

Human Rights & Mental Illness Victoria

**Report of the Reconvened Inquiry into the
Human Rights of People with Mental Illness (Victoria)**

Human Rights and
Equal Opportunity Commission

December 1995

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**Human Rights and
Equal Opportunity Commission Human Rights Commissioner**

5 December 1995

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

Dear Attorney

We enclose the report of the Reconvened Inquiry into the Human Rights of People with Mental Illness (Victoria). 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 concerns 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

A handwritten signature in black ink, appearing to read "Chris Sidoti". The signature is written in a cursive style with a large initial "C" and a long horizontal stroke extending to the right.

Chris Sidoti
Human Rights Commissioner

Dame Margaret Guilfoyle
Commissioner

David Hall
Commissioner

PREFACE

The reconvening in Victoria of the National Inquiry into the Human Rights of People with Mental Illness was initiated and chaired by my predecessor, the first Human Rights Commissioner, Brian Burdekin. Mr Burdekin completed his term as Commissioner in early 1995.

Brian Burdekin succeeded in drawing unparalleled attention to the serious abuses of the human rights of people with mental illness. The recommendations in the Report of his Inquiry have resulted in better laws, better policies and programs and better funding to meet the needs of these Australians. Many of those recommendations, however, have not been adopted or have not been fully implemented. This Report demonstrates that.

On my appointment as Human Rights Commissioner in August 1995, I inherited responsibility for final preparations and release of the Report on the Reconvened Inquiry. I was pleased to be able to conclude this important work of Mr Burdekin and the Inquiry Commissioners.

I wish to place on record my appreciation to Mr Burdekin, Dame Margaret Guilfoyle and Mr David Hall and to staff of the Human Rights and Equal Opportunity Commission for their dedication, professionalism and sheer hard work. Some staff contributed at different times but I thank Rebecca Peters, the Secretary of the Inquiry, Carolyn Bowra, Ian Clyde, Pip Dargan, Nadja Diessel, Barbara Fahey, Kieren Fitzpatrick, Rosemary Grant and David Robinson.

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Chris Sidoti
Human Rights Commissioner

Human Rights and Mental Illness (Victoria)

Table of contents

Background	1
The terms of reference	1
The Commissioners	2
Procedure of the Inquiry	2
Structure of the Report	2
Chapter 1 — Introduction	4
The Victorian policy context	4
Deinstitutionalisation	5
Mainstreaming	5
Coordination of services	6
Case management	7
Developments since the Reconvened Inquiry's hearings	8
Policy	8
Legislation	8
Services	9
Funding	10
This Report	11
Chapter 2 — Intimidation of those advocating on behalf of the mentally ill or criticising the adequacy of services	12
Dr David Leonard	15
Removal of mental health professionals from the Department	17
Other accounts of intimidation	19
The Code of Conduct	20
Intimidation of consumer and non-government organisations	20
Conclusion	23
Chapter 3 — Consultation with non-government agencies, consumers and carers	26
Formal consultative mechanisms	26
The role of advocacy	28
Consultation with consumers	30
Consultation with carers	33
The 'serious mental illness' threshold	34
Consultation in the context of confidentiality	36
Conclusion	38

Chapter 4 — Adequacy of services for especially vulnerable or disadvantaged groups	41
Homeless people	41
Mainstreaming specialist services	42
Aftercare	43
Access to services	43
Ancillary services	44
People with dual or multiple disabilities	45
Falling through the net	45
Mental illness and intellectual disability	47
Lack of expertise	48
The inter-service protocol	49
Training	50
Mental illness and substance abuse	50
Mental illness and acquired brain injury	51
Personality disorder	52
Multiple personality disorder	54
Mental illness and deafness	54
People from non-English speaking backgrounds	55
Indicators of vulnerability	56
Longer hospital stays	56
Lower usage of mental health services	56
Higher rate of physical treatments	58
Resources	59
Women	60
Women with children	60
Safety	61
Children and adolescents	62
Waiting lists for assessment	62
Inpatient family services	63
Placement in adult facilities	63
Day programs	64
Assessment services in schools	65
Rural services	65
Homeless services	66
Adolescents with self-destructive behaviour	66
Elderly people with dementia	66
Accommodation	67
Strathdon Lodge	68
Insensitive treatment	69
Conclusion	70

Chapter 5 — Administration of medication in non-specialist residential facilities	75
Boarding houses and Supported Residential Services	75
Unqualified administering of medication	78
Appropriate care	79
Reliance on medication	80
Legislative reform	82
Deregulation of nursing homes	83
Over-servicing	83
Over-prescribing	84
Medicare fraud	84
Conclusion	85
Chapter 6 — Other significant issues raised in evidence	88
Burden on families	88
Police involvement	89
Conclusion	91
Chapter 7 — Findings and Recommendations	94
General findings	94
General recommendations	94
Intimidation of those advocating on behalf of the mentally ill or criticising the adequacy of services	95
Consultation with non-government agencies, consumers and carers	96
Adequacy of services for especially vulnerable or disadvantaged groups	97
Homeless people	97
People with dual or multiple disabilities	98
People from non-English speaking backgrounds	99
Women	100
Children and adolescents	100
Elderly people with dementia	101
Administration of medication in non-specialist residential facilities	102
Other significant issues raised in evidence	103
Appendix	104
Witnesses appearing before the Reconvened Inquiry	104
Submissions	105

BACKGROUND

This Report documents evidence presented to the Reconvened Inquiry into the Human Rights of People with Mental Illness.

This Inquiry was an extension of the original National Inquiry into the Human Rights of People with Mental Illness. The Report of the National Inquiry, which was tabled in Parliament in October 1993, highlighted deficiencies in mental health policies, practices and services across Australia. Since the National Inquiry, increased public awareness about mental illness has led to a number of positive responses to the Report from both government agencies and non-government organisations. The Victorian Health Minister, the Hon Marie Tehan, initially welcomed the Report as 'an important and wide-ranging contribution'. The Human Rights and Equal Opportunity Commission was disappointed at later criticism of the Report by Dr John Paterson, head of the Victorian Department of Health and Community Services.

In 1994 the then Federal Human Rights Commissioner, Brian Burdekin, received information from clinicians, advocates and public servants that attempts had been made to intimidate individuals and organisations to prevent criticism of mental health services in Victoria. In response to these allegations the Commissioner announced he would reconvene the Mental Illness Inquiry in Victoria. Subsequently the Human Rights and Equal Opportunity Commission received so many calls and letters about other mental health issues that the Inquiry's terms of reference were expanded.

The terms of reference

The terms of the original National Inquiry covered all aspects of the human rights of people affected by mental illness, including human rights in relation to institutional and non-institutional care and treatment. The terms of reference of the Reconvened Inquiry were to examine:

- a) the circumstances in which medication is provided in private hotels, hostels, boarding houses or other non-specialist facilities where individuals affected by mental illness reside;
- b) the adequacy of services for especially vulnerable or disadvantaged groups (including individuals who are homeless, those with dual or multiple disabilities, the elderly, the young and those from non-English speaking backgrounds);
- c) the participation of non-government agencies in policy formulation and program planning for people affected by mental illness; and

- d) whether there has been any intimidation, coercion, detriment or disadvantage suffered by any individuals or organisations advocating on behalf of the mentally ill or criticising the adequacy of existing programs or services.

The Commissioners

The hearings of the Reconvened Inquiry were conducted by the same Commissioners who presided over the original National Inquiry. The then Human Rights Commissioner, Brian Burdekin, chaired the Inquiry, and was assisted by Dame Margaret Guilfoyle and David Hall.

Brian Burdekin was appointed as the first Australian Human Rights Commissioner in 1986, a position he held for 8 years. In June 1995 he took up his current post as Special Adviser to the United Nations High Commissioner for Human Rights.

Dame Margaret Guilfoyle is President of the Royal Melbourne Hospital and Deputy Chair of the Victorian Mental Health Research Institute. Her career has included 16 years as a Senator for Victoria, during which time she held various federal portfolios, including Education (1975), Social Security (1975-1980) and Finance (1980-1983). Dame Margaret is a director of several charitable trusts and a member of the Council of Deakin University.

David Hall is the Chief Executive of the Victorian Deaf Society. He was previously 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 was Victoria's Director of Consumer Affairs (1983-88) and has extensive experience in policy planning and program coordination with federal government departments.

Procedure of the Inquiry

Hearings were conducted in Melbourne on 5 and 6 December 1994. The hearings were mainly public, though a number of witnesses were granted private hearings. In addition, over 100 submissions were received from individuals affected by mental illness, advocacy groups and professionals working in the system.

Structure of the Report

This Report is divided into seven chapters, including an introductory chapter, five evidence chapters and a concluding chapter containing the Inquiry's findings and recommendations.

Chapter 1, the introduction, gives a brief overview of the Victorian policy context in which the evidence to the Reconvened Inquiry was given. It also raises specific issues examined in detail in the following evidence chapters.

Chapter 2, the first of the evidence chapters, addresses the term of reference concerned with intimidation of individuals or organisations advocating on behalf of the mentally ill.

Chapter 3 examines evidence relating to consultation with the non-government and community sector in policy formulation and program planning.

Chapter 4 addresses evidence on the adequacy of services for groups that are especially vulnerable or disadvantaged.

Chapter 5 focuses on the circumstances of the administration of medication in boarding houses.

Chapter 6 addresses two other issues arising from the evidence: the burden on families and the role of police.

Chapter 7 presents the Inquiry's findings and recommendations.

The Appendix lists the witnesses who provided oral evidence under oath or submissions. Some witnesses requested that their names be kept confidential and a few people who made submissions did so anonymously.

This Report was 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 mental health professionals. For many witnesses, contributing to the Inquiry required courage and for some it involved very real professional or personal risks. To all witnesses the Inquiry expresses its gratitude.

CHAPTER 1

Introduction

This chapter discusses the broad principles and policies underlying the Victorian mental health program. It deals in general terms with the evidence on these principles given to the Inquiry. Later chapters discuss this evidence in more detail. The chapter indicates that the principal concern is not with the policies themselves but with the way in which they are being applied and implemented in Victoria.

The Victorian policy context

In April 1994 the Victorian Government launched *Victoria's Mental Health Service: The Framework for Service Delivery* — a five-year plan for the redevelopment and redistribution of mental health services in Victoria. By December 1994 when the hearings for the Reconvened Inquiry were conducted, the mental health system was undergoing significant change. For example, one of the nation's biggest psychiatric complexes, the North East Metropolitan Psychiatric Service (NEMPS), was being dismantled and restructured. At the same time a number of new services had been launched, the most important being the Crisis Assessment and Treatment (CAT) teams and Mobile Support Teams.

In its submission to the Reconvened Inquiry, the Government referred to one of the findings of the Commonwealth Government's first *National Mental Health Report (1993)* which placed Victoria ahead of other states in per capita mental health spending. The second *National Mental Health Report (1994)* showed Victoria still had the highest per capita spending but overall mental health expenditure had declined in the 1993-94 financial year.

While witnesses identified many positive proposals and initiatives in the *Framework* document, there was great unease about the gap between policy and practice and about the rapid pace of change. This was raised, for example, in relation to the shift towards public tendering for services previously provided by government. Under new guidelines, hospitals, community mental health centres and private and non-government service providers must compete for the management of services. While the aim of providing the best possible service is laudable, witnesses claimed the tendering process is fraught with weaknesses that threaten existing services and protections for people with mental illness.

The urgency and manner in which the mental health system is being reformed is contributing to a sense of frustration on the part of service providers, mental health workers, consumers and carers. According to some witnesses, aspects of

the reform program appear to be driven primarily by economic imperatives rather than clinical need.

Deinstitutionalisation

The Victorian Government has followed a national and international trend in its commitment to the deinstitutionalisation of people with serious mental illness. People with mental illness are encouraged to receive treatment and care in the community rather than in psychiatric hospitals. This is in line with the UN's Principles for the Protection of Persons with Mental Illness which are based on the principle of the 'least restrictive alternative for treatment'. While the policy of deinstitutionalisation reflects a commitment to providing the least restrictive alternative for people with a mental illness, its effectiveness depends fundamentally on adequate resourcing for support services in the community.

Witnesses to the Reconvened Inquiry repeatedly stressed that deinstitutionalisation in Victoria is insufficiently resourced. In its submission the Victorian Government argued that 'savings from hospital efficiencies and new funding have been directed into community based services'. However, the second *National Mental Health Report (1994)* shows that a substantial proportion of these savings were in fact returned to general revenue.

The reduction in funding was confirmed by witnesses who argued that the gap between demand and supply of services is actually increasing. According to the evidence, the demand on community services created by the shift away from institutional care is far greater than the re-directed savings can accommodate. This has placed inordinate pressure on community support services to handle caseloads for which they are not adequately funded or in some cases qualified. The needs of individuals depending on this care are often neglected. As a result they are vulnerable to degrading living conditions and distressing experiences from which they have a right to be protected.

Mainstreaming

Many witnesses raised concerns about the policy of mainstreaming mental health services. Under mainstreaming, specialist psychiatric services are being incorporated into general health services such as hospitals. Mainstreaming is intended to provide more accessible services that meet an established standard. Under mainstreaming, budgets for many specialist services have been severely reduced. The intention is for the general service to absorb some of the infrastructure and administrative costs, but the net effect is a shortfall that is eroding the quality of specialist care.

A central problem identified in evidence was that generalist services are designed and resourced primarily to handle acute illnesses and injuries. Mental

illness, however, is often chronic and episodic in nature, requiring long-term treatment or management. This disjuncture is reflected in the strict service eligibility criteria that tend to exclude from assistance many individuals who need early intervention or continuing management. People can reach crisis point before they become eligible for treatment.

When not adequately resourced, mainstreaming is unable to provide continuity of care for people whose management or recovery depends on it. Many witnesses suggested that better resourcing of mainstream services would mitigate the shortcomings of an amalgamated health system. While the Government's stated intention is to increase the allocation of funds to support mainstreaming, many witnesses gave evidence that the distribution of funding will not ensure the viability of those services that are absorbed.

Coordination of services

The rapid implementation of both deinstitutionalisation and mainstreaming has resulted in a loss of coordination between mental health care and other health care services. This is partly because services are being dismantled or restructured and partly because overall funding is being reduced.

