such questions in the presence of their son, who lacked insight into his illness and was apprehensive about hospitalisation, could only be described as mental and emotional abuse of these carers and of the patient.

### **A One-way Screen of Confidentiality**

As already indicated, many doctors cite the duty of confidentiality when refusing to disclose particular information about a patient to family members. While the general issue of confidentiality has been addressed elsewhere in this report (see Chapter 8), it was stressed by so many carers as a principal concern that it requires further consideration.

A genuine conflict will arise where carers are denied information about the patient because the patient has expressly requested that information not be divulged to those particular relatives. Relatives do acknowledge the right to confidentiality for consumers and recognise that it is not a simple issue:

I can see their point of view. They [the doctors] have to be very ethical about confidentiality, but there is a point of confidentiality versus information.<sup>67</sup>

The withholding of such information is a particularly vexed question where the consumer's instructions not to consult with parents or other carers are driven by paranoid delusions or suspicions about the carer in question or the need for secrecy:

The paranoid patient can be very hostile to parents, refusing to allow them to talk to the doctor. Until recently, my daughter did not consent to involving her parents. She was paranoid about her parents for 11-12 years.<sup>68</sup>

In such cases, professionals involved may face difficult choices based on imprecise evaluations. However, if a psychiatrist can recognise the delusional nature of an injunction to deny information to parents, that request should

generally be declined and the carers provided with the information they need.<sup>69</sup>

Carers observed that confidentiality 'does not work both ways,' with the result that relationships of trust between carer and consumer are often jeopardised:

We expect our confidentiality to be respected when we give information. We hope that it won't be relayed to the person, which often has been done, with disastrous results, because that person then believes that his last good friend has betrayed him or her.<sup>70</sup>

I once wrote a letter to my daughter's doctor to explain behaviours which were worrying... The doctor then read the letter to my daughter — the explosive upset which followed did not settle down for many weeks, and increased my daughter's hostility.<sup>71</sup>

Where a doctor is told something in confidence about the patient by the carer, the doctor should seek a way to protect that relationship. It will not benefit the consumer for the doctor to undermine what may already be a fragile relationship in which the consumer depends upon the carer for daily support, companionship and love.

Another complication arises where the consumer is granted a right to exclude relatives from a court or tribunal hearing to determine whether a treatment order should be granted. There is no doubt that there will be instances where the consumer needs to be heard in private. On the other hand, relatives feel they have a right to be heard, especially when there is a history of recurring illness, and the patient is relapsing:

Excluding relatives by granting the right [to confidentiality of the hearing] to the patient once again is an anomaly because the ill person's right [to treatment] may be adversely affected by this decision.<sup>72</sup>

## **Emotional Impact of Mental Illness upon the Family**

Each person with schizophrenia has a family, a mother, a father, perhaps a spouse, brother, sister or child. Schizophrenia ransacks their lives with a ferocity unimagined outside the family circle. Because they love someone whose illness shows itself not as a tumour, not as a heart gone bad or blood sugar gone wrong, but as bizarre and unpredictable behaviour, these families are robbed of peace... and of the humblest but most necessary of pleasures: something to look forward to.<sup>73</sup>

With the initial development and diagnosis of a mental illness, families are often 'plunged into panic, fearful chaos, trauma and despair.'<sup>74</sup> There is a terrible sense of loneliness, a sense that anyone who has not experienced this cannot understand how it feels.<sup>75</sup> There is grief, isolation, shame, loss of

family routine, sometimes the threat or occurrence of violence or aggression and associated tensions and fear, and a loss of social contact, even with extended family and neighbours, to avoid the embarrassment of awkward or unpredictable behaviours. Sometimes community stigma and ignorance lead others to withdraw friendship.

Numerous carers spoke of a sense of continuing bereavement almost more painful than the loss of a loved one through death, since:

It is an ongoing trauma, you lose your son during the illness but...you can't sort of grieve and [then] think you've got your life back again. Every time he goes into hospital we grieve all over again.<sup>76</sup>

Carers described sadness and despair when they recalled what the patient had been like before the illness; some spouses experience a sense of loss as if they had been 'physically bereft of the person they had married.'<sup>77</sup>

Anger at the way the life of the family is irreversibly altered, and at the lack of any real cure for many mental illnesses is also felt, as the Inquiry heard from a father whose 18 year old son was diagnosed with schizophrenia:

Try to imagine our shock when, at the age of 18, our son develops symptoms of a mental illness. Try to imagine the grief that struck our family when this wonderful, active person with so much ability and potential for a good life was 'crippled' mentally.<sup>78</sup>

Later on I had feelings of anger, because the mental illness had disrupted our lives... My anger was directed to doctors and psychiatrists because they don't fix things.<sup>79</sup>

## **Guilt**

It's difficult to get to grips with anything. It is terribly confusing — you experience love, hate, pity, all in one day. I am frightened of him and sorry for him, but I still love him.<sup>80</sup>

Given the general dearth of information and explanation of the illness described by carers, and the stigma associated with mental illness in the community, it is disturbing but not surprising that parents constantly ask themselves 'Where did we go wrong?' and 'Are we to blame?'

If you sat around with a group of people who had relatives with schizophrenia and you said to them, 'Now what do you think caused it?' it would always be laughable because of the diversity of normal everyday family things that they feel guilty about as having contributed to the illness.<sup>81</sup>

As previously indicated,<sup>82</sup> attitudes questioning or blaming the family environment still frequently prevail — notwithstanding modern research.

I've had very supportive friends, but I've also had people who have said to me 'You've got a lot to answer for,' or remarks like that... I don't know how you cope with that sort of community attitude but it's still with us.<sup>83</sup>

Hands up all the saints who have a perfect home life.<sup>84</sup>

Clearly, a 'no-fault' approach is required — one that substitutes positive action for attribution of blame and allows families and professionals to work together in a constructive way. Such an approach would recognise that it is the illness which is the 'enemy', and 'not those who have it, not the families of those who have it, nor those whose profession it is to try to conquer it.'<sup>85</sup>

## Isolation

I withdrew into a silent world of foreboding — worried that others would find out that things weren't terrific anymore... I was ashamed to invite people home. I was frightened of being embarrassed.<sup>86</sup>

When you're struck with this fearful chaos and trauma that you go through, you retreat into yourself; you become very withdrawn. Not only the sufferer, but the whole family... If you were a fairly confident person before, it's not just the sufferer that loses confidence, it's the whole family and it is a very difficult thing to pull yourself up from.<sup>87</sup>

Witnesses to the Inquiry frequently described the withdrawal and loss of confidence resulting from their role as carers. Available evidence suggests that these phenomena are partly due to the difficulty of inviting friends into the home because of rude, aggressive or embarrassing behaviour by the relative, and partly due to stigma and a general desire to hide the situation from outsiders.<sup>88</sup>

Many [consumers] do not wish or are not well enough to participate in day programs so they are at home with their carer, both often at their wits' end. Violence in some, though certainly not in all cases, is just below the surface. Friends and relatives stay away in droves.<sup>89</sup>

In addition, the often constant need to attend to the person at home, particularly an elderly parent or a potentially suicidal person, renders it impractical to go out to socialise. In some cases

relatives described how they were often unable to use their own telephone to ring friends because their mentally ill relative could not tolerate them talking to anyone else.<sup>90</sup>

Indeed, many carers indicated that their own lives are totally dominated by the disease.<sup>91</sup>

## **Stress**

Carers often suffer from stress-related and depressive disorders, particularly older carers or women caring for an elderly parent with dementia.<sup>92</sup> Carers speak of walking a tightrope of fear and anxiety; stressful living 'day and night'; being robbed of peace and something to look forward to; of the home no longer being a place to relax; of being harassed and even assaulted, and being unable to get help.<sup>93</sup>

*The strain on the mental health of carers does not seem to be recognised by many professional care providers... The mental health of many family members may be adversely affected, and other sectors of the health service will often bear the cost of this.*<sup>94</sup>

Physically, 24-hour nursing and sleepless nights impact drastically upon carers, as do the years of trauma and stress often associated with the carer role.

*Carers are usually very tired. It is hard to get five carers at a meeting at one particular time because of the crises that occur in their lives.*<sup>95</sup>

While the number of persons with mental illness who are aggressive or violent is much lower than community fear and ignorance would suggest, the fear or threat of such behaviour is nevertheless a reality for some families:

*The day to day responsibility for care is an overwhelming one, often an unsafe one for a frail ageing mother with a violent, hefty, psychotic adult son. Carers have a right to a safe environment.*<sup>96</sup>

## **Impact on Family Relationships**

*When mental illness develops within the family, the rhythm and quality of life are brutally interrupted... interpersonal bonds are tested to the extreme.*<sup>97</sup>

*Marriages can break up, other children are affected, the ripple effect becomes very far-reaching.*<sup>98</sup>

There are inevitably shifts in roles and relationships between the carer and consumer. Where children are caring for parents with mental illness there is a reversal in the caring role, which, in a single parent situation, may also involve the eldest child caring for the rest of the family.<sup>99</sup> Where a family member has paranoid schizophrenia and regards his or her carers with hostility and fear, it is difficult to rebuild faith and love in that relationship.<sup>100</sup> This causes great trauma to all concerned — with carers grieving for the loss of affection and trust; consumers experiencing fear and a sense of betrayal (particularly where

the carer has sought involuntary treatment for their relative);<sup>101</sup> and siblings caught in the middle.

The Inquiry was also told that a negative interdependency inhibiting development can also be a consequence.

The family become dependent on the ill person because that is where all their energy and focus have gone; the ill person becomes dependent on the family and neither develop to their full potential.<sup>102</sup>

### *Siblings*

You are hurt and embarrassed. You feel you want to do something to help your sister but as a child you feel there is nothing you can do. You feel guilty because you hate her and you don't really know what is wrong with her. No one tells you when you are a child, certainly not the psychiatrist.

Lack of understanding is seen in teasing at school: 'Guess who's got a mad sister?' the kids scream.<sup>103</sup>

Brothers and sisters suffer bewilderment, fear, ambivalent feelings of resentment and sympathy, the disruption of their homelife and stress on their studies. Social activities may be curtailed by a reluctance to bring friends home. Parents sometimes forbid the other children to talk about the problem outside the home, relatives and friends stop calling, and the tension between parents who feel guilt and anger creates intolerable burdens for the whole household.<sup>104</sup>

A teenage boy whose young sister has schizophrenia described the situation:

My little sister became steadily worse which caused divisions within our family. Dad could not see the things which Mum noticed my sister was saying... By New Year's Eve I thought our whole family was going crazy. Tiny problems would turn into loud arguments, everyone was on edge. Anytime there was peace [my sister] was sure to end it.<sup>105</sup>

All the family members long for peace, yet when matters reach a crisis point and hospitalisation is necessary, a sense of loss and dread ensues:

It was as though someone had died, no more yelling and screaming, no arguing or crying; just terrible quiet. Everyone expecting a repeat performance of the previous [bad experiences] at the hospital.<sup>106</sup>

Siblings are forced to cope with a reduced amount of care and concern from their parents, whose energies can be entirely consumed by the son or daughter with mental illness.<sup>107</sup> In turn, an awareness of this imbalance is an added strain upon the parents.<sup>108</sup>



The Inquiry heard that siblings often leave home earlier than they otherwise would have and that they may then be reluctant to visit regularly.<sup>109</sup>

A spokesperson for the Schizophrenia Foundation (Australia) advocated provision of a flexible support program for siblings and children to provide an opportunity for information sharing, discussion and venting of feelings — away from other family members if possible.<sup>110</sup> One sibling described the positive effect of family therapy:

We began family meetings at the Queen Victoria [where] we discussed our individual feelings and expectations. These were a great help as [my sister] continued to improve and communicate normally with us.<sup>111</sup>

### *Relationships with Extended Family*

My mother, aged nearly 83 and diagnosed with schizophrenia... had no support whatsoever except me as a caring daughter, because relatives consider mental illness as a stigma or can't forget the past and give some support.<sup>112</sup>

Evidence presented to the Inquiry indicated that when a relative is affected by mental illness, members of the extended family often stay away, leaving the immediate family — spouse, children or parents — to shoulder difficult burdens without the benefit of traditional support networks.

The difficulties are compounded when young children are left to cope alone with an ill single parent:

All the extended family, like aunts and relatives: no one wanted to know about it, so it was just us three children with my mother, and I was the eldest. And I usually find it is one person in the family, one child who will do something about it.<sup>113</sup>

Evidence also indicated that some relatives are unwilling to visit the ill person in a psychiatric hospital or ward, perhaps due to stigma, and this increases the burden on the primary carer.

During the four months our daughter was in hospital she received visits only from her parents and one sister. Strangely enough, and very hurtful, was that in general the people who are least supportive are extended family and close friends and relatives.<sup>114</sup>

### *Divorce*

The burden of care exists and is extensive. This is reflected in the well established finding of high rates of divorce and separation in marriages where one [partner] is mentally ill. For example, in many cases observed by Brown and colleagues (1966), the patient's illness had been instrumental in bringing about divorce or separation. The divorce and separation

rates quoted in the study were three times the national average for female patients and four times the national average for males.<sup>115</sup>

There is no reason to suspect these divorce rates have diminished. Divorce or separation frequently result when the carer spouse can no longer cope with the burden of care,<sup>116</sup> or where the illness causes a person to be aggressive or violent toward their spouse.

The marital relationship suffered from lack of trust, poor emotional communication and poor sexual relationships. There was a great deal of fighting and frustration interspersed with the disabled spouse having developed a child-like dependence on his or her partner.<sup>117</sup>

Among the many instances related to the Inquiry was the case of a woman with schizophrenia seeking a divorce for reasons apparently associated with delusions about her carer husband, leaving the latter bewildered and confused:

My wife left home talking divorce. The psychiatrist said 'I can't rationalise with her until she is stabilised!' I said: 'could you please tell me when you consider her stable?' He said he could not [break the patient's confidentiality], yet a symptom of the disease is that the sufferer believes that she is not ill but that I am.<sup>118</sup>

More generally, the pressure upon family relationships and home life where parents or grown up children are caring for a relative at home can contribute to serious dysfunction in the family or complete family breakdown.<sup>119</sup>

There are major effects on marital intimacy and family functioning... It is not infrequent for marital breakdown to result, leading to further sources of distress and impact on mental health.<sup>120</sup>

## Family Finances

[Mental illness] causes an excess of financial hardship to be placed on families by the need to provide housing, perhaps private doctors and hospitalisation, medications and loss of earnings.<sup>121</sup>

The financial burden of caring for a person with mental illness, whether or not they live at home, can be considerable. Families frequently resort to private medical care when dissatisfied with the public sector, and years of private care may cost a great deal:

We have a daughter crippled by mental illness and during the past seven years over \$100,000 has been spent on treatment at various capital city hospitals in an effort to make her 'better,' but to no avail... Mental illness is costing this country millions of lost dollars per year.<sup>122</sup>

A number of carers gave evidence of having sold their family home in order to support a relative or to finance private care:

Finally, I ended up taking [my son] interstate for treatment, back to our hospital in Northern NSW... And because of all this treatment, I ended up selling my home and his home.<sup>123</sup>

Other families have been forced to move interstate or to the city, due to the abysmal lack of mental health services in rural and regional areas:

Services... in rural areas are being gradually withdrawn for budget reasons, and carers [who cannot cope] have got to move to the city. It often means massive financial disadvantage for those people. They are moving uphill in a housing situation, moving from a rural area to a metropolitan area.<sup>124</sup>

Where it has become impossible for a difficult or aggressive family member to continue living at home, the lack of suitable supported accommodation has led some carers to purchase a second home for the use of their relative,<sup>125</sup> or at least to pay for rented accommodation.<sup>126</sup> (See also Chapter 10 — Accommodation.) In addition, most families feel responsible for supplementing pension payments or giving 'loans' to assist with basic living expenses including food, clothing, outings and transport.

The financial impact on the family budget can be overwhelming at times. On many occasions I have had to bail my daughter out of a financial wilderness by paying her rent, giving her money for food or just generally looking after her affairs.<sup>127</sup>

Individuals affected by certain mental illnesses may be subject to uncontrollable spending impulses or to simply giving their money away to friends and acquaintances.<sup>128</sup> Families are often left to pick up the pieces by paying fines to avoid court action, paying for credit or hire purchase commitments, damage to property or overdue bills. Many carers want their relatives to achieve financial independence, but are faced with a dilemma:

My son is sick when he does these things. If I don't pay his bills, there will be a court case and he'll go to jail. He's not a criminal. He's sick.<sup>129</sup>

Another concern reiterated by numerous carers is the urgent need for greater understanding and flexibility from staff and policy makers in administering social security benefits.<sup>130</sup> One carer described her daughter's experience with casual work and the benefits system:

Being scrupulously honest, she notifies the Department of Social Security in advance [of starting her new job]. Casual work does not bring in [enough money], causing financial embarrassment. Falling self esteem and deep depression follow and she leaves the job...

She is then too depressed to reapply for sickness benefits, too depressed to cope with the bureaucratic set-up. Her caregivers now naturally resume full time support for several months.<sup>131</sup>

Aside from the direct cost of providing financial support to a relative with mental illness, carers' own employment opportunities are limited, particularly where caring becomes a '24 hours a day, seven days a week' occupation.<sup>132</sup>

Most of the carers have lost their life savings trying to care for the sick relative and we can't work and provide full time support.<sup>133</sup>

My parents had been in partnership with the next-door neighbours in a milkbar. They sold the shop so that they could have more time at home for [my sister].<sup>134</sup>

The impact on family finances is particularly drastic when the person with mental illness was the sole or substantial income earner in the family, and the caring role then precludes their spouse from going out to work. Many families of psychiatric patients are genuinely impoverished — and the seriousness of their plight should not be underestimated.<sup>135</sup>

## Impact on Women

Women are far more likely to be home carers, and to be expected to carry the responsibility for the sick person... and be expected to also maintain high levels of care for the [rest of] the family at the same time... With the high level of sociopolitical push that home based care is best, they will be increasingly expected to provide it, feel guilty and be condemned as selfish if they do not.<sup>136</sup>

Our society has traditionally assumed that women will perform the role of carers: as mothers, wives caring for a home and family, and in particular providing home care for elderly parents, the physically disabled, and the terminally ill. For the home based care of people with mental illness, a similar picture emerges from evidence presented to the Inquiry.<sup>137</sup> (See also Chapter 17 — Elderly People.)

The evidence included submissions from male carers and joint submissions from parents who share the burden of care — and it is not intended to give less recognition to the significant role of these men. But it is most frequently the mother, daughter, wife, or sometimes a sister or daughter-in-law, who assumes the responsibility for care on a day-to-day basis:

The carers of our consumers are mostly mothers, mostly older women in their 50's who are often carers for elderly parents as well.<sup>138</sup>

**A large number of women sacrifice their career opportunities:**

As a result of my son's illness I had to resign from my job, sell the home I was paying off and am reduced to having to exist only on my pension.<sup>139</sup>

**A corollary of sacrificing employment opportunities is the carer's loss of her own future in terms of professional fulfilment and economic independence.**

**The lack of support and services for carers is therefore inherently discriminatory:**

These carers are usually mothers and they are expected by social norms to take the burden and fend as they can for themselves. This is an injustice and does not allow for equal opportunity of this half of our population — women.<sup>140</sup>

**With children caring for a parent, the responsibility often falls on the unmarried daughter.<sup>141</sup> This may again impact upon career opportunities, and also the ability to form relationships. If, for these or other reasons, women choose not to take on the role of permanent or full-time carer, they may experience feelings of guilt and remorse.<sup>142</sup>**

## **Carers' Need for Practical Support**

There have been fairly substantial savings made by... governments around the world from closing down institutions of various sorts, yet the resources which are then applied to that same client group are considerably reduced. What it means is that you have a group of people in Australia — carers — who are picking up a fairly large proportion of the work and responsibility which was previously handled by government, and that needs to be accompanied by an appropriate shift of resources and support.<sup>143</sup>

**The labour which families provide in caring for their relatives with mental illness goes largely unrecognised. Unlike nurses, they have no industrial award to limit hours, no holidays, no sick leave, and no protection or provision for their own health and safety. Family carers are not seeking industrial rights, but in view of their unpaid caring work they do seek recognition of their right to support and to respite.<sup>144</sup>**

**The need for supported accommodation options, rehabilitation services and crisis teams has been addressed elsewhere in this report — but primarily from the consumers' point of view. It is also essential to consider what the denial of these support mechanisms means to carers in their daily struggle to continue in that role and to achieve some quality of life for themselves, other family members, and the person in their care.**

## Home-help/Domiciliary Care

One area we are very concerned about is the administration of the Commonwealth Disability Services Act. We are concerned about equality of access to home based support services, which may be available to *other* groups of disabled people through home and community care programs. Very low priority is accorded to services for people with a psychiatric disability.<sup>145</sup>

Home and Community Care services: Do people know what HACC provides? Home help services, personal care, home nursing, paramedical services, home maintenance and modification, community transport, respite care, and day centres.<sup>146</sup>

Numerous carers and representatives of support groups spoke of the need for access to home care services. Although official guidelines for the Home and Community Care (HACC) program do not in fact exclude provision of services for the psychiatrically disabled, evidence to the Inquiry indicated that such services are generally not provided:

There is discrimination against the use of home care services for people with a psychiatric disability, although we have been assured by officers of the Department of Community Services and Health at the Queensland Carers Conference recently that this should not be the case. However, we believe that a screening process takes place and it is very much at the discretion of the people who are giving that home care service.<sup>147</sup>

Carers believe that these services are also withheld for reasons associated with fear and reluctance of home care workers to assist in the care of psychiatrically disabled individuals, a problem which they believe should be addressed by specific training programs.<sup>148</sup> Another problem is the perception that people with psychiatric disabilities do not need the services in question as much as people with physical disabilities.