The decline in coordination is primarily due to the fragmentation of services resulting from the combined restructuring and funding cuts. The *Framework* document states that a principal objective is to establish a 'comprehensive network of mental health services'. Witnesses to the Inquiry gave evidence that services are focusing their resources internally rather than towards coordinated delivery. The needs of the people whose everyday lives are profoundly affected by mental illness can be easily overlooked in the drive for cost-saving and managerial efficiency.

A direct result of uncoordinated and fragmented service delivery is a focus on short term treatment that cannot accommodate continuity of care. The principles of psychosocial rehabilitation require clients to be able to develop long-term relationships with staff to promote continuity, trust and an ability to work on a treatment plan. Managerial concepts such as 'throughput' directly contradict this aim.

The most disturbing point raised in evidence on this issue was that uncoordinated service delivery makes it extremely difficult to provide appropriate care and treatment to individuals who are so seriously disabled that they are unable to meet the strict eligibility criteria of any one service.

This is particularly evident, for example, in cases where an individual needs the assistance of both intellectual and psychiatric disability services. The lack of

coordination between the two services or the inflexible criteria of each precludes assistance from either service. Witnesses to the Reconvened Inquiry welcomed a new joint protocol between intellectual and psychiatric disability services but expressed reservations about it fulfilling its aim of better service coordination. Ignorance of its existence and logistical problems in its application were cited as particular problems.

Since the Reconvened Inquiry took evidence, the Government has shown further commitment to addressing the coordination problems between services. For example, guidelines for delivery of mobile support and treatment services have been operating since September 1995. A draft protocol between psychiatric services and alcohol and drug services is currently being developed for implementation in 1996. In addition to this collaborative arrangements between public mental health services and private psychiatrists are also currently being considered.

While the commitment on a policy level is evident, the Inquiry is concerned that these initiatives may fail to address the problem in practical terms. The Inquiry was not in a position to determine whether the problems cited about the effectiveness of the protocol between intellectual and psychiatric disability services have been overcome in subsequent initiatives.

The current fragmentation and lack of coordination between services may be symptomatic of a mental health system in transition. Concern was expressed in evidence, however, that the diminished capacity of services to deliver to those most in need is, in fact, the unintended consequence of reform.

Case management

Victoria like other states is introducing case management as a more responsive and efficient way of delivering mental health services. Case management involves allocating to each client of the mental health system a case manager who takes responsibility for ensuring continuity of care. When adequately resourced, case management can simultaneously assist deinstitutionalisation, ensure continuity of care and coordinate service delivery around the needs of each individual. It allows for the 'least restrictive alternative' by enabling people who have a mental illness to have greater control over their care and treatment. It can also provide a safeguard against people falling between services.

Evidence to the Reconvened Inquiry reflected a genuine enthusiasm for the potential benefits of the case management approach to mental health service delivery. Concern was consistently expressed, however, about the serious under-resourcing of the implementation of case management. The most common statement was that there were simply not enough case workers to handle the

load. Witnesses said case managers are severely over-stretched and consumers confused and frustrated at the incapacity of case managers to respond to their needs. Some consumers in fact did not know who their case manager was.

Developments since the Reconvened Inquiry's hearings

The Victorian Government provided the Reconvened Inquiry with a list of major achievements in mental health services since October 1992. Of those, the following relate to developments since December 1994, when the hearings were held.

Policy

- In June 1995 an interdepartmental committee for the development of a strategy to address youth suicide was established. The committee has representatives from a range of departments, the non-government sector and acknowledged experts in the area.
- A draft *Framework for Aged Persons Mental Health Services (APMHS)* was produced in September 1995 and circulated widely for public comment.
- *Better Outcomes through Area Mental Health Services in Victoria: The Next Steps* is a document currently being developed to extend initiatives detailed in *The Framework for Service Delivery* (1994).
- The final framework for Child and Adolescent Mental Health Services will be released early in 1996.
- A policy framework for future expansion of the non-government disability support sector and its place within area-based comprehensive networks of mental health services is being developed in consultation with non-government organisations and will be finalised early in 1996.
- A document *Working With Consumers: Guidelines for Consumer Participation* will be launched in February 1996.
- A draft *Family and Other Carers Policy* is being circulated for comment and will be released in March 1996.

Legislation

- The Mental Health (Amendment) Bill 1995 is currently before Parliament and has been passed by the Legislative Assembly. The Bill amends the *Mental Health Act 1986* to increase the focus on protecting the rights of people with a mental illness.

Services

- In February 1995, a review of the implementation of CAT services was initiated. A report will be completed in December 1995.
- By April 1995, all components of the public mental health service system had an identified auspice agency which assumed management of the services from the Department progressively from 1 July 1995. These agencies include acute hospitals, aged care extended care centres, private hospitals and non government organisations.
- In June 1995 the Women's Advisory Group was established to provide recommendations on improving the responsiveness of services to the specific needs of women as consumers and carers.
- Community-based extended care services for APMHS clients have been further expanded with a new 32-bed hostel opened in March 1995. A 15-bed psychogeriatric acute unit, 30-bed psychogeriatric nursing home and behavioural management support program were also established in July 1995.
- In October 1995, the Department published an interim report on four pilot shared-care projects aimed at enhancing the ability of general practitioners to treat and manage the care of people with serious mental illness.

The Government completed and distributed the protocol between Victoria Police and Psychiatric Services in October 1995.

- *Mobile Support and Treatment Services-Guidelines for Service Provision* were launched in September 1995.
- A project to develop outcome standards for consumers and uniform data collection systems was established in early 1995 and will be completed by early 1996.
- Two new child and adolescent community outpatient teams were established in 1995 in the Eastern Metropolitan region of Melbourne.
- The number of accommodation support places funded has increased from 590 in 1992-93 to 795 in 1994-95, a 35% increase. In 1995-96 the number of places will increase to 950.
- The number of Community Mental Health Clinics has increased from 38 in 1992 to 41 in 1995.

- Teleconferencing equipment has been steadily expanding both in utilisation and the number of established sites over the past 12 months. There are now 11 rural psychiatric services and three specialist metropolitan psychiatric services funded to establish teleconferencing sites.
- The Government provided information and training sessions on understanding mental illness on a regular basis for police training courses.
- The Department produced a draft document *Sharing the Care: GPs and Public Mental Health Services* which provides for shared care arrangements between Psychiatric Services and general practitioners, to be released in February 1996.
- The protocol developed between Psychiatric Services and Alcohol and Drug Services will be released in February 1996.
- Draft Guidelines for General Adult Community Mental Health Services have been circulated for comment, to be launched in March 1996.
- The Department produced draft strategy statement on improving services for people from NESB, to be finalised in March 1996.
- The Department produced draft guidelines for collaborative service arrangements between public mental health services and private psychiatrists, to be released early in 1996.

Funding

- In July 1995, the Psychiatric Services Branch created 1.5 permanent positions to facilitate the employment of consumers on projects for the Victorian Community Advisory Group (VCAG) and on the development of policies and guidelines.
- In August 1995, a new 10-bed adolescent unit was opened at Monash Medical Centre at a cost of \$1.2 million. This increased child and adolescent mental health beds in Victoria by 20%.
- Total funding for statewide capital projects in the APMHS area in 1995-96 is more than \$12.7 million.
- In 1995-96 funding of \$105,000 was provided to conduct a clinical audit of psychiatric suicides in Victoria from 1989-1995.
- Additional \$1 million was allocated to provide 290 new accommodation places by 1995-96 to help people with mental illness live successfully in

in the community. Approximately 25 non-government organisations will receive funding to auspice the accommodation places.

- Resources are being moved from inpatient to community-based services. Victoria anticipates a 46:54 split (community: inpatient) in 1995-96 and is well on target to reach a 50:50 split by 1997.
- A funding and service agreement model which incorporates accountability requirements and consumer outcome targets has been developed and takes effect from early 1996.
- Recurrent funding of \$45,000 has been provided for a Housing and Support project for homeless women with mental illness at the Bedford Street Outreach Service.
- Work commenced on a \$25 million development of the Institute of Forensic Psychiatry, a 120-bed facility to be operational in late 1997.
- Victoria is maintaining expenditure on mental health in accordance with the Medicare Agreement over the five years to 1997-98.

This Report

The evidence in the following chapters should be read in the context of the policies and developments outlined above. In principle the policies are uncontroversial and potentially of great benefit to people with mental illness, their carers and the community. However, evidence from individual consumers and service providers in this Report raises concerns about how the policies are being implemented.

CHAPTER 2

Intimidation of those advocating on behalf of the mentally ill or criticising the adequacy of services

People are frightened. People ring our office to report something that is going on in the hospital and they are literally terrified witless that you might not keep it confidential. You have got to constantly reassure them that you will keep the information confidential.'

The primary catalyst for reconvening the Mental Illness Inquiry was that the then Human Rights Commissioner, Brian Burdekin, received reports alleging intimidation of individuals and organisations in the mental health field in Victoria. This information came from advocacy groups, public servants and clinical staff. The announcement of the Reconvened Inquiry prompted further allegations, often from individuals who were frightened and unwilling to be identified.

By its nature, this was an issue on which witnesses were reluctant to come forward. The alleged intimidation that was the subject of complaint prevented the complainants from speaking out about it. Several witnesses agreed to give evidence in private hearings. The Inquiry was also told of other mental health workers who wished to give evidence but considered the risk of retribution by the Department of Health and Community Services and/or service providers too great. For example, the president of the College of Mental Health Nursing spoke on behalf of nurses.

[Our submission] cannot rely upon statements that can be attributed to recognisable persons working in the mental health area because they are afraid of departmental retribution... The College regrets this but turns on the insistence of its members' anonymity as evidence of the very real concerns held by them for their security.'

Despite these obstacles many witnesses in oral and written submissions confirmed the allegation of a 'climate of fear' in parts of the mental health system.' At its worst the perceived threat is of loss of employment. One psychiatrist in private practice prefaced her submission about deficiencies in the treatment of mentally ill children and adolescents,

I have gathered this information from speaking to many colleagues from different professional disciplines in the public sector who will not speak out for fear of losing their jobs.⁴

Some mental health workers use consumer advocacy groups as avenues of complaint rather than raising their concerns with their employers directly. The director of one group, the Victorian Mental Illness Awareness Council, told the Inquiry,

VMIAC has been contacted by a number of service providers who wanted to secretly and confidentially tell us what has been happening in mental health services in the hope that we could do something, and the reason they gave for not taking action themselves is that they feared they would lose their jobs... The issues raised included, for example, disgusting meals within institutions, [and] people having to discharge clients with nowhere to go because they could not find a service in the community to take them, because they were all overstretched.'

The director of the Mental Health Legal Centre said,

We get [health system] staff ringing us quite desperate and not knowing what to do. We do not advise staff and we do not advise families we work for consumers. We give information in these cases and the information we provide is that the Office of the Chief Psychiatrist will talk to you confidentially. [But] there does not seem to be a great deal of confidence in that process.'

One worker from the community sector said that when the Reconvened Inquiry was announced,

We had literally dozens of phone calls from staff members, ex staff members and also parents — but mainly I am talking about staff members — ringing us anonymously, [which] probably says a lot in itself. When we questioned them why they were ringing anonymously, it's that they have been told.. .that anybody speaking out against the policies or practices of the Department would not be tolerated in any way.'

The fear of retribution appears in some cases to be well-founded. The Inquiry received submissions from the community generally and also from professionals who claimed they were subjected to intimidation and eventually forced into retirement or redundancy, following clashes with the Department over matters relating to standards of care.⁸

The Inquiry also heard that very senior mental health nurses who raised objections to aspects of government policy had been removed from departmental committees on which they had previously been members or been invited to be members.'

In fact, these nurses have said that they support the [basic] policies.. .but their concerns have been mistaken for outright opposition. One senior nurse has said to me 'Those who identify problems with implementation seem to be seen as saboteurs. We are actually trying to be helpful but are not seen as such.' The apparent inability of the Department of Health and Community Services to differentiate between expert advice and scurrilous attacks on its policies contributes to serious difficulties faced by the people who are trying to implement those policies.'

For example, nurses have complained about the difficulties arising from patients now being more acutely ill when they are admitted to hospital, at the same time as the average level of experience among staff has declined. This practical problem is made worse by

the refusal of the Department of Health and Community Services to see identification of this anomaly as anything other than trouble-making by a small group of malcontents."

Nurses are also concerned about rehabilitation units in mental health services being reclassified as community care units. They have complained that this reclassification will result in the loss of professional skills and diminish the quality of patient services. The president of the College of Mental Health Nursing said the Department has dismissed these complaints as 'originating from troublemakers'. In his view, the crisis in mental health care will continue as long as nurses' expert observations are ignored.'

Trade unions representing health workers made this same point in their submissions to the Inquiry. The Health and Community Services Union said that senior nurses, including Directors and Assistant Directors of Nursing, have been told their views on the effects of funding cuts on quality of care 'are not welcome'.

The nurses have been made to feel that any such problems within their area of responsibility reflect badly upon their ability to handle budgets and program delivery. The nurses felt that making these complaints would affect their chances of promotion and secondment.'

According to the State Public Service Federation,

Any reasoned opposition to policy directives has been met with accusations that staff are being resistant and defensive without any acknowledgement of the unfeasibility of the proposed plans. Staff efforts to get them to see the clinical ramifications and undesirability of proposals have been countered with being asked if they are going to resign."

Evidence to the Inquiry indicated that the Department itself has been defensive. One witness in a private hearing listed the terms of abuse which she has heard used.

[They say] that people are stirrers, radicals, [have] no respect for authority, cannot be trusted, hysterical — you name it, you will get labelled.'

A submission from a group of senior occupational therapists stressed the effect on patient care resulting from suppressing constructive criticism.

[The] current climate inhibits staff from raising concerns about programs, treatment options and the impact of policies on practice. This means that programs and individual services may not be delivered in a way which is believed to be 'best practice'.¹⁶

Lyn Allison, a researcher who interviewed participants in all sectors of mental health, commented,

Public servants are going through a difficult time at present, and it is difficult for them to speak out at all. People are expressing concern privately, but only the odd one will speak out. They think the storm will blow over, and the balance [will] return. Originally the unions had too much power, and almost controlled policy. Now the situation has been swept to the other end of the spectrum.'

She reported that even very senior doctors in public hospitals 'have come under considerable pressure which makes them apprehensive about being openly critical of the government'. A consulting psychiatrist told her,

If you want to get on a panel as a specialist, for example the Victorian Government's WorkCover Authority, you have to be careful about what you say publicly, or you will not be given work.'