I think in some cases there are services like Meals on Wheels that had [only] 2 percent of their services going to someone that had a mental illness. I have always been told people with a mental illness don't need these types of services. But I think that if you have, say, a depressive illness, someone to bring a meal, or come in and do the housework might actually be extremely useful.<sup>149</sup>

Other carers ventured alternative reasons for instances of HACC's failure to provide services:

HACC services do not, apparently, consider people with mental illnesses to be disabled!<sup>150</sup>

Carers appealed for greater government recognition of the very high cost to families of a health policy which says 'home care is best.' Financial support is sought, in the form of tax relief or a benefit akin to the very modest Domici-

liary Nursing Care Benefit, which is available to families who provide home care for the aged or for people with physical disabilities, in certain circumstances.<sup>151</sup> (See Chapter 17 — Elderly People.) The fact that this benefit is not available to carers of those with chronic mental illness is officially acknowledged,<sup>152</sup> and carers find this discrimination particularly hard to bear:

I applied for [domiciliary benefit] and was turned down. If you are looking after an aged patient or a disabled child you are entitled to it. The stress and strain of caring for a mentally ill person is much more severe... I was compelled to resign from my job as I had to care for my son... I have no income other than my pension, and cannot even take up a part-time job. Yet I was refused this benefit.<sup>153</sup>

The Inquiry noted that the Mobile Treatment Team in the Ryde-Hunters Hill area of Sydney provides one effective model for delivering practical assistance in the home.<sup>154</sup> (See Chapter 9 — Community Care and Treatment, for more detailed information about this service.)

## Respite Care

There are no facilities at all for the carers of the mentally ill to have respite from their stressful and onerous duties. Shouldn't the Mental Health Service run a few hostels where the patients would be properly cared for a few weeks, to give the carer some respite? I have no family of my own, my son has been ill for over 12 years and I have not been able to take a few weeks break. Isn't that dreadful?<sup>155</sup>

Respite is our right if we are to continue to carry the burden of care.<sup>156</sup>

One of the most vital needs of carers is quiet time away from the demands of full-time care of a relative with mental illness. Carers need to know that they can take a break and that their relative will be supervised and well cared for, either in supported hostel-type accommodation or in the family home. (The need for respite care is also addressed in Chapter 10 — Accommodation. However, the extent of evidence received from carers on this subject and the large number and serious plight of those involved requires further comment.)

There is funding of a special respite supplement in Home and Community Care, so that certain nursing homes take in the aged person...so that the carer can have a break. Why could there not be such an agreement with private psychiatric hospitals and hostels? Are not all citizens entitled to the concern expressed in terms of those caring for the aged?<sup>157</sup>

The lack of respite care for those affected by mental illness was considered by witnesses to the Inquiry to constitute discrimination — a form of institutionalised stigma.

At a recent conference in Brisbane, this question of respite care was repeated time and time again by carers generally, but especially those caring for psychiatrically disabled

relatives. They felt particularly disadvantaged... I believe there is a degree of discrimination and, hopefully, this is going to be addressed.<sup>158</sup>

Currently, the only respite which many carers experience is during periods when their relative is in hospital. Hospitalisation is, as it should be, governed by the clinical needs of the consumer, and carers recognise that it is inappropriate to view inpatient care in a psychiatric facility as a respite option.<sup>159</sup> Genuine options for respite care, appropriate to the needs of both consumers and carers, are therefore urgently required.

Witnesses to the Inquiry generally agreed that a flexible range of respite services is necessary.

Across our group of people and within the same family, our respite needs vary from time to time.<sup>160</sup>

Respite in the form of regular short visits by a community worker for a few hours to allow the carer the time to attend to the shopping or the dentist, for example, or for recreational purposes, is needed... Respite care is needed also to allow carers to go away on holidays. Carers said time away was essential in trying to keep the family situation in perspective, to take stock and from time to time to plan for the future.<sup>161</sup>

Many Australian families caring for a relative with mental illness have not had a holiday together in years:

How can a mother, on whom most of the responsibility for caring for a son or daughter rests, be expected to 'down tools' and go away with an easy mind, leaving a sufferer alone in the house, without wondering every minute of the so-called 'holiday' what is happening back home? Are they coping alright? Is the house about to go up in flames? Have they remembered to take their medication, or might they take too much?<sup>162</sup>

Well planned respite care must take account of the high degree of dependency and feelings of abandonment which may be experienced by the consumer, and the guilt at leaving, which may be experienced by carers. An effective approach to respite care should involve some form of family counselling:

We need workshops to empower the carers, to teach them how to plan for respite, how to feel OK about respite, how to deliver on the spot respite through self care and how to... debrief and let go when necessary.<sup>163</sup>

Carers generally considered that respite care for psychiatrically disabled persons should be government funded or subsidised, as is aged respite care.<sup>164</sup> It must also be geographically, culturally, and age appropriate.



## **Twenty-four Hour Crisis Teams**

As carers, we find that a crisis often happens outside the hours of 9am-5pm, Monday to Friday. Our regular family doctors are not always on call and the mental health workers are unavailable. Knowing that someone is on call to assist us with our family member, if necessary, would be such a relief.<sup>165</sup>

The availability of emergency services in the event of rapid deterioration of a relative's condition while at home is an essential element of community care. Carers are left floundering in the event of crises, which range from threatened suicide or violent assault, to disappearing from home without medication. Effective emergency teams must be in a position to respond to urgent appeals from carers. (See also Chapter 9 — Community Care and Treatment.)

## **A Continuum of Services**

Many carers believe existing community services cannot cope with the most difficult consumers:

It would appear that these services [group homes, satellite housing, living skills training, etc] are available only to the compliant, obedient few... For the non-compliant, difficult, aggressive or abusive population of the psychiatrically disabled, most will return home and become dependent on their families for a range of care and support.<sup>166</sup>

This reality is self-perpetuating, for if a consumer continues to live at home, they will never develop the social skills required to move out of the 'difficult' category. This is a particular problem when the person is severely affected by certain symptoms of schizophrenia, where

it is likely that because of their accentuated withdrawal and reclusiveness they will be found by some service providers not to be sufficiently compliant to qualify for receipt of service or support or rehabilitative care.<sup>167</sup>

Clearly, rehabilitation programs and supported or respite accommodation must cater for people along a continuum of mental illness, avoiding relegation of many consumers and their carers to the 'too hard basket,' which the evidence indicates is often 'the family home.'<sup>168</sup>

Quite often the sickest, most difficult, least easy to treat are those that are left to be cared for in the community and low cost areas of care, and by those with the least training to do so. Herein lies one of the worst paradoxes of modern medicine.<sup>169</sup>

## Family Therapy

Family relationships should be restored as much as possible after a mental illness episode, with appropriate support being given to both the parent and children during that process.<sup>170</sup>

A significant amount of work is needed in adjusting or restoring family relationships which come under considerable strain during the course of a mental illness within the family. Alone, families may spend many months 'trying to restore family functioning and personal equilibrium.'<sup>171</sup> Carers gave evidence that professional assistance may be invaluable in a number of ways.

[My daughter's] psychiatrist started family therapy sessions, which were a help to us and our daughter, by re-establishing communication and understanding.<sup>172</sup>

Some forms of family counselling simply involve giving information and providing families with an opportunity to voice concerns and ask questions. Others are more interventionist, involving group therapy sessions — with or without the consumer present. Several studies have indicated the efficacy of family intervention therapies in assisting families to cope with the care of their relative in the community, and in reducing relapse rates.<sup>173</sup>

Family counselling has also been found to assist families in preserving their own mental health and stability in caring for their relative. Families often struggle to access such services, although ARAFMI and other voluntary self-help groups provide support in an informal setting. One witness to the Inquiry gave evidence of the bewilderment and trauma he had suffered as a child, because of his mother's manic depressive illness and her distressing side-effects from medication. He eventually sought counselling from a service 'for adult children of alcoholics... because there was nowhere else for me to go.'<sup>174</sup> Counselling for this family, and in particular for his carer father, concerning ways to explain the illness to the children, may have alleviated years of unhappiness in the home.

The issue of encouraging and training doctors to initiate family counselling has been addressed by some professionals,<sup>175</sup> but carers indicate much remains to be done:

I have suggested to other members in the [Schizophrenia] Fellowship to ask the psychiatrist treating their son or daughter for family therapy, but most doctors say they do not think that useful — I think they do not know how, nor do they want to learn. It requires ability in facilitating the session, and in steering the discussion along the lines required for improvement all round. It also requires more time than pushing out pills and encouraging words.<sup>176</sup>

While most carers who had received counselling or some form of family therapy viewed the experience positively, several stressed the importance of carefully and sensitively explaining the purpose and dynamics of such therapy:

Family therapy sessions were confusing, uncomfortable times. We had no idea what to expect and were given no guidance as to what was expected of us.<sup>177</sup>

## Family Living vs Independent Living

It is to be noted that in many cases mentally ill people who live with their families are not there because that is clearly the best place for them to be, having regard to their developmental or rehabilitative needs, but because there is just nowhere else that they can go where they will receive care and support to the extent needed.<sup>178</sup>

It is increasingly acknowledged by health care professionals that providing suitable supported accommodation, as an alternative to living in a situation of dependency with carers, can be healthier and more conducive to recovery:

Life-stage and age-appropriate accommodation is very important in people's levels of confidence and their sense of moving on in their society and with their life at appropriate times... We now need to allow parents to retire from being parents and we need to encourage our clients to form relationships in a natural way — and to have their own space, and their own facilities.<sup>179</sup>

It may not be in the best interest of a mentally ill person to live with family. There is a need for the person to be encouraged to take responsibility for many of the tasks of daily living, eg cooking meals. However, the relations may feel unable to make rules or the person may not take notice of such rules. In such a case the rights of the family are being infringed — to the detriment of all parties.<sup>180</sup>

The relationship of dependency which arises, and the relative's frequent failure to develop living skills such as shopping, cooking, managing finances and cleaning, leave carers asking the question 'what happens when I die?'