Dr David Leonard

Dr David Leonard, the Director of Clinical Services at Mornington Peninsula Hospital, gave the Inquiry an extensive and disturbing account of his conflict with the Health Department's Psychiatric Services Branch. It began when he wrote a letter to the *Age* newspaper about the shortage of hospital beds for people with acute psychiatric illnesses. He asserted that on some days not a single bed was available in Melbourne for an acute psychiatric admission. He received a response from Alan Hall, Assistant Director of the Branch, asking him to substantiate his claims. He then began keeping a diary of admissions. The diary showed that in one month on 10 occasions no hospital in Melbourne had a bed available.

As a result, a number of people in our area had to be kept on waiting lists for admission. Of these, during that one month period, two attempted suicide, one smashed up her parents' home and another presented to the emergency department with a physical collapse. I stress that [this] is in one area of Melbourne and over a one month period, and it was my view that similar events were occurring all over town.'

After sending his diary to Psychiatric Services, Dr Leonard received a further letter from the Assistant Director, disputing his claim that no beds had been available on the days cited and stating that the Department's computer had listed vacancies on those days. Dr Leonard told the Inquiry,

The possibility that the computer may have been in error rather than the hospital's admitting officers was not considered. In point of fact, the source of error was clearly apparent to all clinicians. The computer listed as vacancies beds which were being held for a number of bona fide reasons and [which] were not available for admissions.²⁰

Dr Leonard also raised his concerns at the regular conference of Directors of Psychiatry, where his colleagues from other hospitals 'confirmed that their units too were experiencing often unbearable pressures as a result of the problems locating acute beds'. The conference passed several resolutions relating to the

shortage of acute beds and other inadequacies in the mental health system. Dr Leonard later reiterated his concerns in a television interview.

Shortly afterwards, the chief executive officer of Mornington Peninsula Hospital, Mr Stan Capp, received a letter from Ms Jennifer Williams, who is the Director of the Psychiatric Services Branch, stating that this hospital was as well resourced as many other areas in the provision of beds, and that while other services seemed to cope, our hospital did not... She stated that my personal view appeared to be affecting the delivery of services and stated that she had 'strong concerns when the activities of your staff seemed geared to promoting public concern about a crisis in relation to access to acute beds.'

Ms Williams' letter concluded by stating that she wished to conduct a review of the hospital's psychiatric service, as she lacked confidence in its ability to meet the needs of its local area. Dr Leonard saw this as an attempt at intimidation.

I saw the threat of an inquiry as not only baseless, but as an attempt to intimidate and discredit me. I also saw it, incidentally, as extraordinarily bad management. It would be my view that if any of my staff were complaining of problems, it would be my responsibility to go and talk to them rather than to threaten them; and given that administrators are appointed for their management expertise I must say I was quite amazed at such behaviour.²²

Dr Leonard received strong support both from within the hospital and from other sections of the health system. The directors of psychiatry at five of the six other gazetted psychiatric hospitals in Melbourne supported him, 'all indicating that their hospital has experienced similar and in some cases more severe problems than our own due to the acute bed shortages'. The Board of Management at Mornington Peninsula Hospital passed resolutions expressing the utmost confidence in Dr Leonard and his staff, noting that the shortage of acute beds clearly applied across the mental health system and rejecting the Government's proposal for a review.

Dr Leonard described himself to the Inquiry as 'close to being the most senior and longest serving psychiatrist still stubborn or foolish enough to remain in the public sector'. He is a highly respected clinician and teacher with extensive links to the community sector. He stated that he was very tempted to resign as a result of this incident. It was only the support of the hospital and his colleagues that caused him to remain.

Despite my documentation of the widespread nature of the problem and despite this support, the Psychiatric Services Branch has not withdrawn its threat of an inquiry, nor has it given me an apology for the views that they expressed. As an exercise in intimidation, although not particularly successful with me, it has had an impact on others. A number of psychiatrists have told me that they would certainly be very loath to speak out in public, having seen what happened to me.'

Another example of suppression cited by Dr Leonard involved the police shootings of people who had a mental illness. He was approached by the Victoria Police seeking his views on the shootings. When the Health Department's Regional Director heard of the request he directed that Dr Leonard not meet with police or discuss the shootings with anyone. 'All communication with regard to the police shootings was to go via the Chief Psychiatrist.'

Removal of mental health professionals from the Department

An additional factor contributing to the climate of fear in Victoria is an alleged change in direction in the Department's staffing policy. Numerous witnesses referred to the practice of removing people with mental health experience from positions of responsibility in the system and replacing them with professional or generalist managers. According to one psychiatrist,

There are 70 staff employed in psychiatric programs of the Department... No more than five have had any experience in clinical psychiatry. Only two have extensive clinical experience.'

Dr David Leonard pointed out that neither Dr John Paterson, Head of the Department, nor Jennifer Williams, Director of Psychiatric Services, has any background in managing health services. Dr Leonard referred to a statement made by Dr Paterson in a media interview.

In answer to a criticism that there had been an increase in numbers of people spending time in emergency departments on trolleys overnight, he commented that all organisations should operate at or near full capacity and that this meant at times they should go over their limits. Therefore the trolley problem was somehow an indication of increased efficiency within public hospitals. I am sure the people lying on trolleys would be much comforted by this knowledge.'

Another witness who had worked in several areas of the mental health system had a similar impression of the Department's stance on these issues.

What [it] is saying is that the individual does not matter; that an individual who experiences some form of abuse or neglect does not really matter. All that matters is figures... People's experiences do not matter because that is all 'anecdotal'. Yet in every hospital you will have a quality assurance program... If you are going to look at quality assurance then you have to look at individuals rather than figures.'

Dr Leonard claimed there was only one psychiatrist working in the Psychiatric Services Branch, the Chief Psychiatrist, a statutory position required under the *Mental Health Act*. He also expressed concern about whether the Chief Psychiatrist has sufficient independence from the Department.

For instance, the Chief Psychiatrist's Advisory Panel.. .was to be selected by others within the Department, without reference to the Chief Psychiatrist. It was only by his making the strongest possible protest that this decision was reversed. In other words, his advisors were to be appointed by other people without reference to him."

'In short', said Dr Leonard, 'those who administer psychiatric services have no expertise in psychiatry.' He acknowledged that professional managers have an important role to play.

Chief executive officers of large hospitals, for example, often do an excellent job in running the business side of hospitals while facilitating the role of health professionals. They do not, however, consider themselves qualified to muscle their way into operating theatres to tell the surgeons how to operate or into consulting rooms to tell physicians how to diagnose and treat.

The management of psychiatric services in Victoria are not hampered by any such humility. Despite the lack of any credentials in the field, with a breath-taking grandiosity, they feel quite entitled to make public pronouncements on all manner of psychiatric matters and to instruct professionals in how to do their jobs. The standard response to any criticism is to attempt to stifle it and/or to discredit the critic.'

The State Public Service Federation (SPSF) told the Inquiry that the move to de-emphasise clinical expertise among administrators pervades the entire mental health service.

I have seen a concerted effort on the part of regional and central management to discredit our local management, to undermine their authority which has been respected by clinical and administrative staff alike, and replace them with less qualified and less experienced administrators who enjoy no respect from and no authority over facility personnel... Appointments to senior positions have been made primarily on the basis of a willingness to comply with the directives of their seniors rather than on competence.³⁰

According to one witness who gave evidence in private,

People are frightened to speak out and it is not just at junior level. I have [heard] CEOs say their regional director is almost paranoid that they might say or do something that they will not know about beforehand.. .but when they want the regional director to take up an issue, like there is not enough funding or there are not enough beds, or they have got a particular problem, the regional director will not take it up on their behalf.'

Replacing mental health workers with generalist managers was seen by some staff as a way of silencing dissenters.

Many of those people who have been forced to take redundancy packages [were] the experienced people and the people who had the commitment and the experience to speak about what is wrong and wanted to fix it... There are no rewards for being honest any more.³²

The Inquiry heard that this practice has affected morale and made staff feel insecure. An even greater concern is the potential effect on patient care. The SPSF claimed there had been 'a disturbing increase in unethical work practices by poorly supervised staff'.³³

In addition to administrators, many mental health nurses have taken redundancy and not been replaced.

There is now a shortage of adequately qualified staff; and many nursing positions are being filled on a daily basis by more costly agency nurses, who are strangers to staff and patients alike. Consequently, clinical care has deteriorated, with increased danger to patients and staff.³⁴

Temporary nurses hired through agencies are often general nurses with no mental health experience. One very senior administrator, in a confidential submission to the Inquiry, said it was not uncommon for two extremely young nurses with no background in mental health to be left in charge of a large ward of acutely psychotic patients overnight. In such circumstances the nurses must rely on sedating the patients as a means of ensuring safety.³⁵ Using sedation as a routine management tool, with no therapeutic justification, is contrary to recommended clinical practice. It is also a clear breach of Principle 10 of the United Nations Principles for the Protection of Persons With Mental Illness, which stipulates that 'medication shall be given only for therapeutic or diagnostic purposes and shall never be administered as a punishment, or for the convenience of others'.

Other accounts of intimidation

Witnesses in private hearings described other incidents of retribution against mental health workers or advocates seen as critical of the Department. One person who works with mentally ill people living in supported accommodation described several incidents in which colleagues were explicitly threatened or punished for providing too much assistance to patients. Their acts of 'insubordination' had included putting patients in contact with advocates, seeking additional support for a patient whose needs were especially acute and attempting to relocate a patient whose mental illness was being exacerbated by an unsuitable housing placement.³⁶

In one incident a mental health worker had expressed concern about an inappropriate practice by the supervisor of a residential care unit.

The result was the staff person who made the query was disciplined, and the reported incident still continued. So the person was disciplined but the incident she was talking about did not ever get investigated.'

Contract workers are particularly vulnerable to disciplinary action, which can include

not being offered any more casual work, reduced hours, unsuitable changes to their roster, [being] relocated to another facility, employment contracts not renewed... If they do speak up they are reminded when the date of the contract is up for renewal and they have [been told] this behaviour will be considered at that time.

There are a number of staff who've been effectively blackbanned or blacklisted from receiving any more future employment — good quality staff. Staff who have people's interests at heart are not being given work because they speak out in support of people's rights. Staff are made an example of. At staff meetings people say: did you see what happened to Sue X.. .because she spoke out? Beware, because that could happen to you.'

One witness gave evidence of middle-level managers in a mental health service responding to complaints by coercing their staff into writing letters to senior management, stating that there were no problems in the service. Staff were allegedly advised that if they did not write the letters they would face 'unfavourable consequences' .³⁹

The Code of Conduct

Several witnesses referred to the Code of Conduct for the Victorian Public Sector as a gag on criticism by mental health workers.'

Recently a piece of paper was sent around that everybody had to sign saying that they would not discuss any conditions or any circumstances directly related to their work outside of the Department... I actually did not sign mine and nobody else did either, but that is sort of symptomatic of the public service, I suppose.'

The Code of Conduct states that the Victorian Constitution forbids a person employed in any capacity by the state from making public comment on the administration of any state department. Similar restrictions on public servants are not unusual among other state or federal governments. However, some mental health staff appear to be especially resentful of the Code and fearful of how it is used because they feel there is no avenue for constructive criticism to be heard within the Department.

Intimidation of consumer and non-government organisations

Advocacy groups representing people affected by mental illness and their families play a crucial role in the mental health system. Most groups are funded at least partially by state government grants, which makes them vulnerable if the government disapproves of their actions.

One very prominent non-government organisation in the mental illness field is the Schizophrenia Fellowship. The Fellowship director at the time, Dr Margaret Leggatt, wrote in her submission,

It [is] difficult to pinpoint 'direct threats' but it is very real that the Fellowship has felt threatened and inhibited under the present government. The Fellowship relies heavily on government funding.⁴²

For example, the Fellowship had recently suffered a reduction in government funding that forced it to cut back the opening hours at its office. Dr Leggatt wrote a notice to put on the door explaining why the hours had been reduced. But she was advised to remove the notice because it 'would not be in the interests of the Fellowship' to display it.'

Fear of funding cuts had also inhibited Dr Leggatt and her colleagues from participating effectively in the public debate on issues related to mental illness.

The Fellowship is constantly asked to comment on public incidents that occur involving the mentally ill and to comment on difficulties we are experiencing in our organisation in relation to Government policies. We have declined to comment on most occasions, feeling that to do so would not be in the best interests of the Fellowship.'

Fellowship president Rosemary Webster said the time had come to put these fears aside.

When Dr Leggatt told me in late 1992 that she believed that criticism of government policy meant reduction in our funding, I agreed that we should follow a low profile... However, approximately four months ago, angered by spokespeople for the Minister always claiming that everything was fine, that no criticism was justified, I suggested to our director (and it was subsequently passed by our Committee of Management) that, in future, either she or I would be prepared to speak out to the media.'

In her oral evidence Dr Leggatt said that the climate had recently begun to change. She had been appointed to the Ministerial Advisory Committee and she hoped this would allow some of the Fellowship's concerns to be addressed more effectively.

Several witnesses who gave evidence in public subsequently told Inquiry staff that, on the basis of their experience, they felt intimidated by the mere presence of Health Department officers in the hearing room. Jenny Gee, director of the Mental Health Legal Centre, explained,

I am concerned that we may lose our funding. It is obviously a concern when you have the director of the Department and most of the bureaucracy sitting here listening to what you are going to say."

Lyn Allison's research project, commissioned by the Australian Democrats, revealed a widespread reluctance to speak out among community groups. She noted that a television station had recently 'rung around' seeking an advocacy group to appear on a program about the mental health system, without success.

According to Ms Allison even individual consumers are affected by the climate of fear.

A major concern is there is no independent complaints mechanism, or provision of assistance to people in lodging complaints. People are frightened to complain because they fear they will lose the services they have, because there is not enough to go around.'

A witness from a non-government organisation providing mental health services told the Inquiry of intimidation by a hospital. The organisation was interested in tendering for part of the hospital's services which under State Government policy were to be transferred to the community sector. The hospital itself was apparently hostile to the policy and its administration threatened the organisation with grave but unspecified consequences as punishment for expressing interest in tendering. The hospital controls the distribution of all mental health funding for its region. There appeared to be no avenue available for the organisation to complain about this threat."