Members of our group, especially the older members, agonise over this point. They will be leaving behind someone whose behaviour is not accepted by society.<sup>181</sup>

Many carers fear their son or daughter being left alone in the world, or else becoming a potential burden on siblings who may have their own lives and children, and who may in any case be unwilling to sacrifice their mobility and autonomy as their parents have done.<sup>182</sup>

Another real danger for highly dependent adults with mental illness who lose a parent carer is the potential for severe relapse. Even consumers whose condition has been stabilised with medication and a secure home environment

will be at risk of relapsing, with the grief and trauma of loss and the possible threat of dislocation from all that is familiar and safe.

While relatives seek recognition in their role as carers and consultation where they do form part of the caring team, they also seek alternatives in the event that they cannot or choose not to provide full-time care. Some carers emphasised that families should not necessarily be expected to assume the role of principal support and carer — at least not for ever:

It is not appropriate that families be... set in concrete as part of the caring team. They have a role to play, certainly, but this should be as loving parents, brothers, sisters, wives or husbands of a person in need — not the primary source of support.<sup>183</sup>

Certainly, family members should not be made to feel guilty or selfish if they cannot provide appropriate full-time care indefinitely.

## **Conclusion**

Increasingly, carers have become aware of the benefits which would accrue to all concerned if their rights to support and services were given appropriate prominence on the mental health agenda. Carers provided a great deal of evidence about the needs of consumers, on whose behalf they spoke passionately — including about the need for more research, better financial support and more supported accommodation options. It is clearly time that governments and our community acknowledged that carers' rights must be respected if the rights of many thousands of Australians affected by mental illness are to be realised.

Mental illness is a two way street, affecting both families and sufferers... If the community supports both, everybody gains.<sup>184</sup>

1. Phil Donnelly, Coordinator, Steering Committee, National Carers' Association. Oral evidence, Hobart 12.11.91, p207.
2. E Bacon, carer, Queensland. Submission, p4.
3. Alliance for the Mentally Ill (AMI), Australia. Submission, p2.
4. Dr Margaret Leggatt, Executive Director and Rosemary Webster, President, Schizophrenia Fellowship, Victoria. Submission, pp8-9. See also A Rosen, V Miller, and G Parker, *Area Integrated Mental Health Services Standards Project*, Research Project funded by the NSW Health Department, and supported by the University of NSW School of Psychiatry, Royal North Shore Hospital and Community Health (Mental Health) Service, Sydney 1990, p59.
5. Name withheld, carer. Private hearing, Brisbane 14.8.91, p1481. Also name withheld, carer. Private hearing, Brisbane 14.8.91, p1471.
6. Name withheld, carer. Submission No440, p11. Also J Nicol, Schizophrenia Fellowship of South Queensland, submission, p4; Pat Carberry, ARAFMI, WA. Submission p3; AMI, op cit (submission), p2; Bacon, op cit, p3.
7. Jan Brown, carer, NSW. Oral evidence, Sydney 20.6.91, p488. Also Bacon, oral evidence, Brisbane 16.8.91, p1674; Joan Harwood, carer, Tasmania, submission, p1.
8. Carers' submissions (names withheld) No301, NSW; No755, SA; and Bacon, op cit, (submission) p3.
9. Bacon, op cit.
10. See Chapter 8 — Inpatient Care and Treatment, which describes the experience of a Western Australian couple who were not told of their daughter's spoken intention to commit suicide before her discharge from hospital (Submission No602, p1).
11. Name withheld, carer, WA. Submission No555, p7.
12. Name withheld, carer, NSW. Private hearing, Newcastle 9.7.91, pp776-777. Also Anthony Ormerod, Victoria. Paper provided to the Inquiry, p5.
13. Name withheld, submission No 555, op cit, p1.
14. id.
15. Anne Davis, Executive Officer, ARAFMI, NSW. Oral evidence, 18.6.91 Sydney, p152.
16. Nicol, op cit, p3. Carers describe how the relative will often suggest to the assessing doctor that it is the carer who needs psychiatric help: see Dr Margaret Leggatt, Executive Director, Schizophrenia Fellowship. Oral evidence, Melbourne 8.4.91, p88; and Alan McKenzie, carer, Victoria. Submission, p3.
17. V Meyers, carer, Queensland. Oral evidence, Brisbane 14.8.91, p1436.
18. *ibid*, p1437.
19. Orme Hodgson, Member, Schizophrenia Fellowship, Queensland. Submission, p7.
20. P Ingram, ARAFMI, Tasmania. Oral evidence, Hobart 12.11.91, p247. (See also 'A Cry for Help from Sufferer's Family,' *Newcastle Herald* 22 Oct 1992.)
21. See, for example, F Carr-Boyd, carer, NSW. Submission, p2.
22. *ibid*, p3.
23. Anne Newham, AMI and ARAFMI, NSW. Oral evidence, Sydney, 19.6.91, p309. See also oral evidence of carers (names withheld), Melbourne 10.4.91, p368; and Perth 11.2.92, p270.
24. Newham, op cit, p310. Other carer and self-help groups strongly supported the concept of a 'therapeutic alliance'. Eg Richard Woon, Self-Help Mood Disturbance Prevention (MDP) Inc/Mental Health Action Group, SA. Submission, p1; and Nicol, op cit, p7.

25. AMI Australia, *Taking the Us and Them Out of the Treatment of Chronic Mental Illness, A Guide for the Mental Health Professional*, 1990. Booklet provided to the Inquiry.
26. J Hoult, 'Community Psychiatry,' in P Beaumont and R Hampshire, *Textbook of Psychiatry*, Blackwell, Sydney 1989, pp320-321.
27. Rosen, Miller and Parker, op cit, pp62-64; and G Fadden, P Bebbington and L Kuipers, 'The Burden of Care: The Impact of Functional Psychiatric Illness on the Patient's Family', in *British Journal of Psychiatry* v150, 1987, pp290-291.
28. Win Leslie, carer, Victoria. Oral evidence, Ballarat, 11.4.91, p628; and submission, p3.
29. Mrs Vance, carer, Queensland. Oral evidence, Townsville 12.8.91, p1200.
30. Name withheld, carer, Qld. Oral evidence, Brisbane 14.8.91, p1464.
31. Leslie, op cit (submission), p3.
32. ARAFEMI Victoria. Submission, p9.
33. Carberry, op cit (submission), p3.
34. Brian I'Anson, carer, ACT. Oral evidence, Canberra 18.3.92, p108. See also R Gale, Coordinator, Mental Health Resource Centre, ACT. Oral evidence, Canberra 18.3.92, p58. It is especially difficult when a relative is released from hospital after a suicide attempt and there is no counselling or follow-up: Brown, op cit, p487; and name withheld, Submission No602, op cit, p1.
35. Carberry, op cit (oral evidence), p249.
36. Leslie, op cit (submission), p2.
37. MacKenzie, op cit, p1.
38. See, for example, name withheld, Submission No602, op cit; Carberry, op cit, p2; name withheld, Submission No555, op cit, p1; D Wheeler, carer, Qld. Submission, pp2-3; and T Wade, sub-committee convenor, Qld Association for Mental Health. Oral evidence, Brisbane 15.8.91, p1576.
39. Name withheld, carer. Private hearing, Brisbane 14.8.91, p1468. Also Submission No516, pp3-4.
40. Dr Ian Siggins, Health Services Commissioner, Victoria. Also Leggatt and Webster, op cit (submission), pp8-9.
41. Brown, op cit, p495.
42. Leggatt and Webster, op cit (submission), p2; Bacon, op cit (submission), p4.
43. Barbara Hocking, *An Education Strategy for Schizophrenia*, Schizophrenia Foundation (Australia) 1990. Paper provided to the Inquiry.
44. Bacon, op cit (oral evidence), p1677; Carberry, op cit (submission), p3.
45. Robyn Greene, Coordinator, ARAFMI, Newcastle. Submission, p2.
46. Libby Steeper, Convenor, ACT Mental Health Taskforce (ACTCOSS). Oral evidence, Canberra 18.3.92, p27.
47. Name withheld, carer. Private hearing, Brisbane 14.8.91, p1463.
48. Name withheld. Submission No555, p1.
49. Leslie, op cit (oral evidence), p631.
50. Hodgson, op cit, p13.
51. M Barra, carer. Oral evidence, Townsville 12.8.91, p1179.
52. Nicol, op cit, p7.

53. Leslie, op cit (oral evidence), p634.
54. B Raphael, G Byrne, and B Kelly, 'Women as Carers,' in *Perspectives on Continuity for Mental Health Care: Proceedings of a Conference at the Capricornia Institute of Advanced Education*, Rockhampton 1989, p49. The authors cite L C Deasy and O W Quinn, 'The Wife of the Mental Patient and the Hospital Psychiatrist', *Journal of Social Issues* v11, No49, 1953.
55. Leslie, op cit (oral evidence), p632. Also Nicol, op cit, p6.
56. Name withheld. Oral evidence, Sydney 20.6.91, p489.
57. Di Gordon, President, Australian Association of Social Workers, ACT. Submission, p4. Also Margaret Lukes, Founder of ARAFMI, NSW, oral evidence, Sydney 20.6.91, p426; Fadden et al, op cit, p289; and Raphael et al, op cit.
58. Andrew Czechowicz, Director, Carramar Clinic, Adelaide. Submission, p1: 'The carers themselves need group support from understanding peers, especially when crises occur, eg when...the team face the fact that a patient who was attending had committed suicide.'
59. Name withheld. Submission No602. Extract from a letter of complaint, sent to the State Minister for Health, about the hospital's handling of her daughter's case (copy provided to the Inquiry). The witness reported that after she lodged this complaint, the hospital did send a formal letter of sympathy — two months after her daughter's death.
60. Hoult, op cit, pp320-321: 'In the past, mental health professionals promulgated theories that blamed parents for the mental illness of the patient. This caused much guilt and also resentment in the parents'.
61. Brown, op cit, p487. Also Elizabeth Bleby, social worker, SA. Submission, p7.
62. Name withheld, carer, Qld. Oral evidence, Townsville 14.8.91, p1463. See also E Fuller Torrey, *Surviving Schizophrenia, A Family Manual*, Harper & Row, 1988, p276: 'few members of the mental health profession have focussed on the amount of harm that has been done by the idea that parents and families cause schizophrenia. Psychiatrists...see themselves as unlikely to cause harm. We know that this is not so.'
63. Hodgson, op cit.
64. Leggatt and Webster, op cit (submission), p8.
65. Davis, op cit, p154. See also Carr-Boyd, op cit, p1.
66. Vance, op cit, p1199.
67. Leslie, op cit (oral evidence), p628. Also Leggatt, op cit (oral evidence), p91; and name withheld, ARAFEMI member, Victoria. Private hearing, Melbourne 10.4.91, p372.
68. Name withheld. Submission No440, pp5-6. Also Carberry, op cit (oral evidence), p249; and Davis, op cit, p153.
69. Fuller Torrey, op cit, p311: 'Professionals must not hide behind the facade of confidentiality...but rather must share information regarding their patient's condition, exactly as if the patient had Multiple Sclerosis or Alzheimer's disease.'
70. A Whitehead, carer. Oral evidence, Brisbane 16.8.91, p1677.
71. Name withheld. Submission No440, pp6-7. Also Nicol, op cit p7; Bacon, op cit (submission), p3.
72. Davis, op cit, p153.
73. Leggatt and Webster, op cit (submission), p5.
74. Leslie, op cit (oral evidence), p623.
75. Name withheld. Submission No301, p8.

76. Leslie, op cit (oral evidence), p632.
77. Fadden et al, op cit, pp286-287.
78. J Du Ross, carer, NSW. Submission, p1.
79. ibid, pp4-5. Also Rosemary Nairn, Child and Adolescent Unit, ACT Mental Health Services. Submission, p15.
80. Schizophrenia Fellowship, Victoria, *Coping with Schizophrenia, The Relatives' Perspective*, Paper provided to the Inquiry. This report details the results of a survey of carer members of the Fellowship, undertaken in 1987.
81. Leslie, op cit (oral evidence), p632.
82. Also in Fadden et al (see endnote 27) 'the psychological impact on the wife having to consider her own possible role in the development of her husband's illness,' citing J A Clausen and M R Yarrow, 'The Impact of Mental Illness on the Family', *Journal of Social Issues*, v11 No3, 1955. What is most disturbing is that in the nearly forty years since the study referred to was undertaken, the evidence suggests that little has changed. See Davis, op cit, p154; Leggatt and Webster, op cit, p8.
83. Leslie, op cit (oral evidence), p632.
84. Du Ross, op cit, p4.
85. M Walsh, *Straight Talk for Families and Friends*, William Morrow and Co, New York 1985, quoted in *Coping with Schizophrenia*, op cit, p103.
86. Du Ross, op cit, p5.
87. Leslie, op cit (oral evidence), pp624-626.
88. Fadden et al, op cit, p286. An early study reported that one-third of spouses caring for a person with mental illness adopted a pattern of 'aggressive concealment,' making drastic changes in order to avoid or cut off former friends, with some moving to a different part of town. Another third had told only members of the family or close friends who either understood the problem or had been in a similar situation themselves (Clausen et al, op cit). Tragically, continuing ignorance and stigma ensure that this is still a common experience for families today.
89. Brown, op cit, pp489-490.
90. *Coping with Schizophrenia*, op cit, p79.
91. Nicol, op cit, p5. Also Greene, op cit, p1: 'Carers suffer lack of companionship, lack of time for themselves and decreased social activity'; Leslie, op cit (oral evidence), p629: '...it is very difficult to nurse seven days a week and not get any sleep for weeks on end'.
92. Raphael et al, op cit, p10; Fadden et al, op cit, p290.
93. Submissions from Du Ross, op cit, p5; Leggatt and Webster, op cit, p6; AMI, op cit, p3; Brown, op cit, p489; Schizophrenia Fellowship, Queensland, p1; Nicol, op cit, p5. Also M Wasow, *Hospital and Community Psychiatry*, v44 No3, March, 1993: 'The ongoing stresses of having to take on the role of case manager, of seeing their relative suffer and being unable to help, and of living in fear of the next catastrophe exhaust family members and leave terrible scars.'
94. Bleby, op cit, p7. Also Bacon, op cit (submission), p5.
95. Donnelly, op cit, p207. Also, names withheld, Members of ARAFEMI, Victoria. Private hearing, Melbourne 10.4.91, pp367-8; Hocking, op cit, p23; P McFadyen, Aged and Disability Services Development Committee (Bendigo), Home and Community Care, Victoria. Submission, p1.



96. AMI, Australia. Paper provided to the Inquiry. Also Leggatt and Webster, op cit (submission), p7; Du Ross, op cit, p5; Brown, op cit, p490. By contrast, a mother expressed similar fears about her teenage daughter's aggression toward her: Brown, op cit, p487.
97. H Lococo, Support Group for Relatives of People with a Psychiatric Disability, Victoria. Submission, p1. Also J Gray, President, Schizophrenia Fellowship of South Queensland. Oral evidence, Brisbane 15.8.91, p1621.
98. Carberry, op cit (oral evidence), p252.
99. See Chapter 16 — Children of Parents with Mental Illness.
100. Brown, op cit, p487; T Fowke, carer. Oral evidence, Perth 11.2.92, p222; Carberry, op cit (oral evidence), p252.
101. See also the earlier section discussing confidentiality and information given by the family to doctors.
102. Carberry, op cit (oral evidence), p252.
103. Lukes, op cit, p426. Also Ormerod, op cit; Hocking, op cit, p33.
104. Leggatt and Webster, op cit (submission), p6. Also Lukes, op cit, p428; and name withheld, Member ARAFEMI, Victoria. Private hearing, Melbourne 10.4.91, p368.
105. Ormerod, op cit, p6.
106. id. The witness recalled his younger brother asking 'Does this mean we can be a real family like we used to be?', when his sister's discharge date was announced.
107. Name withheld, ARAFEMI member, Victoria. Private hearing, Melbourne 10.4.91, p368; and name withheld, carer, NSW. Submission No181. Also A S Brodoff, *Schizophrenia Bulletin* v14 No1, 1988, pp113-16.
108. Anne Deveson, *Tell Me I'm Here*, Penguin Books, 1991, p84.
109. Name withheld, Member ARAFEMI, Victoria. Private hearing, Melbourne 10.4.91 p368. See also *Coping with Schizophrenia*, op cit, p79.
110. The Inquiry was told ARAFEMI has informal young persons' groups for this purpose.
111. Ormerod, op cit, p11. This witness concludes his paper on a positive note, stating that coping with his sister's acute mental illness has 'brought the family closer together.'
112. Harwood, op cit, p1.
113. Name withheld, carer. Private hearing, Perth 11.2.92, p270. Also see Chapter 16 — Children of Parents with Mental Illness.
114. Name withheld. Submission No440, op cit, p12.
115. Fadden et al, op cit, p286.
116. Joan Willman, carer, Victoria. Submission, p2.
117. *Coping with Schizophrenia*, op cit, p87. In this survey, undertaken by the Schizophrenia Fellowship of Victoria, 13 out of 36 carers who responded to the set of questions (about the relationship with their ill partner) had divorced or separated.
118. McKenzie, op cit, p2.
119. Carberry, op cit (oral evidence), p252.
120. Raphael et al, op cit, p21.
121. Carberry, op cit (oral evidence), p252. See also Fadden et al, op cit, p287.
122. Name withheld, carer, NSW. Submission No270, p1.
123. Meyers, op cit, p1438. Also name withheld, carer, NSW. Submission No257, p1.

124. Donnelly, op cit, p208.
125. *Coping with Schizophrenia*, op cit, p64: 'We thought that if we set our son up in a little flat not far from us he would gradually learn to look after himself and become independent...but he kept coming home... So, not only had we gone to the expense of setting him up in a flat, we still had to fork out for him because he came home so much. It became too expensive, so we had to give up the flat.'
126. Leslie, (submission), op cit, p1.
127. Name withheld, carer, ACT. Submission No660, p3.
128. See *Coping with Schizophrenia*, op cit, pp65-66.
129. ibid, p66. Also name withheld, carer. Private hearing, Newcastle 9.7.91, pp845-6; and Brown, op cit, p490.
130. Leslie, op cit (submission), p1.
131. Name withheld, ARAFEMI member, Victoria. Private hearing, Melbourne 10.4.91, p372.
132. Donnelly, op cit, p207. Also McFadyen, op cit, p1.
133. Georgina Skews, ARAFMI & AMI (Australia), *Respite for Carers — A Matter of Strategy*, 1990. Paper provided to the Inquiry, p3.
134. Ormerod, op cit, p9.
135. Fadden et al, op cit, p287.
136. Raphael et al, op cit, p14.
137. Greene, op cit, p1.
138. Nicol, op cit, p3.
139. Name withheld. Submission No257, op cit, p1.
140. N Hotchin, Carer, Victoria. Submission, p2.
141. Personal communication, received from ARAFMI (NSW), after the close of submissions.
142. Raphael et al, op cit, p14.
143. Donnelly, op cit, pp206-207.
144. ibid; Woon, op cit, p1; AMI, op cit, p2; ARAFEMI, op cit, p9-10; Harwood, op cit p1; Hocking, op cit, p29; McFadyen, op cit, p1.
145. Name withheld, ARAFEMI member, Victoria. Private hearing, Melbourne 10.4.91, p366.
146. Trish Benson, Chairperson, Mental Health Task Force, NSW. Oral evidence, Sydney 18.6.91, p152.
147. Newham, op cit, p310. Also Donnelly, op cit, p208; Hotchin, op cit, p2; J and P Simpson and Great Lakes ARAFMI Group, NSW. Submission, p3.
148. id.
149. Benson, op cit, p152.
150. J and P Simpson, op cit, p2.
151. Name withheld, carer, ACT. Submission, p3. Also McFadyen, op cit, p1.
152. National Health Strategy, *Help Where Help is Needed*, Issues Paper No.5, AGPS, Canberra, 1993, p60: 'Carers of people with mental illness do not receive the following supports offered to carers of other groups in the community: (i) the Carer Pension, which is oriented to those caring for people with high home nursing needs; (ii) the Domiciliary Nursing Care Benefit, which requires that a person be 'otherwise eligible for admission to an approved nursing home'. The report goes on to say that: 'Commonwealth and State

- governments need to resolve jointly how carers of people with chronic mental illness will be assisted to relieve the financial and personal burden of care.'
153. Name withheld. Submission No257, op cit, p2.
  154. Michael Longhurst, NSW. Submission, p4.
  155. Name withheld. Submission No257, op cit, p5. Also Nicol, op cit, p3; Donnelly, op cit, p208.
  156. Skews, op cit, p2.
  157. Name withheld. Submission No257, op cit, p5.
  158. Donnelly, op cit, p208. Also Newham, op cit, p310; and J and P Simpson, op cit, p3.
  159. McFadyen, op cit, p2; Newham, op cit, p310; AMI, op cit, p3.
  160. Skews, op cit, p2.
  161. ARAFEMI, op cit, p10.
  162. *Coping with Schizophrenia*, op cit, p80. Also Newham, op cit, p249; Ingram, op cit, p247; and submissions from John Briggs, carer, Victoria, p5; and AMI, p3.
  163. Skews, op cit, p2.
  164. Name withheld. Submission No257, op cit, p5. Also, Donnelly, op cit, p208.
  165. J and P Simpson, op cit, p1. Also Davis, op cit, p155.
  166. Raphael et al, op cit, p20
  167. Briggs, op cit, p3.
  168. Skews, op cit, p2. Also, Davis, op cit, p157.
  169. Raphael et al, op cit, p20.
  170. C Flynn, Mental Health Coordinating Council, NSW. Submission, p21.
  171. Greene, op cit, p2; Siggins, op cit, p8.
  172. Name withheld. Submission No440, op cit, p15.
  173. Fadden et al, op cit, p290, citing studies by Vaughan and Leff, 1976 and 1984, Barrowclogh and Tarrier, 1984: 'The results confirm that improving the way relatives deal with the burdens of looking after a schizophrenic patient in the home has a beneficial effect on the course of the illness.' There are different schools of thought about the best approaches to family intervention, but it seems clear that equipping families with better coping skills and providing professional and mutual support networks is effective in reducing relapse rates.
  174. Name withheld. Submission No555, op cit, p7.
  175. Rosen et al, op cit, pp61-64. The authors propose a fully integrated model for carer/family involvement, incorporating information and skills based education of family members; interventions (for example identifying conflicts or stresses that exist); and family support groups — either establishing these or referring families to existing groups such as the Schizophrenia Fellowship.
  176. Name withheld. Submission No440, op cit, p15.
  177. Names withheld. Submission No516, op cit, p2.
  178. Briggs, op cit, p3.
  179. Dr Roger Gurr, Clinical Director of Psychiatry, Blacktown Community Health Centre. Oral evidence, Sydney, 18.6.91.
  180. Gordon, op cit, p2.