A contrasting view was put by Psychiatric Disability Services Victoria (VICSERV), the peak body representing non-government service providers. Executive director Dr Lyn McKenzie told the Inquiry that VICSERV has never suffered any intimidation in its relationship with the Government.

VICSERV has made many representations to Psychiatric Services Branch on behalf of the NGO psychiatric disability support sector and on behalf of individual member agencies. Some of these have concerned matters of complaint or of differing views on the implementation of government policy, particularly at a regional level. VICSERV believes these representations have been taken seriously by the Branch and by Regions. At no time has VICSERV felt intimidated or disadvantaged by making these comments to the Branch.'

Certainly VICSERV has been able to have a vigorous debate and disagree on a number of areas of policy implementation and policy formulation with Psychiatric Services Branch without fear of intimidation.'

In the case of the non-government agency threatened by the hospital, the witness said the agency had complained to VICSERV and sought its support, without success.' However, Dr McKenzie told the Inquiry she could not recall any organisation being threatened or intimidated.

I quite firmly state that I have no knowledge at all of any of our non-government services being intimidated. It is very true that complaints do come to VICSERV in relation to resource availability, funding arrangements, relationships with regional offices and [these] are conveyed to Psychiatric Services Branch, and I believe that the branch has taken those complaints seriously and, in one instance particularly, has acted upon that complaint in a very effective and quick way, to the extent that the Minister did make an announcement the next day in relation to funding issues.'

The Government's witness at the hearings, Jennifer Williams, also denied the allegations of intimidation. She told the Inquiry the Department had processes that encourage people to come forward and talk about their concerns.

I have had many meetings with people who come to me and tell me about the concerns they have got, and there are concerns that they are expecting us to take on board. People that have worked in government circles in senior positions will know that it is very much a part of your job to take on board complaints that people have about what is happening, and to take action. In many cases they are not substantiated, but more often than not there is a legitimate concern there that needs some action taken — so much of what we are doing is addressing that concern. I do not see that there is a climate of not encouraging people to come forward.^l

The Inquiry welcomes these reassurances but remains concerned about the widespread perception that criticism, or acts or suggestions that might be interpreted as criticism, will not be tolerated by the Department. In some cases that perception appears to have proved accurate.

Conclusion

Freedom of expression is a fundamental human right. In a mental health care system the views of experienced clinical staff and consumer advocates must be taken into account to ensure the needs of patients are met. Suppressing views inevitably results in adverse effects on the quality of patient care, through the deterioration of staff morale and the adoption of clinically inappropriate solutions. In a system that has undergone major change, the need for genuine avenues of complaint and comment is especially acute. Complaints and comments should be considered on their merits rather than interpreted as attacks on the Department itself.

The director of the Victorian Mental Illness Awareness Council, which represents consumers, said intimidation does not necessarily involve an explicit threat of funding cuts.

There are more subtle ways in which things can work in order to silence people's views or to prevent people from having input... Certainly I think something as simple as time is one of those things. If you are moving forward very quickly with a whole heap of changes, then it can be very difficult to have an input and to actually make the best decision on the basis of the information available.^m

The related issue of dissatisfaction among community organisations with the policy consultation process is discussed in Chapter 3.

1 Name withheld, public servant (oral evidence).

2 Michael Cully, Australian and New Zealand College of Mental Health Nursing (oral evidence), p107.

3 For example Margaret Leggatt, Schizophrenia Fellowship of Victoria (oral evidence), p56; Jenny Gee, Mental Health Legal Centre (oral evidence), p93; Peter Norden, Melbourne Catholic Social Services (oral evidence), p98; Lyn Allison, Australian Democrats (oral evidence), p115-118; Gerry Hoogenboom, psychiatric nurse (submission); Name withheld, service provider (oral evidence); Name withheld, service provider (oral evidence).

4 Dr Pia Brous, psychiatrist (submission), p4.

5 Penny Drysdale, Victorian Mental Illness Awareness Council (oral evidence), p72.

6 Gee, p82.

7 Name withheld, service provider (oral evidence).

8 Dr Christopher Percival, psychiatrist (submission); Name withheld, health worker (submission).

9 Cully, p106-7.

10 *ibid*, p108.

11 *ibid*, p109.

12 *ibid*, p111.

13 Kaye Williams, Health and Community Services Union (submission), p5.

14 Warren Fraser, State Public Service Federation (submission), p4-5.

15 Name withheld, public servant (oral evidence).

16 Executive of the Statewide Senior Occupational Therapists in Psychiatry (submission), p2.

17 Allison, p117.

18 *ibid*.

19 Dr David Leonard, Mornington Peninsula Hospital (oral evidence), p227-228.

20 *ibid*, p228.

21 *ibid*, p229.

22 *ibid*, p230.

23 *ibid*, p230.

24 *ibid*.

25 Brous, p5.

26 Leonard (submission), p3.

27 Name withheld, public servant (oral evidence).

28 Leonard (oral evidence), p231.

29 Leonard (submission), p4-5.

30 Fraser, p4. This point was also raised by Disability Action Network (Sunraysia Branch) (submission), pl.

31 Name withheld, public servant (oral evidence).

32 Name withheld, public servant (oral evidence). This point was also raised by Cully, p109.

33 Fraser, p4.

34 *ibid*, p5.

- 35 Name withheld, hospital administrator (submission). This point was also raised by VMIAC (submission), p7; David Plant, Australian Psychiatric Disability Coalition (oral evidence), p216.
- 36 Name withheld, service provider (oral evidence). A similar account came from Name withheld, carer, who told the Inquiry that following cutbacks at her local community mental health centre, her son's excellent social worker had been instructed to cease seeing some of his clients under threat of losing his job.
- 37 Name withheld, service provider (oral evidence).
- 38 *ibid.*
- 39 Name withheld, service provider (oral evidence).
- 40 For example submissions from Fraser; Williams; and Allison and Campbell.
- 41 Name withheld, public servant (oral evidence).
- 42 Leggatt (submission), p3.
- 43 *ibid*, p3-4.
- 44 *ibid*, p4.
- 45 Rosemary Webster, Schizophrenia Fellowship of Victoria (oral evidence), p57.
- 46 Gee, p88.
- 47 Allison, p116. A number of consumers also raised intimidation in their submissions to the Inquiry.
- 48 Name withheld, service provider (oral evidence).
- 49 Dr Lyn McKenzie, VICSERV (submission), p9.
- 50 McKenzie (oral evidence), p277.
- 51 Name withheld, service provider (oral evidence).
- 52 McKenzie (oral evidence), p278.
- 53 Jennifer Williams, Psychiatric Services Branch, Department of Health and Community Services (oral evidence), p323.
- 54 Drysdale, p71.

CHAPTER 3

Consultation with non-government agencies, consumers and carers

[Consumers] said time and time again that they are not spoken to directly on issues, that they do not have the opportunity to address issues in a public manner, and that there are no formal structures for them to take part in.'

The success of deinstitutionalisation depends on adequate resourcing for and close cooperation with the community sector. This sector includes non-government agencies providing specialist mental health services, as well as general welfare organisations involved in fields such as housing or employment. It also includes advocacy, self-help and support groups representing people with mental illness and/or other disabilities (consumers) and groups representing the families and carers of people with mental illness. Equally important are the efforts of individual families who often carry the principal emotional and economic burden of deinstitutionalisation.

In Victoria the community sector is especially important. The State Government's policy is to transfer progressively the responsibility for delivering mental health services from government to non-government organisations. Local non-government organisations have been encouraged to take over the operations of specific services traditionally based in hospitals, such as rehabilitation and disability support services. This shows confidence in the practical abilities of the non-government sector. Nevertheless, evidence to the Inquiry reflected significant discontent among community organisations about the extent of the Government's consultation with them in policy making and program planning. In addition, both carers and consumers reported that their views are very often disregarded when treatment decisions are made in individual cases.

Formal consultative mechanisms

In its submission the Victorian Government pointed out that it had three advisory groups able to transmit the views of community organisations to the Health Minister: the Framework Implementation Group, the Ministerial Advisory Committee and the Victorian Community Advisory Group or VCAG.² At the time of the hearings, the Framework Advisory Group included a single 'community' representative, the executive officer of VICSERV, which is the peak body of non-government mental health service providers. The Ministerial Advisory Committee included representatives of carers and non-government service providers, including VICSERV. VCAG included representatives of carers, service providers and consumers.

Witnesses from the community sector suggested that within these committees the agenda was controlled by the Government.' However, Dr Margaret Leggatt of the Schizophrenia Fellowship, a member of the Ministerial Advisory Committee, told the Inquiry this had recently improved so that she had begun to feel able to make a genuine contribution.'

Dr Lyn McKenzie, executive officer of VICSERV, was on both the Framework Advisory Group and the Ministerial Advisory Committee. She said that her organisation was constantly involved in consultation, in fact that 'consultation is almost coming out of our ears' .⁵

Other witnesses confirmed that non-government service providers are involved in substantial consultation. However, carers and especially consumers clearly do not feel adequately represented by that process. The interests of service providers are not the same as those of carers or consumers. For example, service providers stand to benefit directly from the policy of transferring responsibility to the non-government sector, whereas carers and consumers have doubts about the potential consequences of this policy.

The main avenue for consumer and carer participation in mental health policy is VCAG. Evidence to the Inquiry repeatedly suggested that, although a few consumers and carers were members, the structure and processes of this Group tended to stifle genuine input.

For example, the Australian Psychiatric Disability Coalition (APDC), which represents about 40 consumer groups in Victoria, pointed out that the Community Advisory Groups in other states consist entirely of carers and consumers. The inclusion of service providers on VCAG has decreased the representation of consumers in Victoria.'

In addition, the APDC said that the existence of VCAG has been used by the Government as an excuse to avoid wider consultation.

The response I have got from the Victorian Government...was basically that 'we talk to VCAG and that is enough' .⁷

A specific concern is that VCAG is chaired by John McGrath, who is a carer but also a National Party Member of Parliament. Witnesses stressed that they did not question Mr McGrath's personal integrity or commitment.⁸ However, because he is a an MP for one of the parties which forms the Coalition Government, carers and consumers felt he was limited in his ability to put forward views critical of the Government's policies and practices.

The Victorian Mental Illness Awareness Council also claimed the presence of Mr McGrath, a carer, was used to justify denying consumer groups input into important decision-making processes.

They say, 'Well, you can't be involved in that or you can't be on that [committee] because John McGrath is representing consumer views'... [So] organisations like us are not actually able to be involved... That is a more subtle way of silencing our views.'

For example, Mr McGrath sat on the Framework Advisory Group and Ministerial Advisory Committee, representing VCAG, so there was no separate consumer representation on those committees.

VMIAC also complained about the secrecy of VCAG's operations.

The minutes and the agenda are secret... In addition the names and addresses of members of the VCAG are not public, so if anyone wants to raise issues with a member of the committee they don't know who to contact. 10

Belinda Thurlough, a consumer who was appointed to VCAG, worked at VMIAC as an advocate. However, she was told that she had been appointed to VCAG as an individual." This meant she was not allowed to discuss the agenda or decisions of VCAG with any of her colleagues or any other consumers who belonged to VMIAC. She had great difficulty obtaining the minutes and agenda of a meeting she missed; when she asked to have them posted to her at work she was made to 'absolutely swear that no one else would see them'. She told the Inquiry,

I can understand that people would want Minutes etc to be confidential to a degree, but my concern is that if it is a representative group and.. .if those documents are completely confidential and not to be spoken [about] or discussed — how can you raise the issues that are coming up on the VCAG with the community that you are supposed to be representing?"

She told the Inquiry this restriction made the consumer and carer input on VCAG 'so tokenistic as to be non-existent'.

VMIAC has since informed the Inquiry that in response to evidence given at the hearings VCAG had agreed to relax the confidentiality of its operations. The agreement was that members would be free to discuss VCAG's work with constituencies and that information about the membership of VCAG would be publicly available •13

The role of advocacy

Evidence to the Inquiry indicated that the Victorian Government's relationship with mental illness advocacy groups was essentially antagonistic. Several

witnesses referred to disparaging remarks about advocacy groups made by Dr John Paterson, head of the Department of Health and Community Services.

There has been a greater emphasis on cutting clientless programs, as we would call them. People take offence at that, but advocacy programs or piss-and-wind programs or whatever... (Dr John Paterson, quoted in *The Age*, 12 August 1993)

According to the executive officer of the Australian Psychiatric Disability Coalition, such comments 'significantly undermine' consumers' faith 'in their ability to have a voice and be heard'.¹⁴ The director of the Schizophrenia Fellowship said that her organisation had always been respected by governments and that the stance taken by Dr Paterson was a complete turnaround that left the Fellowship 'very concerned about what to do' •15

Jennifer Williams, the Department's Director of Psychiatric Services, explained Dr Paterson's reported comment and the Department's position.

I would like to differentiate between service providers and advocacy groups... It is most important that when we have this discussion we do distinguish between people that are delivering either clinical or non-clinical support and other services... I would agree with the sentiments that are expressed behind [Dr Paterson's] words... where advocacy on its own is of no real usefulness in designing systems.

...The government does not see it as appropriate, funding just advocacy groups, because we are service providers [and] we are funding service providers.'

The view that advocacy on behalf of vulnerable people with disabilities has no value in itself is completely at odds with the spirit of consultation. It also shows a failure to grasp the critical role of advocacy in making participation possible for people who, without advocacy, would be invisible. Consumer advocacy is an essential part of quality management in mental health services. People who have a psychiatric diagnosis often are especially in need of advocates, because their concerns when voiced are frequently dismissed simply as symptoms of mental illness. The difficulties caused by serious mental illness are compounded if a patient is treated in a dehumanising or disrespectful manner by the mental health system. Evidence to the Inquiry indicated that consumers' complaints and cries for help are often disregarded, with a consequent worsening of their condition.'

The denial of the legitimacy of advocacy groups may arise from the Department's concern about criticism. Yet as the Mental Health Legal Centre pointed out, the Department should expect to be criticised.

We do not hear any good stories. Nobody rings us up and says: 'gee, the psych system is perfect, we had a great time with it.' It does not happen. Our job is not to do that."

The Department's attitude towards advocacy groups also reflects the low priority given to advocacy within mental health services. VMIAC said there is an urgent need for both individual advocacy, supporting consumers and following through complaints, and systemic advocacy, putting the views of consumers as a group. However, consumer advocacy groups have been excluded from advisory bodies and the *Framework* document makes no mention of advocacy.