181. Name withheld. Submission No660, op cit, pp2-3. Also name withheld, ARAFEMI member, Victoria. Private hearing, Melbourne 10.4.91, p368.
182. Du Ross, op cit, p5.
183. Marie O'Donoghue, Changing Attitudes Towards Schizophrenia (CATS), Victoria. Submission, p4.
184. Name withheld, carer, ACT. Submission No660, p3.

## Chapter 16

### CHILDREN OF PARENTS WITH MENTAL ILLNESS

The illness is not yours, but it has covered up your whole life, it is incredibly painful. It is just chaos, absolute chaos. With no extended family, it is hell. When you are in a family with mental illness, you think you are the only one going through this and you feel totally isolated, and as a child, you just do not know what is going on.<sup>1</sup>

Most submissions to the Inquiry made by family members — parents, children and siblings of people with mental illness — demonstrated the devastating effect that living with a person with a mental illness has on every member of the family. The evidence relating to the children of parents affected by mental illness was particularly disturbing.

Witnesses included mothers who had experienced post-natal depression; community workers and health professionals dealing with mothers whose young children had been taken away from them; teenagers with a parent with mental illness trying to cope at school and at home; and adults whose experience of growing up in a family with a parent affected by mental illness had had a profound effect on their lives. Evidence concerning the welfare of adult children responsible for the welfare of elderly sufferers of dementia and other mental illnesses is discussed in Chapter 17 — Elderly People.

Because resources for supported accommodation and for continuing care in the community are so sparse, most families must simply attempt to cope with the continual stress and the shared suffering of the person, with very little help from appropriately qualified professionals.

#### Post-Natal Depression and its Effects on Infants

The president of the Post and Ante-Natal Depression Association (PaNDa) in Victoria<sup>2</sup> gave evidence concerning the prevalence of misdiagnosis and, in some cases, the complete failure to diagnose post-natal depression (PND) when a woman first raises the matter with her doctor.

We could write a book [of accounts] from women suffering PND about the difficulties in getting help... One woman was finally accurately diagnosed for PND by her priest, after visiting more than ten health professionals.<sup>3</sup>

The results of failure to diagnose and effectively treat this common and serious illness can include serious neglect of other children in the family and emotional deprivation or even physical harm to the baby. (This issue is further addressed in Chapter 19.)

If it is severe and untreated, post-natal depression or post-natal psychosis can, in rare cases, lead to death — death of the mother by suicide or the death of the baby by neglect or by harm inflicted by the mother.

The evidence submitted to the Inquiry, which is supported by recent research, indicates that priority needs to be given to early diagnosis and treatment of PND and that, wherever possible, immediate intervention measures to support the mother and other family members must be taken — not only to help the mother cope with her illness and develop adequate parenting skills, but also to protect the child.<sup>4</sup>

## **Welfare, Care and Custody Issues**

The Inquiry also heard evidence concerning women whose first episodes of mental illness occurred after they had married and had children. The lack of support services for these mothers and their families has had devastating consequences. As one social worker told the Inquiry:

It seemed to me that action in removing their children was often swifter than with other women... Many of the children who are 'taken into care' are those of mentally ill women. While I can understand society's uneasiness, it seems a particularly harsh 'punishment' for someone whose only misdeed has been becoming ill. Certainly, workers who have psychiatric training are needed as Child Care Officers, and there needs to be a special fostering scheme set up to care temporarily for children [of a mentally ill mother], with the aim of rejoining mother and child quickly.<sup>5</sup>

In some cases, young children are 'lent' to relatives, made State wards or, more commonly, placed in temporary foster care while their mother is being treated for a mental illness. A community support worker in Sydney told the Inquiry:

There has been no attempt, I understand, to help foster-parents, who seem a bit afraid of mental illness. And there is no attempt to be sure that the child (who is only fostered, remember, not adopted)...understands that her mother is ill, that her natural mother loves her... Foster parents are apprehensive (about mental illness), like other people in the community: they have a child who could display symptoms of mental illness...I do think that there needs to be somebody in the staff of those government departments who understands what is happening in the families where there is mental illness.<sup>6</sup>

The need for relevant and effective counselling and information for people who foster children of parents affected by mental illness was forcefully made in a submission from a Sydney woman who had been fostered from early childhood.

People who foster the children of the mentally ill should be extensively counselled on what to say to the children about their natural parents. The children should not be told that the parents have abandoned them, do not care about them, never think about them. They should be encouraged to think well of their ill parents, and to regard them as true parents, and not cut off from all their natural relatives. Grandparents, aunts, uncles and cousins should have free access to the children who are being fostered.<sup>7</sup>

Welfare officers had regularly visited the home to ensure that her physical care was adequate, but the subject of her natural mother's mental illness was treated as if it were a 'taboo' area by these workers, as well as by her foster mother.<sup>8</sup>

Gender differences in the onset of schizophrenic illness have been noted in a number of recent studies and are now well-recognised.<sup>9</sup> The first episode of schizophrenia in young males commonly occurs in late adolescence; whereas young women often experience their first episode in their early to mid-twenties. This means that, in many instances when a young woman develops schizophrenia, she may already have one or more children. The results can be tragic. The Inquiry was frequently told that the onset of schizophrenia precipitated a marriage breakdown and the disintegration of a very young family.<sup>10</sup>

### **Parents Who Have Lost their Children Due to Mental Illness**

The Inquiry heard evidence from mothers who had been removed from the family when they developed a mental illness and who had experienced long-term grief over the loss of their children. In several cases, the children's father had been awarded custody, causing the mother to suffer continuing grief, feelings of guilt, social failure and failure as a parent — as well as having to bear the pain of her own illness.

The Inquiry also received a number of confidential submissions from fathers who had had a mental illness and been permanently denied custody or access to their children for that reason.

In certain cases, these men acknowledged there could have been some risk to their children during a psychotic episode. Regardless of the level of risk, however, they had generally been offered no guidance, counselling, or assistance to enable them to interact with their children sufficiently for the authorities to monitor decisions concerning access. These men expressed sadness, frustration and anger at having lost their children and their opportunity to be a father.

Their experiences were typified by a man who had been denied access to his son for over five years, since the child was 18 months old:

I felt I had lived my life acceptably to society...over the last five years, I have not had a relapse. For the last 18 months I have actively tried to get things changed as far as my son is concerned... One of the doctors at the hospital sent a letter requesting an answer as to why I had not seen my son, as he felt it was unjust. [Losing my son] made me feel very small, useless and of no value to society and myself.<sup>11</sup>

Another submission to the Inquiry was made by a mother who had pursued every avenue, including attempting to take legal action herself, to get her children back:

A psychiatric assessment performed on me...was used to have my children removed from my custody... I am treated as a criminal because I had the misfortune to contract a mental illness. They will not give me a chance to prove I can care for my children safely, even though I have undergone regular psychotherapy treatment willingly, so that I can be responsible for my children, as well as for myself, so that I can improve my own wellbeing and take control of my life... Yet they treat me — and my husband — with contempt, splitting us apart, not helping us to raise our children all together, safely and in a loving home.<sup>12</sup>

Yet another submission came from a woman whose young sons had been taken away from her four years earlier by her former husband, who had succeeded in a Court application for custody. Her illness was later found to have been incorrectly diagnosed, but she has not been able to get her children back:

I am now stable on Lithium and Tegretol — too late! I have already lost custody of my sons. [That doctor's] mistake was a costly one in human terms and the consequences of it will be far-reaching in the lives of my sons and [myself and other family members]... Manic depressive disorder is no reason for a mother to lose her children — many have been given custody with this illness. It is too late for us, though — I have no money and no immediate prospects of earning any — how do I get my children back?<sup>13</sup>

The Inquiry heard evidence from a Church-based service operating in inner Melbourne suggesting that women who are finally able to leave an abusive relationship sometimes experience some form of 'mental illness' which can lead to the loss of their children.

After being in an abusive relationship for many years...[these] women were sometimes able to leave the relationship, with the help of refuges or community support...During this period of independence, [they often] experienced a mental and emotional breakdown. These women had no history of mental illness, but during this breakdown they were placed in a psychiatric hospital... This illness was a 'one-off' occurrence resulting from years of abuse. Whilst the women were...in hospital, their former husbands were able to gain custody of the children through the Family Court, on the basis that their mother was



mentally unstable, as proved by her presence in a psychiatric hospital... The children...have often been simply passed on to the paternal grandmother's care.<sup>14</sup>

One consequence of an episode of mental illness, or merely of admission to a psychiatric hospital, can therefore be use of the incident by that person's partner to influence later decisions about their fitness as a parent. Another consequence can be the ongoing 'labelling' effect of 'mental illness' — which may have long passed.

This label can affect many areas of the person's future life in relation to his or her children, in matters such as regular access, participation in decisions about education, and sharing recreation and leisure pursuits with the children. The Inquiry received evidence from many parents (both mothers and fathers) deprived of all these experiences, because the label 'mental illness' had followed them relentlessly.

### **Children who Remain with Mothers Affected by Mental Illness**

A number of witnesses gave evidence about the lack of appropriate emergency accommodation facilities for mothers with a mental illness who manage to keep their children with them. (Also see Chapter 10 — Accommodation; Chapter 18 — Homeless People; and Chapter 5 — Mental Health Services.)

Workers often have contact with young women with a mental illness who are also mothers. It is a great concern that children of these young women are sometimes placed at risk, due to insufficient support for the mothers. While not all women with a mental illness place their children at risk due to their behaviours, there are situations in which [they] are at risk: physically, mentally, emotionally through inadvertent neglect, or as a result of witnessing their mother's behaviour.<sup>15</sup>

The Inquiry was also presented with a number of case studies documenting the inadequacy of accommodation options for those mothers affected by mental illness who are still caring for their children.<sup>16</sup>

Another witness involved in a women's shelter in Adelaide told the Inquiry:

[There is a greater incidence of mental illness in] women seeking shelter from domestic violence for themselves and their children. More and more of the referrals we're getting have this added element... Often, they are not appropriate to shelter accommodation. Where they do come in, within a matter of hours you see that they aren't really going to be suitably placed with us and we have to move them on — they live very transient lifestyles. They either go from one abusive relationship to another or they head back to the same partner. You'll hear of them moving in and out of that relationship, often with the children in tow... We need some sort of supported accommodation for women with mental illnesses so that they can go there with their children. Their children can stay with them and be appropriately cared for and their issues can be looked at in a safe environ-

ment where there's more privacy. Most shelters work on a communal basis and that seems to be most inappropriate for these particular families.<sup>17</sup>

While there is still little reliable data concerning causal links between domestic violence and the development of mental illness, several witnesses gave evidence that women in such situations are frequently agitated, anxious, depressed and extremely fearful. One professional counsellor<sup>18</sup> told the Inquiry that many of her clients have ended up in psychiatric hospitals: some because they had developed a diagnosable mental illness, but many others because they presented in such a severely agitated and distressed state that they were assumed by clinicians to be psychiatrically disordered. (See also Chapter 19 — Women.)

Abused women may be incorrectly diagnosed for two reasons. First, because they are often reluctant to tell doctors the real reason for their distress for fear of retribution from the abusing partner. Second, neither psychiatrists nor general practitioners routinely ask questions about possible abuse, and tend to make their diagnosis solely on the basis of the woman's presenting symptoms. Therefore, they are often not in possession of the full clinical picture when diagnosing and referring for treatment.

## Effects on Young Children

Evidence presented to the Inquiry clearly indicated that the children of those affected by mental illness are seriously disadvantaged. They are also often seriously at risk. The Melbourne-based Coalition of Child and Adolescent Mental Health Professionals told the Inquiry:

The rights and needs of children whose parents suffer from a major mental illness are not the direct responsibility of any service.

When the mother is referred to an adult psychiatric service, it is not customary to inquire whether she is actually a parent, and even when it is asked, further questions about the current whereabouts of the children, their needs, who's caring for them, and whether anyone has taken an interest in how the children are handling the stress, are not routinely pursued. This is a major concern, because children whose parents suffer from a major mental illness are the most at-risk members of our community of developing a mental illness themselves in later life, both genetically and environmentally.<sup>19</sup>

These children can develop emotional, behavioural, social and psychiatric problems because their needs are overlooked by existing services where the needs of parents with a mental illness are seen to be of paramount importance.

Other recent research indicates that children of depressed parents demonstrate significantly greater levels of anxiety, depressive symptoms and physical

illnesses than children of non-depressed parents. They have more difficulty in school, with discipline, and in relating to their peers.<sup>20</sup>

The Melbourne-based Coalition did not consider that children should automatically be removed when a parent suffers a mental illness. Members emphasised, however, that in some cases the needs of the parent and those of the children conflict, so that a very careful assessment must be made.

During their evidence to the Inquiry, representatives of the group referred to a growing body of research which indicates that, with the implementation of preventive programs appropriate to the child's needs, with proper assessment of whether the ill parent's parenting skills are independent of the illness, and with dependable input from other caring adults, it is often possible for the family to remain intact and functional.<sup>21</sup> Indeed:

Clinicians can no longer assume that having a psychiatrically ill parent has to place a child at risk... They must consider the protective factors.<sup>22</sup>

### **Prevention and Intervention Strategies**

It's not a depressing scenario, really — or it need not be. Sometimes these families surprise us with how well they do, when proper supports are provided.<sup>23</sup>

Many experts suggest that protective and supportive measures are vital to the family's continued capacity to function if a parent is affected by mental illness.<sup>24</sup>

In Perth, the Inquiry heard evidence concerning the need for skilled family counsellors to visit families with troubled children — but there are no resources to cover such a program.

In terms of providing outreach services, we are very much constrained. We are requesting resources to provide these services, against the current economic climate — so the dilemma becomes one of whether we can reduce the clinic services we're providing, so that we can go ahead and extend our outreach plans. We have decided in favour of retaining our current services, because they are useful and necessary.<sup>25</sup>

A senior specialist clinician from Western Australia expressed grave concerns about the future parenting skills of the children of families where a parent has a major mental illness and is therefore providing an abnormal parenting model for his or her children. He indicated that an absence of appropriate supports for that family in the child's developmental stages means severe cross-generational dysfunction can result.<sup>26</sup>

Research drawn to the Inquiry's attention by several witnesses indicates that in the psychological and emotional development of children, the type of mental illness a parent has appears to be less significant an influence than the severity and chronicity of that illness.<sup>27</sup> Not surprisingly, given the daily interaction of most children with their mothers, available evidence suggests that maternal illness bears a much stronger relationship to the child's likelihood of psychiatric disorder and poor adaptive functioning than does paternal illness.<sup>28</sup>

The most harrowing exposure to mental illness that a child may undergo occurs when his or her parent suffers from one of the long-term chronic illnesses with recurrent episodes of mania or psychosis, or a constant level of significant disorder.

*Every child needs to grow up in a stable environment with consistent relationships. Many children are instead subjected to unending crises, stemming from a parent's mental illness and repeated hospitalisations, which provoke chronic uncertainty and unresolved grief. This can be more stressful to a child than the loss of a parent through divorce or death... Besides having to deal with the problems any child has dealing with the illness, such children are subjected to stress that recurs over long periods of time... Children may grieve for the normal mother they never had. The grief work may never be completed, for as long as the mother is alive, the child may hold onto the fantasy of her recovery.<sup>29</sup>*

It is notable that Professor Jane Sturges of Yale Medical School developed extensive expertise in this field and wrote about it in the early and mid-1970s. Evidence to the Inquiry indicated that, although the ground-work establishing the importance of prevention and intervention was publicised so long ago, Australian resources have not been developed to establish appropriate services which could have not only ameliorated family dysfunction and personal disruption, but also saved substantial amounts of money in subsequent treatment costs.

Indeed, the evidence submitted to the Inquiry by parents, children, clinicians, community support groups, health professionals and crisis service providers, indicates that Australia has basically failed to provide adequate services to meet the needs of children with parents affected by mental illness. (Such a situation is clearly inconsistent with the requirements of Article 18.2 of the Convention on the Rights of the Child,<sup>30</sup> which Australia has recently ratified.)

Supplementary evidence presented by the Melbourne Coalition concerning preventive programs appropriate to the needs of children of a parent with mental illness detailed three types of programs: first, information, support and education programs for children while the parent is an inpatient; second, information, support and education programs for children while the parent is receiving continuing community treatment as an outpatient; and third, assistance

for children who need intervention for their own psychological, emotional or behavioural difficulties.<sup>31</sup>

There are a very small number of services established to respond to needs in primary and secondary intervention.

One example of a primary intervention service is Clara House Women's Residential Unit in Prahran, Melbourne — a crisis house where women with psychiatric problems can go with their dependent children when they become aware that an acute psychotic episode may be about to occur. The program is essentially a short-term 'circuit-breaker'. It provides intervention before the woman has reached the point where admission to a hospital acute unit becomes necessary. It often avoids the necessity for the children to be sent to residential care or placed in a foster home.<sup>32</sup>

One of the few comprehensive secondary intervention services is Charmian Clift Cottages Incorporated, in Sydney. This service was set up in the mid-1980s specifically to work with mothers affected by mental illness with young children. It provides longer term residential options with a range of activities and supports which are desperately needed by many such women and their children. It provides a model which could well be adapted to meet the local needs in other States and Territories.<sup>33</sup>

Prevention and intervention strategies are discussed in more detail in Chapter 27 — Prevention and Early Intervention.

## **Effects on School-Age and Teenage Children**

Evidence presented to the Inquiry indicated that school-age children with a parent affected by mental illness not only suffer serious disruption to their home and family life, but are also likely to undergo severely stressful experiences in school and social environments — with little or no assistance in dealing with their parent's illness or the resulting stress.<sup>34</sup>

The Inquiry also heard that the problems facing school-age and teenage children differ substantially from those affecting very young children. The Inquiry heard from witnesses, now in their late teens, who had grown up with a parent with mental illness; and from people involved with adolescent members of the various family support organisations, such as The Alliance for the Mentally Ill (AMI), The Australian National Association for Mental Health (ANAMH), the Schizophrenia Fellowship and The Association for the Relatives and Friends of the Mentally Ill (ARAFMI).

One witness recounted a typical incident involving a boy whose mother had developed schizophrenia when he was pre-adolescent. His parents were separated and he was given no information or support until he was 15, when he attended an ARAFMI family education course.

I used to think that I had schizophrenia too. Now I know the positive and the negative symptoms and I feel better. I wish I had known all that stuff before. I was really worried, but I didn't want to tell anyone. I cried a lot and I didn't know what was wrong with me, I just thought I must be going mad.<sup>35</sup>

This secret fear of becoming mentally ill was a recurring theme, particularly in situations where no one would talk to the child about their parent's illness, about its symptoms, and about their own role and responses.