It does not talk about independent complaints mechanisms; it does not talk very much about peer support and self-help...so we feel very much the future is going to be leaving those things out. So we are wanting to make sure that people understand the importance of that and what a vital role it does play for people.'

The capacity for advocacy in the Victorian mental health system has also been reduced by the curtailment of the Office of the Public Advocate (OPA), which traditionally served as a 'watchdog' agency. Its advocacy program specifically for people with psychiatric disabilities is no longer funded. The single advocate who was working in mental health advocacy at the time of the hearings has since left OPA. At the time of the hearings the statutory position of Public Advocate was filled on an acting basis by a public servant on secondment, which limited OPA's ability to take a view independent of the Government. This arrangement lasted over two years, until late September 1995.

Consultation with consumers

The executive officer of the Australian Psychiatric Disability Coalition told the Inquiry,

Consumer members [of APDC] are very concerned about their lack of involvement in policy development and program planning issues... They are not asked opinions, they are not involved in processes.²⁰

VMIAC said that consultation with consumers requires a different approach from consultation with non-government service providers. The usual method of consultation 'can in fact prevent people's views from being taken into account'.

Often the way that consultation occurs, either there is a lack of time or there is a wad of fat documents that you cannot possibly get through in the time available, or they are written in language that is difficult for many consumers to understand.'

According to VMIAC, even when consumers are allowed some contribution, this may have no effect at all on policy or program decisions. The implication was that the Department has an agenda which it pursues regardless of consumers' views 22

Witnesses provided numerous examples of issues on which consultation with consumers was refused. Some of these were major policy decisions, such as tendering out government mental health services.

There has been very little consultation in terms of the selection criteria, how they will select who is the most suitable tender and how the safeguards will be written into the contracts with those organisations to make sure that the rights of people with mental illness are protected.'

[We] have been approached by consumer members about not being consulted about the way tendering documents are pieced together, [about] not being involved in or understanding the process of selection, those sorts of issues.'

Another example concerned the development of protocols for police dealing with mentally ill people, following several shooting deaths. A VMIAC witness said,

[We] were told: 'Well, that is an inter-agency document between the Police Department and the Health Department and it is not being sent out for comment.' But we would have thought to consult with people who have experienced mental illness would be very important.'

Further evidence about police dealings with mentally ill people is discussed in Chapter 6.

Consumer advocates also told the Inquiry that complaints from people affected by mental illness are not thoroughly investigated by the Health Department.

[A patient] put in a complaint in a Melbourne psychiatric hospital and it was 3-4 months before they ever heard a result of that complaint... [And] often.. .the response to the complaint is more like a defensive justification of what happened, rather than any will to change the system."

One consumer had made a complaint about the crisis team's failure to assist him.

The health professionals that I dealt with.. not only failed to meet my needs, but when I complained about this failure, they provided misinformation about their interventions, refusing to take responsibility for their actions. Because it was their word against mine, as is often the case when you are a patient, and because you have a mental illness, they get away with it. This is not an uncommon experience.'

Complaints about medication are 'raised in nearly all the meetings we have', according to VMIAC.

Often people's complaints or concerns about their medication are ignored, and people are viewed as simply making trouble or being difficult or not wanting to take their medication — when often there are very good reasons...including very difficult side effects and things like that."

The Mental Health Legal Centre's director, Jenny Gee, reported that recently the Health Department had become much less interested in communicating with her organisation.

We used to have a continuing open dialogue with the Department which was pretty full and frank, and that no longer occurs. We used to speak to the Department probably daily; that no longer occurs. So that kind of openness is not there... The information flow is just not there anymore.'

Ms Gee submitted that the Department should take advantage of the Centre's unique knowledge.

We could be useful. We are not hostile. We have as an agenda the improvement of conditions for people with mental illness. We would hope the Department had that as their agenda too. It is certainly stated so.

We should be working together towards change and, no, that is no longer happening. It is disappointing. We do not expect them to do what we want — that would be an outrageous and wondrous thing — but we would like to at least be involved in the dialogue.³⁰

Ms Gee argued that complaints should be seen not as vexatious but as an important form of feedback for the Department.

We deal with around 5000 people with mental illness a year, which gives a reasonable idea of what the issues are — because they are basically complaints. We do not get many calls from people happy with the service... We would have thought that information was a useful resource for a department which was 'putting people first'. However, we are rarely consulted. Letters that we send asking questions are quite often not answered. Sometimes when they are answered, they are answered with a great deal of anger and denial, and I think it is that defensive reaction again.'

The Department's attitude toward the Centre was demonstrated in two instances cited by Ms Gee. In one case the Centre's criticism of a departmental policy provoked a response so vehement as to be potentially defamatory of the Centre's staff.³²

In the other case the Centre was concerned that not enough research had gone into the introduction of residential provisions in Community Treatment Orders. It conducted a small survey on the concerns held by service providers and consumers about the new policy. This brought 'a very, very angry response from the Department...criticising the research and the way the research was structured and [saying] that everything would be fine'.³³

The Centre then took the unusual step of writing to the Minister. Ms Gee said, 'We do not like to do that because Ministerial [questions] tend to make bureaucrats quite angry'. Ultimately this produced a positive response. The survey results were taken into account and a better policy was produced. However, the Centre said that the policy was now being contravened in practice. It faces a new battle convincing the Department to examine what is happening in the field.

Consultation with carers

We are finding that, because carers are not consulted nearly enough, we have many families...living in fear and terror of what their mentally ill relative might do to them, because the illness is way out of control.'

One of the most important groups representing carers of people with mental illness is the Schizophrenia Fellowship, whose Victorian director and president at the time both gave evidence. The director, Dr Margaret Leggatt, pointed out that widespread discussion and consultation are essential because serious mental illness is still so poorly understood. There is no agreement on the best models of treatment, rehabilitation or support. She acknowledged that 'very substantial improvements have been attempted, particularly the CAT teams and Mobile Support and Treatment teams'. However, she said there are still far too many philosophical differences and disparate viewpoints for coordinated care to become a reality.

Dr Leggatt and the Fellowship's President, Rosemary Webster, both used the term 'token' in describing the Government's consultation with carers. For example, one of the most significant changes was the redevelopment of the North East Metropolitan Psychiatric Service. People who had lived in hospital for many years were being moved out to live in Community Care Units. Relatives concerned about how the patients would cope with this change were 'consulted' or at least informed, but felt their views were 'given very little weight' by the Health Department.'

In reality, even where carers are being invited to give information...action is not taken on the input from carers.³⁶

Numerous examples were offered in evidence of issues raised by carers with little or no response on the part of the Government. With regard to the serious shortage of hospital beds, carers were repeatedly told that their experiences were isolated.

We are being told that there are enough acute beds. I do not know whether there are or there are not, but why is it then that, if there are enough acute beds, that our members are informed — and this happens frequently — that hospitalisation is not possible because there are no available beds. And this is occurring even when our families are in extreme

Another major concern of carers is the poor coordination and communication between existing services. According to the Schizophrenia Fellowship,

We had a recent example where one [CAT] team believed that a person should be certified. That person flew the coop, came under another CAT team and that CAT team said there was nothing the matter with the person. This is the sort of confusion that we are experiencing."

Carers' input on the critical issue of coordinating funding also seems to be lacking. In one instance, this had held up a potentially beneficial housing project.

There just are nowhere near the sort of resources we need to carry out the programs that are needed... I mean, we are faced with a ridiculous situation at the moment where the Ministry of Housing is supplying us with housing stock... We have got 13 new flats coming on that we are being allocated, but I am not getting any support staff to be able to run those flats. So there is again another example of where something is happening but something else is not happening. So there is no coordination. That to me seems to be what is the major problem, that it is not all connected.³⁹

Another example given of poor consultation and coordination involved the closure of the Malvern Community Mental Health Centre.

I have to mention the loss of the enormous resource that was the Malvern Community Mental Health Centre, that was given to another welfare organisation so that 500 mentally ill clients had to be relocated to what I consider, and what the carers and the people with mental illness themselves consider, are now inferior facilities.'

The 'serious mental illness' threshold

It's terrifying when you know you are getting sick and nearing crisis point and you need somewhere to go but there isn't anywhere.'

One mother [said] to me: with what other illness do you wait until they are so sick that you then help?'

One of the greatest concerns of consumers and carers is the routine denial of treatment to people who are deemed not sick enough.' The *Framework* document emphasises the commitment to providing treatment for people who are 'seriously mentally ill'. Consumers and carers stressed that the Government arrived at its construction of what constitutes 'serious mental illness' without consultation. The Inquiry heard that in practice this construction has been used to restrict access to mental health services, which are overstretched and under-resourced. The threshold of 'serious mental illness' has been set so high that it excludes a great many people in need.

[The services] have needed to cut back the number of people in the target group in some way, so what they have done is said, 'well, only people with psychosis are serious, or only people who have schizophrenia or manic depression will be considered serious.' There are, of course, a whole heap of other people who may experience extraordinary needs for service. They may be suicidal, they may be in enormous anguish, they may be harming themselves but they are not considered serious enough and so they are denied services."

A consumer told of her own experience of being 'quite psychotic'.

That psychosis lasted for about three weeks and I was in constant contact with the CAT team each day... They were fantastic in that they would ring me dead on the knocker of 10 o'clock every night, but that was it, that was all they would do... Towards the end of that three weeks one of the CAT team members was saying I really should be in hospital and he was ringing around every hospital in Victoria — and of course, we [supposedly] do not have a shortage of beds in Victoria, but he could not find me one. But he still did not deem me to be in crisis enough to warrant a home visit from the CAT team, although he thought I ought to be in hospital.'

She told the Inquiry of another consumer whom the CAT team had refused to attend.

He lived in very poor boarding house facilities where he got no support and was having great difficulty getting ongoing appropriate psychiatric treatment. He contacted the CAT team and was told he was not in crisis, that he was 'lonely'. He died that night. There was evidence of a large number of tablets having been taken... Whether he died of a heart attack or an overdose is not yet on the record, but the fact that he died the night that he contacted the CAT team who refused to respond to him is in itself a fairly poor indictment.'

The guiding principles of public health are prevention and early intervention. Many people with mental illness can recognise the early warning signs of an approaching crisis. The narrow focus on 'serious mental illness' means that they cannot receive the assistance they need until their condition deteriorates and becomes beyond control. By then they may no longer be able to seek that assistance, either because they are too disturbed or because they have inflicted severe physical injuries on themselves.

My dignity will not allow me to slash up anymore or take an overdose to get help; I prefer to ask for it in the appropriate manner. [But] it seems that when you ask for it appropriately you are seen to be not in crisis. It is almost as though psych services are encouraging people to act inappropriately to get the help they need.'

For the mentally ill person, the impact of this policy can be devastating. Consequences may include increased psychological trauma, longer time to recover from an episode, damage to personal relationships, potential entry into the criminal justice system, greater likelihood of hospitalisation and the possibility of serious injury including death.

There are also adverse consequences for the mental health system, including more stress on staff, bad publicity arising from a suicide or violence involving the mentally ill person and increased costs associated with an acute admission.

Our limited resources are really not being used to greatest advantage. For example, if we fail to give early intervention to people and we have a crisis team, maybe visiting every day for perhaps a fortnight and intervention not being given, eventually these people end up in hospital anyway when they are much sicker than they need have become. They then

need far greater and longer treatment. We believe that a lot of this could really be prevented which would also mean a much better use of resources."

Consultation in the context of confidentiality

A major complaint about consultation is that carers are denied information and participation into treatment decisions about their mentally ill relatives. One woman told the Inquiry of her attempts to get help for her 16 year old son with schizophrenia.

My own questioning of Alex's medical treatment was brushed aside. When I was upset that Alex's suicidal behaviour was not being treated adequately I was told by [his] treating psychiatrist, 'The whole hospital is talking about you,' and that 'we will know when he is suicidal.'⁴⁹

Shortly after these events Alex committed suicide.

Patient confidentiality is commonly cited as a reason for not listening to family members. Yet families are the primary carers for very large numbers of seriously mentally ill people. Their task is made far more difficult by a lack of knowledge. In addition, families are often in the frontline when untreated mental illness results in difficult or violent behaviour. The Schizophrenia Fellowship recommended as a minimum that training courses be held for mentally ill people and their carers in how to cope with mental illness.

Untrained, uninformed people manage badly and we find that very, very many of the families are really quite distraught from the fact that they are being asked to cope with something that they really do not know how to handle, and when they go for information and help on how to manage this, often that help is not available...often on the basis [of] confidentiality.'

One of the most distressing situations arises when a mentally ill person does not accept the need for treatment and health professionals refuse to hear the contrary view of a carer who knows the patient very well.

When somebody is irrational because of their illness and is saying there is nothing the matter with them, therefore they do not need treatment; and you talk to the family and you find that really, when they are making that sort of statement, that really is the time when they are in very great need of treatment. Often what the patient says is what is being believed, and what the families are saying is discredited.'

While acknowledging the complexity of this issue, Dr Leggatt made recommendations for addressing it.

I think we have to start from the premise that family members have rights the same as people with a mental illness, and that families should be able to give information in their own right. They should also be able to get support and training in their own right... Families need direct services in much the same way as people with mental illness need

direct services. I think then if you start from the premise that families must be involved, then we have to look at ways.. .to involve them and how to overcome that difficulty.'

She stressed that carers are not seeking to breach confidentiality but they often have information that is important in assessing a person's condition.

I think patients are absolutely entitled to confidentiality, but there are very, very grey areas where.. .keeping that confidentiality is not in the best interests of the person with the mental illness... If you are not going to be able to get an accurate assessment of how ill a person is unless you talk to third parties, people who are in close contact with that person, then you are going to give an inaccurate assessment of that person's condition. You will not provide the best treatment for them.

...We really must look at this because it is leading to inappropriate, inadequate and inaccurate assessments being made of people with serious mental illness. It is widespread: I am not just talking about a few cases.'

Dr Leggatt said that some psychiatrists do manage to balance the rights and needs of consumers and carers. This shows it can be done. She urged that their solutions be investigated and written into guidelines so that mental health workers generally will know how to deal with their patients' families.

Jenny Gee from the Mental Health Legal Centre, which represents consumers, acknowledged the difficulties imposed on families by the requirement of patient confidentiality. However,

We also see a lot of times where the interests of the person and [those] of the family do not necessarily coalesce; and the right of a person to be treated with respect and confidentiality we see as being absolutely paramount.'