Another member of ARAFMI was 13 when her mother became ill with manic depression. She recounted a typical story:

I was in the dark. I didn't know what was going on. My father isn't very communicative ... For two weeks I kept it to myself... I'd done science at school, I knew what genetics was about and that there is a genetic element in manic depression. I thought hey, this is going to happen to me, and I'm afraid... I see Mum in me, but I don't know if that is the genetic bit or the environment bit. No one talks to me about that, so there's this fear.<sup>36</sup>

She spoke of how isolated and alone she felt at school, how she could not talk to her friends about her mother's illness. She described what had happened at school after her mother had attended a parents' meeting one evening in a florid mental state, just before her admission to hospital:

A few days later, kids whose parents had mentioned it to them said to me, 'Your mum is weird!', and I said 'Yes, she's gone to the loony bin.' I feel really guilty about that now, but I was only 13. I didn't know what was really happening, so how could I explain it to them? I would have liked [the young ARAFMI school presenters about mental illness] to come to the school and to help the other kids to understand about my mum... Seeing your mum in hospital is terrifying — your mum, who's looked after you, and she's not looking like your mum... it's horrible, and I felt so alone... People who haven't experienced this don't understand.<sup>37</sup>

This young woman emphasised the misery of feeling different, at being singled out, just at the age when young people want most of all to be like their peers, to be accepted as one of the group. When she was 16, one of her teachers had asked her, in front of her whole class, if she had any problems. She spoke of the profound effect this unsolicited attention had on her:

I was 16. Teenagers don't want to be singled out, they don't want to be different. It was so humiliating... I've cried about this so many times...<sup>38</sup>

Her evidence demonstrated the need for the thousands of Australian children enduring similar experiences to be able to talk about it with each other in order to help overcome some of their sense of shame and the resulting alienation and loneliness. As this young woman pointed out, statistics indicate that approximately one person in five is affected by some form mental illness at some time in their lives. In her school, which had 1,000 students, there would have been dozens of other children in close contact with someone with mental illness, some of whom were probably experiencing the same kind of stress and loneliness she was. Until recently, no one in the school environment was prepared to speak out about the effects of having a parent with mental illness.<sup>39</sup>

When a child has a parent with mental illness, particularly the mother, evidence to the Inquiry indicated that there is often a reversal of the normal parent-child relationship, in that the eldest child frequently takes on the role of 'parenting' not only the mother, but often the younger children in the family — cooking, seeing to their homework, assisting in dressing them and doing laundry and household chores.

The founder of ARAFMI described the responsibilities taken on by a 15-year-old boy:

This young man...is the primary caregiver in his home. His mother has schizophrenia and is separated from her husband. He looks after his mother, supervises her medication, gets her to hospital when necessary, washes and irons school uniforms for his young sisters. In fact, he takes on the role of the mother...as well as taking a degree of responsibility for the mother's care and medication and calling for emergency assistance when a crisis occurs.<sup>40</sup>

This role reversal can clearly have serious implications for that child's relationship with brothers and sisters (which becomes skewed by the adoption of the pseudo-parental role) and for his or her own adjustment in later life.

Each stage of a parent's mental illness creates a different set of stresses and problems for children. In order to give children effective support, expert counselling and a range of other therapeutic interventions are recommended by health professionals:

Children will often talk of the anxiety they felt over the meaning of the person's bizarre behaviour... They may experience temporary relief after the ill person is admitted to hospital, but subsequent to this, may feel increasingly guilty. Younger children...may believe they have caused the ill person to be sent away. Older children also express guilt about their part in the situation prior to the person's being hospitalised... After the patient is discharged from hospital, children may experience ambivalent feelings... Many experience fear that the events of the past may recur. Patients often do regress around the time of discharge, so this fear is sometimes confirmed.<sup>41</sup>

The urgent need for appropriate intervention programs, services and supports for both the children and their parent (or parents) with mental illness was emphasised both by experts and by community service providers.

## **Adults Whose Parents Were Affected by Mental Illness**

The Inquiry also received evidence from adults whose parents were affected by mental illness throughout their formative years. One witness, now aged in her early thirties, remains so traumatised by the experiences of her childhood and adolescence with a schizophrenic mother that she found it very difficult to speak to the Inquiry:

It is only now that I have been through so many things myself, that I can actually feel strong enough to come to terms with it. I had to go through an enormous cycle to get to this point. It is incredibly hard to speak about it.

I was a child. I was maybe 13 or 14, having to deal with all this. I don't feel like my own life has even started yet, it has just been completely taken over and covered over by this illness, and there has not been any support... What we did, we just read everything about it we could get our hands on — we had to educate ourselves because no one else told us anything about it.

My mother developed schizophrenia in her early forties, so there is another 'missing statistic': it is not only the younger parents who develop this disease. Nobody seems to know, or want to know, what it is like in a family like this. People turn their backs on it.<sup>42</sup>

Another witness, a health professional who also grew up in a family where the mother suffered from schizophrenia, told the Inquiry:

It is stigmatising to come from a family like this — not just because there is mental illness, but because it is chaos to live in a family in which a parent is mentally ill with one of the major mental illnesses. It is unpredictable, it may be violent; I do not necessarily associate mental illness with violence, but in my case, it was.

The children, as children, are voiceless and are damaged because of the chaos associated with it. Once you become a professional, you do not own up to it. As an adult, you remain damaged and stay voiceless, or you step out of it and find a route through.<sup>43</sup>

Neither of these witnesses' families had the benefit of professional support, or community service intervention, throughout their childhood. As children they experienced a lack of protection of their basic rights. We now have a better appreciation of the education, prevention and intervention strategies needed to establish an appropriate range of responses to deal with these problems. However, evidence to the Inquiry clearly demonstrates that we have not yet done so. The lives of thousands of children are being permanently damaged as a result.



1. Name withheld. Oral evidence, Perth 11.2.92, p270.
2. Terry Smith, President of PaNDa (Post and Ante-Natal Depression Association), Victoria. Oral evidence, Melbourne 10.4.91, p433.
3. Terry Smith, President, and Jo Rogers, Secretary, PaNDa, Victoria. Submission, p4.
4. Deborah Gross, 'At Risk: Children of the Mentally Ill', *Journal of Psychosocial Nursing (Canada)*, v27 No8, 1989, p15: 'When the interactions between depressed mothers and their three-month-old infants were compared with non-depressed control groups, depressed mothers were found to be significantly...more unresponsive towards their infants than well mothers. When three-month old babies of depressed mothers were observed with non-depressed mothers, the babies showed aberrant interactive responses.'
5. Beverley Innis, Queensland. Submission, pp2-3.
6. Margaret Lukes, founder of ARAFMI. Oral evidence, Sydney 20.6.91, p427.
7. Vicki Eyles, NSW. Submission, p1.
8. Eyles. Supplementary submission, p1: 'Foster parents of the children of the mentally ill need a very special kind of counselling... Some fantastic foster parents who are reasonably intelligent cannot explain things properly, because there is such an enormous stigma attached to mental illness... It is a difficult task to explain their parent's illness to the children...[and] everyone needs support in handling difficult tasks.'
9. Ivor H Jones, 'Schizophrenia,' In P Beumont and R Hampshire (eds), *Textbook of Psychiatry*, Blackwell Scientific Publications, Sydney 1989, p78; and M Bashir, I Richards, and M Schwarz, 'Adolescent Psychiatry', in the same text, p214.
10. Many submissions from consumers who requested anonymity gave accounts of the disintegration of their marriages after the onset of a schizophrenic illness.
11. James Fry, Queensland. Submission, pp1-2.
12. Name withheld, South Australia. Submission No731, p1.
13. Name withheld, Victoria. Submission No15, p3.
14. Pastor Robbi Dawson and Jill Cameron, Port Melbourne Baptist Church, Victoria. Submission, pp2-3.
15. Bernie Lazarus, The Young Women's Issues Forum, South Australia. Submission, p7.
16. id. One case quoted by the Forum concerned a young woman suffering from paranoid-type delusions. She had a 20-month-old child with her and was staying in supported accommodation for women in Adelaide. The mother believed she was being watched and followed, so she held onto the child, never letting it out of her arms. Staff at the service held fears for the child's safety, but there were simply not enough staff to provide the mother with the intensive support she needed, and to protect the child's safety and allow him the normal freedom of movement essential for a young child's development.
17. Julie Felus, Irene Women's Shelter. Oral evidence, Adelaide 22.10.91, pp293-4.
18. Topsy Evans, Chairperson, Domestic Violence Action Group, Hobart. Oral evidence, Hobart 13.11.91, p313.
19. Jennifer Luntz, President, Coalition of Child and Adolescent Mental Health Professionals, Victoria. Oral evidence, Melbourne 8.4.91, p36.
20. Gross, op cit, pp15-16; and M M Silverman, 'Children of Psychiatrically Ill Parents: A Prevention Perspective', *Hospital and Community Psychiatry* v40 No12, Dec 1989, p1259.
21. Gross, op cit, p18: 'Hospital stays are too brief to treat parenting disorders... However [the parental] hospital assessment can identify and arrange appropriate services following discharge... Early intervention programs in Chicago...include assessment and enrichment

of the young child's cognitive, sensor/motor and socio-emotional development, as well as guidance for the parents.' See also M A Zeitz, 'The Mothers' Project: An Overview of a Program to Help Mothers with Mental Illness', paper presented on behalf of Thresholds, Chicago 1989, pp2-8. The Chairman of the Inquiry visited Thresholds' programs during an inspection of several major US mental health projects in April 1992.

22. Silverman, op cit, p1262.
23. Eileen Anderson, Secretary, Coalition of Child and Adolescent Mental Health Professionals. Oral evidence, Melbourne 8.4.91, p40.
24. id.
25. Patrick Marwick, senior social worker, Warwick Child and Adolescent Community Mental Health Clinic, Perth. Oral evidence, Perth 10.2.92, p99.
26. Dr Hugh Cook, Consultant Psychiatrist, Warwick Child and Adolescent Community Mental Health Clinic, Perth. Information provided to Inquiry, Jan. 1992.
27. Silverman, op cit, p1257.
28. Gross, op cit, p16.
29. J Sturges, 'Talking with Children about Mental Illness in the Family,' *Health and Social Work Aug 1977*, pp104-7.
30. Article 18.2 of the UN Convention on the Rights of the Child states: 'For the purpose of guaranteeing and promoting the rights set forth in the present Convention, State Parties shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children.'
31. Coalition of Child and Adolescent Mental Health Professionals, Victoria. Supplementary submission. The information provides a recommended list of questions about children and their care, to be routinely asked of people affected by mental illness on admission to a psychiatric hospital.
32. Dr Joan Clarke, Executive Director, Prahran City Parish Mission, Victoria. Information on Clara House provided with submission.
33. See Chapter 5 — Mental Health Services, for information about Charmian Clift Cottages.
34. Melissa. ARAFMI member. Tape provided to the Inquiry by ARAFMI, Sydney: 'Strange things were happening... I was in the dark — I didn't know what was going on... I couldn't talk to anyone... I couldn't talk to my friends. I did say Mum was in a mental hospital, so they stopped coming around. I didn't do normal teen things... I found it difficult to stand up for myself.'
35. Recounted by Margaret Lukes, op cit, p428.
36. Melissa, op cit.
37. id.
38. id.
39. The ARAFMI schools program is described in more detail in Chapter 6 — Role and Training of Health Professionals and Others.
38. Lukes, op cit.
41. Sturges, op cit, pp93-101.
42. Name withheld. Oral evidence, Perth 11.2.92, p270.
43. Maria Harries, President, Australian Association of Social Workers, (WA Branch). Oral evidence, Perth 11.2.92, p269.



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