She pointed out that mental health staff should not automatically assume this conflict exists.

I would ask, has the service always asked the person do they mind if their information is shared. I suspect that sometimes that conversation has not taken place; and that in fact better communication between carers and hospitals and medicos could take place if that consent was given. I think quite often it would be freely given.'

Dr Leggatt said the Schizophrenia Fellowship had set up a working party to examine the problems associated with the use of confidentiality as a reason for not involving carers.

We did this on the basis that the coroner in one of her findings said that she was quite concerned.. .that she believed some of the suicides that she had been investigating might have been prevented if families had been given very much greater support and information about what was happening.'

Conclusion

The effectiveness of the mental health system depends on how well it responds to the experience and needs of people who have a mental illness and seek or require care and treatment. It is a paradox then that the views of people affected by mental illness are overlooked or rejected in policy making and program design. Even in decisions about their own individual cases, consumers' views are ignored to an extent that would never be tolerated in the treatment of physical illnesses or injuries.

Advocacy groups representing consumers have an important contribution to make to the policy process. They can provide feedback from consumers which the Health Department would otherwise never hear. Yet their attempts to contribute have met consistently hostile and defensive responses.

Family carers carry the burden of care for the vast majority of people affected by serious mental illness. Every time a decision is made to cut costs by closing down a service or retrenching a mental health worker, the pressure on families increases. These family members are another group whose work and experience should be valued and sought out by the Department. Again this appears not to be occurring.

Non-government agencies that provide direct services to mentally ill people have fared better in the consultation stakes, through VICSERV. In fact, VICSERV clearly has a close working relationship with the Department. However, consultation with service providers cannot replace or equate with consultation with consumers, carers and their advocates. Although these service providers are non-government agencies, increasingly they are effectively contractors to the Government providing specific services.

The exclusion of consumers and carers from the decision-making process has detrimental consequences for the health of individual consumers and carers and for the effectiveness of mental health services overall. In particular, the narrow definition of 'serious mental illness' is leading to a higher degree of suffering in the community and more acute illness among those patients who do succeed in obtaining treatment by the crisis teams or are admitted to hospital.

1 David Plant, Australian Psychiatric Disability Coalition (oral evidence), p213.
2 Victorian Government (submission), p9. The Inquiry was told subsequent to the hearings
that the Framework Implementation Group was disbanded in mid 1995 and has since been
replaced by the Better Health Outcomes Reference Group.
3 For example, Rosemary Webster, Schizophrenia Fellowship of Victoria (submission) and
(oral evidence), p59; Penny Drysdale, VMIAC (oral evidence), p70; Plant, 212.
4 Dr Margaret Leggatt, Schizophrenia Fellowship of Victoria (oral evidence), p56.
5 Dr Lyn McKenzie, VICSERV (oral evidence), p277.
6 Plant, p212.
7 *ibid*, p217.
8 Drysdale, p71; Plant, p212.
9 Drysdale, p78, 71.
10 *ibid*, p71.
11 Belinda Thurlough, VMIAC (oral evidence), p78.
12 *ibid*, p74.
13 VMIAC (submission), p22.
14 Plant, p213.
15 Leggatt, p62.
16 Jennifer Williams, Department of Health and Community Services (oral evidence), p304-5.
17 For example, Leggatt, p55-6; Drysdale, p68; Thurlough, p73; Plant, p215-6; Angela
Incigneri, carer (submission).
18 Jenny Gee, Mental Health Legal Centre (oral evidence), p93.
19 Drysdale, p79.
20 Plant, p212.
21 Drysdale, p70.
22 *ibid*.
23 *ibid*.
24 Plant, p217.
25 Drysdale, p70.
26 *ibid*, p72.
27 Timothy Martin, consumer (submission), pl.
28 Drysdale, p69. This was also stressed in a comprehensive submission from Paul Hill,
consumer.
29 Gee, p92-3.
30 *ibid*, p94.
31 *ibid*, p84.
32 *ibid*, p89.
33 *ibid*, p84-85.
34 Leggatt, p54.
35 Webster (oral evidence), p59.
36 Leggatt, p56.

- 37 ibid. The shortage of beds was also raised in submissions from VMIAC, Dr David Leonard and the College of Mental Health Nursing; carers including Angela Incigneri and Denis Vardon; and consumers including Timothy Martin and John Beavis.
- 38 Leggatt, p63.
- 39 ibid.
- 40 ibid, p56.
- 41 Heather Brown, consumer (submission), p2.
- 42 Leggatt, p55.
- 43 For example, ibid, p63; Drysdale, p67-8; Gee, p85; Incigneri, p1-2; Peter Norden, Melbourne Catholic Social Services (oral evidence), p104; Dr Pia Brous, psychiatrist (submission), p5; Colleen Simon, carer (submission), p2; John Beavis, consumer (submission), p1; Margaret Bayliss, carer (submission), pl.
- 44 Drysdale, p67.
- 45 Thurlough, p73.
- 46 ibid.
- 47 ibid.
- 48 Leggatt, p56.
- 49 Sandra Oliver, carer (submission), pl.
- 50 Leggatt, p55.
- 51 ibid, p60. This point was also made in submissions from carers including Colleen Simon, Ted Bryan and Gordon Ortmann.
- 52 Leggatt, p60.
- 53 ibid, p60-61.
- 54 Gee, p89.
- 55 ibid.
- 56 Leggatt, p54-55.

CHAPTER 4

Adequacy of services for especially vulnerable or disadvantaged groups

Arbitrary policy is no way to deal with the issue of people who are not 'fitting' neatly into the legislative framework.'

The Reconvened Inquiry received extensive evidence on the inadequacy of mental health services for people with particular vulnerabilities. This chapter describes the problems experienced by mentally ill people who are homeless, those with dual or multiple disabilities, mentally ill people from non-English speaking backgrounds, women affected by mental illness, mentally ill children and adolescents and elderly people with dementia.

Each group encounters particular obstacles in the mental health system. There were, however, two common themes in the evidence: the inadequacy of appropriate specialist services and severe disadvantage when using general mental health services. The consequences include delays in intervention, misdiagnosis, inappropriate treatment and frequently abuse, resulting in a greater prevalence and severity of mental illness.

For all these vulnerable groups, falling through the services net is both a symptom and a determinant of their disadvantage. One expert witness to the Inquiry attributed this to the dominant 'medical model' of mental health service, which is incapable of taking into account special needs and complex contingencies.

Service providers rarely, if ever, explore with the patient the impact that having a mental illness is having on their life. In other words, treatment and care is confined to a medical model approach which largely dehumanises and degrades the individual to nothing more than someone with a mental illness... The end result.. is that the medical model plays a major role in the continuation and accentuating of the level of mental illness people have to endure.'

Homeless people

The bottom line is: my son is in urgent need of care, is homeless, and has not been found.'

Homeless people with a mental illness have rights to housing, employment, social security, medical care and other services. However the obstacles they face in securing these rights are overwhelming. A mentally ill person who is homeless will often be caught in a cruel loop: being homeless increases the likelihood of the mental illness going undetected or untreated, which in turn makes the chance of securing appropriate housing more remote.

A contributing factor to homelessness among people with mental illness is the gap between the demand and supply of housing, hospital and community support services. The Inquiry heard this gap has been increased by the process of 'mainstreaming' specialist services into the general health system.

Mainstreaming specialist services

As the pressure on our general hospital system in this state continues to be evidenced, we are seeing compromises in standards lessening the care of mentally ill individuals in the general hospital system.'

Paul McDonald of the Crossroads Housing Support Network told the Inquiry that mainstreaming poses particular dangers for homeless people affected by mental illness. General hospitals are designed to deal with acute illnesses and injuries, whereas mental illness is more often chronic and long-term. General hospitals are also more likely to discharge patients earlier than a psychiatric facility. Both these problems are exacerbated by the funding squeeze on general hospitals.

According to Mr McDonald, mainstreaming of specialist services for people with a mental illness is not having the intended effect of increasing access and improving care. This is because hospitals must absorb these additional services and at the same time adjust to funding cuts and continuing threats to resource allocation.

He also considered general hospitals less likely to understand the importance of discharge planning and follow-up for mentally ill patients when they leave hospital.

People in need of inpatient services are not being adequately assisted and people in continuing need of inpatient services have been discharged, clearly unwell or acutely psychotic.'

Inadequate planning compounds the severe difficulties already created by the shortage of appropriate and affordable housing and by the lack of services to assist the mid-to-longer-term settlement of people with a mental illness. The combination of these factors entrenches a pattern in which many people discharged from hospital slip into a cycle of homelessness and dependency on crisis support. This pattern already occurs with dedicated psychiatric facilities. Crossroads fears it will worsen under mainstreaming because the budgets for psychiatric services within general hospitals are insufficient to ensure that the specific needs of mentally ill patients are addressed. The result would be a continuing increase in the proportion of homeless people who also have a mental illness.

Since the hearings, the Inquiry was told that the Government is developing collaborative service arrangements between public mental health services and private psychiatrists. These collaborative arrangements, expected to be in place by mid 1996, may improve both the quality of care within mainstream services and the transition process from hospital to aftercare.

Aftercare

Perhaps also, if some long-term accommodation had been available [my son] could have been more accurately medicated and would not have spent so long living in squalor.⁶

Crossroads submitted that discharge practices generally do not involve organising continuing accommodation or care. The shortage of aftercare services makes it difficult for staff to make referrals even if they are committed to the notion of continuity of care.

Paul McDonald reported on the results of a three-week survey of people presenting with psychiatric illness at a St Kilda crisis centre in November 1994. The most critical finding was that 28% (almost one in three) presented because they were affected by mental illness and were homeless. 70% of the total had no continuing community health or mental health support that they could identify.'

The survey also revealed that

On discharge 60% had been discharged from a psychiatric hospital, 13% from jail, and 23% from the general hospital system.'

In the absence of formal aftercare, many families find themselves providing the continuing care needed by family members who are mentally ill and who would otherwise be homeless. The Inquiry heard extensive evidence from carers of family members with a mental illness, who provide aftercare with little or no support or respite.

My plea is to establish aftercare facilities, between hospital and home (if these patients have a parent with a home at all) — a place where they can go after discharge for a time, supervised by psychiatric staff, where their medication is given at the right time and yet they could feel not institutionalised and can then gradually begin to get a feeling of self-worth and self-reliance... To let them go, straight from hospital to the streets, or some crumby boarding house, or even an overtired parent, is not the answer.'

Access to services

Homelessness is not just a consequence of discharge practices and the lack of aftercare services. The problem begins for many people when seeking access to services in the first place, due to the 'serious mental illness' threshold described in Chapter 3.

A witness gave evidence to the Inquiry about her son's homelessness and eventual suicide when he was turned away from two psychiatric hospitals due to a shortage of beds.

The pressure on mental health professionals to ensure that only the most urgent are admitted to hospital (intensified by the fact that it was the start of a 'long weekend' and there would be a natural reluctance to fill the available bed or beds even before the holiday started) means that many who need help are sent away.'

A consumer reflected on the system's tendency to push people with a mental illness to crisis point before assistance is even a possibility.

In the.. Framework for Service Delivery.. two criteria are required for a hospital admission. The first of these is the severity of the illness. The second of these is the degree of risk. Both must be extreme before admission is made. To me as a sufferer this means that psychosis is insufficient reason for admission. What this means to the public is psychosis on the street."

In some cases, homelessness may be a result of being pushed to crisis point. Mental illness which is left untreated and allowed to escalate into an acute stage can unnecessarily result in the loss of an ability to care for oneself and the loss of employment and housing.

Ancillary services

Individuals who are homeless and coping with a mental illness are often unable to seek mainstream health services unassisted. They may need to be actively targeted through outreach programs and supported in accessing a particular service.

Many people with severe mental illnesses do not make use of the public health services they are eligible for. Many of the barriers relate directly to the effects of mental illnesses and the associated factors of socioeconomic disadvantage that go with this. Several submissions to the Inquiry focussed on the problems faced by homeless people in obtaining dental care. One submission outlined a proposal for a dental program that would include outreach and education components aimed at people with a mental illness who are unable to seek access to public services.

The people with mental illnesses that have been examined have poor dental health and poor access to dental services. They require a specific dental service that allows an outreach worker to help them access the service; a dental hygienist to work with the clients, carers and families; and a dentist and dental nurse with an understanding of psychiatric illnesses. These clients often require liaison with doctors, psychiatrists, family and carers, and all of them take more time than the 'average' dental patient to treat. Thus funding for chair time alone is inadequate.¹²

The reasons given for the necessity of this service apply equally to other specialist health areas.

There is sometimes a need to make initial contact with a person away from a dental setting, both to establish a rapport with the person, and to identify what particular barriers are preventing this person from attending a dentist, and assisting them to negotiate the system. This is particularly problematic, as it is difficult to get funding for any service which will have a high number of broken appointments, or clients who may arrive and then refuse treatment, or need a lot of explanation and reassurance, or are unreliable attenders. Dental services are moving towards unit-based funding, where services are only funded for work actually performed. Case managers at community mental health clinics do [encourage attendance]...but are only able to assist very small numbers of people in this way, as they have other priorities, and not all of the target group have case managers anyway. Sometimes case managers need a dental worker to assist them, as they may not be able to persuade someone to seek dental treatment without assistance... There also needs to be liaison between different service and agency providers in addition to direct assistance provided to clients.'

Outreach programs are particularly vulnerable to funding cutbacks and resource rationalisations. The Inquiry heard that the stringent criteria used by both Commonwealth and State Governments often undermine the success of these programs and in some cases prevents their establishment.

The situation is becoming more and more urgent — we have a very long waiting list for these clients while we await funding. Yet no government department seems interested in funding the delivery of an appropriate service. Funding arrangements are complicated and no one body is taking responsibility.'

People with dual or multiple disabilities

People who have both a mental illness and another disability are among the most disadvantaged of the vulnerable groups. Yet there are virtually no services that provide the multidisciplinary approach to diagnosis and treatment they need. In effect the most disabled groups are those worst provided for.

The Inquiry heard evidence about the inadequacy of services for people with mental illness and substance abuse, mental illness and intellectual disability, mental illness and acquired brain injury, mental illness and deafness, as well as for people with a personality disorder.

Falling through the net

People who suffer from a dual disability.. .tend to be shuffled between the different services with no one actually meeting their needs. It appears that a great many of these people fall right through the net and the ones that do receive appropriate treatment tend to have inordinate difficulties in accessing the services.'

The inadequacy of service provision for people with dual or multiple disabilities is evident across all areas of need, in clinical and support services. For these

patients, the difficulties caused by under-resourcing in mental health are compounded by the lack of resources in other areas of the health system, such as drug and alcohol services.

When funding is tight and staff are overstretched they are much more reluctant to provide assistance for people who have dual disabilities and who may be more time consuming.¹⁶

The consequence can be aggravation of one or both disabilities and greater strain on community support organisations. People with dual disabilities are falling through the mental health services net because preventive services do not pick them up and crisis services are closed to them — both due to restrictive client eligibility.

One person with a mental illness, mild intellectual disability and brain injury was excluded from a psychosocial rehabilitation program. The official reason was that he did not have a serious mental illness — although he had been hospitalised for mental illness was currently on medication and receiving treatment. This person was demanding of staff time, which may have been the reason for his exclusion.'

One submission to the Inquiry presented the findings of a study on how a particular community mental health service responded to people with both a mental illness and an intellectual disability.' The service was unable to meet these clients' needs for several reasons. Staff reported that deficiencies in community support sometimes resulted in clients being readmitted to hospital, setting back their progress substantially. The absence of suitable housing also hindered the service's ability to help. A lack of resources within the service prevented staff from investing the time and effort these clients needed. However, the major complaint was the reluctance by the Health Department's Intellectual Disability Services to become involved with people who also have a mental illness.

Evidence to the Inquiry suggested that these findings would be equally applicable to services that deal with people with any other dual disability.' The lack of resources and the reluctance of one type of health service to assist people with more than one disability were raised many times in evidence.

When services do reach people with dual disabilities, the lack of a multidisciplinary approach often results in misdiagnosis, inappropriate treatment (for example over-medication or involuntary restraint) or endless shuffling between specialist services. Too often all three processes occur simultaneously.

Witnesses expressed frustration at the lack of coordination among different disability services, particularly in relation to referrals, assessment and treatment. One witness described how the pressure to reduce duplication has devastating

consequences for people who, for example, require the specialist skills of psychiatric as well as intellectual disability services.

Both services indicate that they are working to capacity and therefore if a person appears to be receiving services from one department they slip to the bottom of the priority list for the other, and consequently receive no services at all.'

In an attempt to address this lack of coordination, the Government has developed a protocol between psychiatric services and intellectual disability services, and another between psychiatric and drug and alcohol services. These protocols are referred to below. While the policy objective of these initiatives is sound, the Inquiry is concerned that the ability of protocols, guidelines and agreements to meet their objectives depends on funding which acknowledges and supports collaborative arrangements between services.

Mental illness and intellectual disability

If you take the population of Victoria as approximately 4 million.. .80,000 people will have an intellectual disability and half of that number will have both intellectual disability and psychiatric disability — so that is 40,000 will have [this] dual disability.'

People who have an intellectual disability and a mental illness have been made invisible by a succession of dominant medical models. In the late 19th century, intellectual disability was not distinguished from mental illness. People with either or both disorders were placed in institutions for psychiatric treatment.' The current medical model draws a clear distinction between developmental or intellectual disability and mental illness but it continues to overlook the special needs of people who have both.

Dr Julian Davis, an expert in this field, told the Inquiry that 40 to 50% of all people with an intellectual disability also have a mental illness.' Despite this high prevalence, Victoria has no services providing appropriate diagnosis and ' treatment for these people. In fact, they are doubly disadvantaged by the present policy of closing specialist services. According to another submission,

The current philosophy of mainstreaming and deinstitutionalisation is severely limiting the number of inpatient beds which are available for the psychiatrically unwell. This situation combined with deinstitutionalisation of services for people with intellectual disabilities has made the availability of inpatient care doubly scarce for people who have both intellectual and psychiatric disabilities.'

Both the Psychiatric Services Branch and Intellectual Disability Services are failing these vulnerable individuals.

There are not the resources, either within IDS or [Psychiatric Services], to manage people who have special needs when they are psychiatrically unwell. We do not even, in this state, have a unit where people with severe behavioural problems — who are not

even psychiatrically unwell and just have a major behavioural problem — can be managed safely by trained staff... They are currently managed in the general wards.. .of our psychiatric hospitals.. .and that is an extremely disturbing situation.'

Lack of expertise

Very little is known about how mental illness manifests in people with intellectual disabilities.

It is very hard to get an intellectually disabled person into a psychiatric hospital, and I do not think that represents any malice. I think it represents a total lack of knowledge — because when it comes to psychiatric illness and intellectually disabled persons, it presents in a totally different way in many cases.'

Dr Davis stressed that diagnosing psychiatric illness in a person with an intellectual disability is difficult and time-consuming." People with dual disability are especially vulnerable to 'diagnostic overshadowing', when a symptom of the intellectual disability is interpreted as an aspect of the mental illness or the reverse, or else vital indications are simply not detected.'

When intellectually disabled people become unwell.. .their psychiatric illness is not picked up, or it is improperly diagnosed. Behavioural disturbances are possibly the commonest manifestation of psychiatric illness in the intellectually disabled... [Such] problems present in 90% of psychiatric diagnoses that we make. [But] because this system is divided into OPS and IDS, intellectually disabled people tend to be labelled as having behavioural problems all the time and so they are treated within IDS as behavioural problems.²⁹

Evidence to the Inquiry included the results of a survey of all Victorian psychiatric trainees about the psychiatric care of people with intellectual disabilities.

All of them identified the fact that they had hardly any knowledge of this area... At the College level, general practitioner level, intellectually disabled persons' services worker level, admitting officer level, psychiatric nurse level — there is very little understanding.'

Although the survey results indicated a high degree of interest in the psychiatry of intellectual disability, 30% of respondents said that their lack of training led them to prefer not to treat people with this dual disability.

What a dilemma to face as a provider of psychiatric care: on the one hand being a provider of care which you believe is deficient, and on the other hand sending intellectually disabled people into a community where resources are so inadequate that you or another medical practitioner has to prescribe anti-psychotics to compensate for these deficiencies.³¹

Due in part to the lack of expertise, the treatment options currently available, whether in hospital or in the community, are unsuitable for patients with most acute need.

It is not appropriate to manage.. .very behaviourally-disturbed people in the community, if they are tearing the place apart...self-mutilating...running out in the street... assaulting staff and clients... You cannot manage this type of problem in a residential setting with people who are unsure of their skills... The behavioural intervention support teams offer a certain type of service, which [for] the very acutely disturbed person, or the very severely disturbed behavioural problem, is not the appropriate way to go. These people require a lot of containment, they require medication, they require observation in case there is an underlying physical disorder or psychiatric disorder that has not yet manifested.³²

As a result, they often become involved in situations that compound their problems.

People like this who are not assessed properly and managed properly, they get assaulted, they get put in prison, they go to court, people walk out on them, their families go mad, they get shunted from one Community Residential Unit to the other because the staff cannot cope with them; that is a form of abuse.'

Dr Davis also told the Inquiry of his experience with community mental health workers frustrated by the lack of appropriate facilities or specialist training, assistance or support. They at times openly pursued over-medication as a way of managing people with this dual disability.

I have care workers who cry in the sessions, they are so stressed-out... who beg me for a psychiatric diagnosis because if you give them a psychiatric diagnosis then they can hang their hat on something and order treatment — chemical restraint and things like that.³⁴

The inter-service protocol

The protocol.. .is to facilitate the communication between IDS and OPS and to overcome some of the problems... I have sat on hearings of the Guardianship Board which have just revolved around who is going to take this person, an amazing waste of time and resources, and really a total failure in treating people on a proper bio-psycho-social model.³⁵

To facilitate the multidisciplinary approach to care needed by people with an intellectual disability and a psychiatric illness, a protocol was developed in mid-1994 between the Psychiatric Services Branch and Intellectual Disability Services. The protocol aims to coordinate the skills offered by the two services and use them more efficiently. Some reservations were raised at the Inquiry about its effectiveness.

The protocol as written down is very good. I can see some problems, however, in having a psychiatric case manager and an IDS case manager. It is going to depend on the co-

operation between them and there will be problems: who does a doctor ring up, which case manager does [the protocol] identify?'

An additional problem with the protocol appears to be the widespread ignorance of its existence or purpose. This was a finding of the study of the inner city community mental health service.

All staff were unaware of the protocol... It appears that although the protocol was released in June 1994, it was not yet implemented by the agency due to a lack of knowledge of its existence... It appears that IDS staff may also need to be fully briefed on the new protocol if service responsibility and accountability are to be resolved for this group.'

Training

The protocol is a step towards better integrating services for people with an intellectual disability and mental illness. This strategic coordination needs to be backed up with specialist training of professionals to create a pool of skills from which to draw. The lack of expertise on the ground urgently requires more resources directed towards specialist training.

At the time of the hearings Dr Davis was Victoria's sole source of specialist training in the psychiatry of intellectual disability. The Development Disability Unit at the University of Melbourne, where he teaches, aims to establish a core of psychiatrists with expertise in intellectual disability by offering traineeships to psychiatrists interested in the area.

Mental illness and substance abuse

Drug rehabs have sent him to psych institutions and psych institutions have sent him to drug rehabs, an endless circle that never seems to get anywhere.'

Many people who have a mental illness are also substance abusers. Often substance abuse is the result of self-medication to control the symptoms of depression and other affective disorders. On the other hand, mental illness may be caused or aggravated by drug or alcohol abuse."

Mental health services have come under pressure to deal with their patients' substance abuse problems, even though they are not equipped to do so.

There is a lack of adequate services for people with substance abuse problems. Many of these people are referred to psychiatric services, but such services are not designed to cope with them. The reason that they are referred to our psychiatric services [is] the closure of drug and alcohol programs in the State.'

The Inquiry heard that many services will not admit or attend to an individual, regardless of need, if drug or alcohol abuse is evident. Drug and alcohol facilities may also exclude people who have a mental illness. The Health and

Community Services Union described how the strain can lead to inappropriate responses by health service staff.

A substance abuse patient was recently admitted to NEMPS. When it came time for him to be discharged, he refused to leave, and three carloads of police had to be called in... He should have been in a specialist drug and alcohol facility [with] programs and treatment available for this type of client.'

A carer provided insight into this dilemma in relation to his son's dual disability.

He got discharged from Fairfield Hospital because the nurses found six Serepax tablets under his pillow that one of his friends had smuggled in. I protested and I was told that they cannot have people bringing drugs in. I said, 'He is a drug addict. He has got psychiatric problems... Six Serepax is not the end of the earth.' Anyway, he was discharged and I had to take him home and look after him at home.'

In another instance when the carer was trying to have his son detained in Austin Hospital,

[The hospital] did not want to have him certified; said that I had to take him home. I said, 'My son is telling me in the ward that he is going to kill himself the minute he gets out of the hospital, and I am insisting you have him certified for his own protection.' [The] hospital refused... on the basis that there was drug and alcohol involvement... They said if there was drug and alcohol involvement we cannot have him certified."

This witness's son was also HIV positive, a third disability which further increased the difficulty of receiving assistance.

The Inquiry was told subsequent to the hearings that the Government is developing a protocol between psychiatric services and alcohol and drug services. The protocol aims to establish a model of collaboration between services to address the needs of people with both a mental illness and alcohol and drug abuse problems. The Inquiry's concern is that this protocol could be weakened unless both areas are adequately resourced to meet the more intensive requirements of collaboration.

Mental illness and acquired brain injury

People with acquired brain injury seem to fall between the gaps... as there is no clear legislative basis for their treatment."

The Inquiry was told of a disturbing trend in one hospital's handling of people with acquired brain injury and a mental illness. The Mental Health Legal Centre claimed people with this dual disability have unnecessarily been reclassified as involuntary patients.

Psychiatric Services have this year changed the status of a number of ABI patients at the NEMPS campus to involuntary. This is despite the fact that they have active guardians who have consented to these patients residing in the hospital, as the most appropriate environment.'

The *Mental Health Act* specifies that involuntary detention may be used only where the patient is unable or refuses to consent to treatment. If a guardian has given consent to hospitalisation, the person cannot be made an involuntary patient. The Inquiry was told that the motivation in changing these patients' status is apparently economic. Involuntary patients are cheaper to treat, because they have no right to challenge or refuse individual treatment procedures.

The Centre gave an example of how this reclassification disadvantages patients.

There is a young man in the brain trauma unit at NEMPS. There is much supporting evidence.. .that [he] does not need psychiatric care but does need 24-hour support. A careful program has been developed in conjunction with NEMPS, moving towards discharge to a new community-based program which will provide that support. During this transition, increased outings provided by NGOs and activities have been organised ...and his condition has improved dramatically, despite his psychiatric diagnosis being dementia which normally does not improve. Unfortunately, this young man was one of the people made involuntary by that policy move. A subsequent Mental Health Review Board hearing confirmed his [involuntary] status. An appeal was lodged to the AAT; a change of status occurred immediately prior to the AAT hearing — not an uncommon thing.'

This evidence suggests a disregard for the legal protections for people in this vulnerable group.

Highlighted in this case were the issues around jurisdictional complications when a person has a guardian and responsibilities under the *Guardianship and Administration Board Act*, which are in practice overridden by the powers of the authorised psychiatrist under the *Mental Health Act*.'

The Centre also expressed concern over the result of its attempts to investigate the possibility of negligence in this case.

This person's acquired brain injury was a result of attempted suicide whilst in hospital. In looking at possible negligence implications, the Centre sought the medical file... [but] it was sent to another hospital for research purposes. No permission was sought or gained from the guardian for this. The file, we are now told, has been lost — which does make us wonder a little. It probably has been [lost], but it does make you wonder."

Personality disorder

He kept telling me, 'You have to face facts. The medical fraternity cannot help your son — he falls through the net.'

Personality disorder is not commonly accepted as a mental illness and yet people diagnosed as having a personality disorder are referred to the psychiatric system for care. The Mental Health Legal Centre suggested that people with personality disorder generally fell into two distinct categories, each facing a different crisis of access to appropriate services:

Young men.. .who are likely to be in forensic circumstances... and young women who seem to have personality disorder diagnosis who are being denied service but are quite actively suicidal or self-harming... Our concern is that they desperately need services... [The latter] group needs services and cannot get in, and [the former] is getting services for the purposes of preventative detention.'

The concept of 'personality disorder' is ill defined. In many cases it appears to be a convenient label for people whose condition is considered too difficult and time consuming to treat.

In one case a consumer was seeking help for escalating problems, but was categorically refused hospital treatment until she overdosed. She was then certified. When she queried why she was ineligible for voluntary treatment because of her personality disorder diagnosis but able to be certified, she was told that she suffered from schizophrenia and not from a personality disorder. It appears that the change in diagnosis was made for the purposes of the certification only, because on discharge she discovered she once again apparently had a personality disorder.'

At the time of the Inquiry, it appeared likely that personality disorder would be included in new amendments to the *Mental Health Act.*' However, the Health and Community Services Union questioned the Government's commitment to assisting this vulnerable group.

Serious problems exist in the area of services for people with personality disorders. In the Department's Framework document, Minister Tehan said specifically that such people were a target group for mental health services. However, the Minister has recently denied that her Department was responsible for the handling of cases involving personality disorders."

People with a personality disorder are caught by a legal and policy paradox. They are legally ineligible for mental health services unless they also have needs additional to the diagnosed personality disorder, in other words, a dual disability. Yet, evidence showed that people with a dual disability are often precluded from services because of their dual diagnosis.

One witness to the Inquiry provided extensive evidence of his son's inability to receive assistance when he needed it.

The CAT team came a few times but after the first two or three times they have refused, point blank refused to attend. They say their rules — and whether the rules have changed in the last two years I do not know — but their rules forbid attendance because it is a personality disorder we are talking about rather than a psychiatric illness; and secondly,

.....

there is drug and alcohol involvement. On one or both of those grounds they will therefore not attend."

Multiple personality disorder

I guess it is hard for people to appreciate what it means to be more than one self — the workload is enormous. The coming and going of personalities, always having to compromise, negotiate, set boundaries, make safety... The dynamics and complexity of our lives are not understood. We are often treated in a degrading and demeaning way.⁵⁵

One submission to the Inquiry focussed on people with dissociative personality disorders, such as 'multiplicity' or multiple personality disorder. The abusive experiences which underlie this disorder are often dismissed as irrelevant and therefore not addressed.

It is easier to label people with MPD as borderline schizophrenic and to hand out drugs to make the problem go away."

To receive at least some assistance with their disorder, many people tolerate dismissive treatment by the health establishment. The submission cited these individuals' experiences.

I've stayed with the same [psychiatrist] only because the story's so complicated I couldn't bear to go through it all again. He doesn't believe in multiple personality and I literally have to change my language to accommodate him — still — after five years.

All these doctors were standing round the bed saying, 'Your MRI scans are normal, you're faking.' And that's the word they used, 'faking'... Then everyone just walked away from the bed and just left me. And I just remember feeling absolutely bereft.⁵⁷

Mental illness and deafness

Deaf people who react to isolation within the psychiatric hospital setting by becoming agitated are often misdiagnosed and treated with sedatives, seclusion or restraints. Using restraints to contain a deaf person who communicates manually is equivalent to gagging a hearing person."

The Inquiry heard from one witness the problems faced by people who are mentally ill and also deaf. Like people from non-English speaking backgrounds, these patients are vulnerable to misdiagnosis and inappropriate treatment as a result of communication difficulties not being appropriately addressed.

The absence of staff able to communicate in sign language was raised as a particular area of concern.

That's why I had such a bad time in hospital. I was put in a lock-up three times because they didn't understand. I was so frustrated and angry with them, they thought I was sick so they put me in the lock-up — and it was only because they didn't sign.'

Insufficient resourcing of services has placed the responsibility for this group onto deaf community organisations that have no expertise in mental illness.

[Deaf NGOs] were seen by mental health agencies as 'experts in deafness'... The response of clinicians is often 'refer this deaf person to the experts in deafness and they will take care of the individual's needs.'

One deaf person attended only one activity, ie a practical class. Other activities, such as discussion groups, stress management and relaxation training were often inaccessible to deaf people. Psycho-social programs were not able to provide interpreting services to deaf participants due to funding limitations.⁶⁰

The lack of interpreters, of training in deaf community languages for mental health staff and of appropriate communication equipment made this group particularly vulnerable to discriminatory conditions and in some cases abusive treatment.

I think I've had a really bad time over the last seven years. In hospital, no interpreters, I didn't get the full information. I wanted to know what was wrong with me. They told my parents, but they didn't tell me and I just didn't feel comfortable to ask. I would rather have a deaf psychiatrist in Melbourne so I can question everything in Auslan and that would be so much more easier for me.'

The Victorian Mental Illness Awareness Council noted that the lack of interpreters also dramatically increases a patient's isolation in the ward, as they are unable to communicate informally with other patients. Communication between patients is considered to be one of the most beneficial aspects of hospitalisation.'

People from non-English speaking backgrounds

If you were to take Melbourne and...take together those people who were overseas born and their children, or children who have at least one overseas born parent, then the proportion is about 40%. It is a very substantial part of Melbourne's population.'

People from non-English speaking backgrounds make up a large proportion of the population. However those with mental illness face substantial barriers to accessing services appropriate for their needs. These barriers were described to the Inquiry by an eminent specialist in this field, Associate Professor Harry Minas, Director of the Victorian Transcultural Psychiatry Unit (VTPU). He outlined issues of concern to consumers, advocates and service providers.

Access to services.., the availability of appropriate skills amongst the clinical staff working in both public and private sectors, and the range of treatment options.. available to non-English speaking patients — [are all] substantially narrower than [those] available to the general community.'

Indicators of vulnerability

Mental illness within non-English speaking communities is probably more common than among the Australian born community⁶⁵ The prevalence and experience of mental illness varies widely across different country of origin groups.

At the same time,

[The] rate of use of mental health services by NESB immigrants is probably substantially lower than the rate of use by the Australian born community... If those two points are taken together, a higher prevalence and a lower rate of use, then the rate of use according to existing need is probably very low.'

Longer hospital stays

Victorian case register statistics show that patients of non-English speaking background are admitted to hospital at rates at or below their representation in the broader community. Once admitted, their hospital stays are around 21% longer than those of Australian born patients. This suggests that by the time they are admitted they may be more severely ill. It also suggests difficulties in assessment and management, both prior to and during admission.

The low level of interpreter usage in hospitals also probably contributes to longer stays. An inability to communicate in a patient's first language is likely to prolong diagnosis and recovery. Several disturbing findings about the use of interpreters have emerged from the work of the VTPU.

[Only] 13% of clinicians indicated that an interpreter was always present when the clinician deemed it necessary... Use of untrained interpreters in inpatient settings, which carries with it ethical difficulties and practical limitations, occurred in some 38% of cases.

The average time of consultations, contrary to what would be expected given the difficulty in communication and use of interpreters, was significantly shorter for non-English speaking background patients than the Australian-born.'

In an acute psychiatric inpatient unit,

People...whose English is such that they require the assistance of an interpreter have access to an interpreter on average once every seven days... It is difficult to imagine how assessment is carried out, how treatment is carried out, how discussions with family and with the ill person are conducted, with those sorts of rates of access to interpreting services."

Lower usage of mental health services

Reluctance on the part of people from non-English speaking backgrounds to access services has been attributed to a range of problems affecting the quality

and appropriateness of the services. A shortage of health professionals who speak community languages, the absence or inadequacy of interpreter services, a lack of culturally sensitive services and insensitive attitudes on the part of health professionals were all mentioned in evidence.

[A] survey of public mental health services indicated that clinicians lacked the necessary knowledge and skills to effectively deal with persons who were culturally different to themselves. In addition they rated the quality of services delivered to ethnic patients to be substantially below that received by English speaking patients... Clinicians [also] considered the clinical outcome for ethnic patients to be poorer than that of English speaking patients.⁶⁹

One witness spoke from personal experience.

Most mental health professionals in Victoria try to force patients belonging to minority groups to 'conform' to mainstream society — rather than helping them cope with the discrimination that mainstream society throws at them and helping them to be accepted by mainstream society as decent people in their own right.'

A lack of trust in services providing assistance and treatment for mental illness may be compounded by experiences of alienation associated with the migrant experience.

As a result of the highly unsatisfactory attitudes... of mental health professionals, many patients belonging to minority groups avoid mental health professionals and as a result never resolve their problems. They may go a whole lifetime under extreme stress without being able to do anything about it, particularly those without any close relationships. When other problems (eg unemployment, isolation, lack of social skills, etc) occur in addition to the many problems related to the person's stress related to their discrimination, life becomes unbearable.'

Inaccessibility of inpatient mental health services due to the regionalisation of services is another factor in the low usage rates by people from non-English speaking backgrounds. Two surveys conducted by the VTPU show the low usage rates of inpatient and especially outpatient mental health services and the high level of dependence on general practitioners by people from non-English speaking backgrounds. A survey of 10,000 consultations on a single day showed that, of those patients whose English was described as poor, about 75 to 80% were able to find a general practitioner who spoke their language. However, clinicians employed in the public psychiatric system who spoke a common community language indicated that they had the opportunity to use those languages in fewer than 5% of clinical contacts. The Inquiry was told that bilingual clinicians in the public sector do not have the flexibility to treat patients referred to them from out of their area.

There has been no systematic attempt to put those clinicians who do speak a language in touch... with those patients who need a bilingual clinician.⁷²

The trend towards case management may also exacerbate these rigid area divisions if the flexibility is not incorporated to allow for people from non-English speaking backgrounds to be allocated to bilingual case managers.

Higher rate of physical treatments

I agree that the potential for abuse of rights is much greater when people are unable to communicate and to make clear and to advocate on their own behalf. Now, I think that the rights of non-English speaking people are less well attended to in every sector of the mental health system. It goes across issues of informed consent, explanation in terms of medication or other treatments, explanation of treatment options, explanation of their legal rights in relation to involuntary admission and so on.'

The Inquiry was told the failure to provide interpreters or bilingual clinicians leads to over-medication and other inappropriate treatments for patients from non-English speaking backgrounds.' Outside the hospitals, where interpreter services are concentrated, these patients depend heavily on bilingual general practitioners for their mental health care. This dependence has produced a greater reliance on physical treatments such as sleep medication, minor tranquillisers and anti-depressants. The Inquiry was told a significant reason why doctors tend to rely on medication for this group is the lack of options for referral to specialist services.⁷⁵ Without specific training in mental illness or support from services with expertise in the area, general practitioners are often totally responsible for looking after individuals who in fact need specialist care.

The tendency to rely on physical treatments, however, is not restricted to general practice.

Even when patients not fluent in English were able to obtain specialist treatment, they were much less likely to receive psychotherapy... The implication is that treatment may be less intensive, and may place more reliance on medication.'

The primary barrier to accessing non-physical treatments such as psychotherapy is that these treatments are communication-based. The capacity to communicate effectively is central for both assessment and treatment. Without it both the effectiveness of the treatment and probably the clinical outcome is compromised.

We have significant concerns that in an area such as psychiatry, where communication is the principal tool both of assessment and treatment, that most of the treatments... are at the moment essentially unavailable to this group of people with mental illness... There is clear evidence that suggests that whether somebody is likely to get treatment with psychotherapy from the public system is determined more by that person's English fluency than by clinical need.'

Resources

Treatment available to people from non-English speaking backgrounds is even more limited outside Victoria's larger urban centres.

The possibility of seeing a doctor or another clinician who speaks the language is much more restricted outside the metropolitan area. At least] many people are able to find a GP who speaks their language in Melbourne.'

Recent moves by the Government to address the unequal distribution of overall health resources were raised in evidence. Of particular concern was that funding and structural reforms may entrench the problems people from non-English speaking backgrounds already face in accessing specialist mental health services.

While the current thrust of reform of the mental health system in Victoria... is likely to improve the quality of mental health services overall, by equitably distributing resources across the state, and treating the mentally ill in the community, it may have unintended adverse consequences for ethnic patients... Under the new system, community mental health services will have strict catchment areas, smaller than the current health regions. Those managing the service will be responsible only for those patients resident in their catchment area... This means that the limited expertise which exists within the public mental health system, in terms of bilingual clinicians, and those with knowledge of different cultures may be denied to patients who are not resident in a particular region, increasing the risk of mis-diagnosis or a reduced standard of treatment.'

As services become more regionalised and managed in smaller and smaller components, those few services in metropolitan centres that are large enough to include appropriately trained or skilled staff may be downgraded.

The kinds of flexibilities available in services which are larger and have larger numbers of staff, for instance bilingual staff.. will be lost, and it may be that the quality of services and the access, particularly to bilingual clinicians across the range of disciplines, will be reduced even further.'

Non-governmental agencies referred to the failure of the *Framework* document to allocate additional resources to areas with high immigrant populations. Overall funding cuts to interpreter services were also mentioned."

The move to community-based services may also lead to a lower overall rate of service usage by people from non-English speaking backgrounds. The rate of use of community-based mental health services is currently even lower than for in-patient services.

There are efforts to improve the situation for people from non-English speaking backgrounds by better coordinating existing services. For example, a small number of specific research and demonstration projects are currently underway in the Melbourne metropolitan area examining the establishment of a liaison service between psychiatry and general practice. However, the Inquiry was told

there had been no commitment from the Government to support a service to improve the capacity of general practitioners to assess and treat people with mental illness from non-English speaking backgrounds.'

Women

Particularly in the case of single mothers there is every chance they will lose temporary, and often permanent, custody of their children due to having a mental illness.'

Women who have a mental illness meet particular difficulties in seeking adequate services. Two issues of concern arose in evidence: the lack of services and understanding of the needs of mentally ill women with children, and safety.

Women with children

The Mental Health Legal Centre told the Inquiry many mothers affected by mental illness are afraid their children will be taken away if they seek assistance. With mandatory reporting of child abuse or neglect and widespread lack of understanding about the nature of mental illness, the danger is that a mentally ill mother will be automatically deemed an unfit parent.

Women, particularly who are single parents, trying to get into hospital.. .are quite often ringing our service saying: 'if I speak to my psychiatrist will I therefore come in contact with Child Protective Services and will I lose my children?' In all honesty we cannot say they will not."

As a consequence they often fail to seek the psychiatric services that they urgently require.

Women are too afraid to access services and are, therefore, effectively being denied a service, becoming quite ill — and the potential for actual neglect of kids becomes a lot greater because of those fears. That is all too common a call. They are really afraid of losing their kids to either fostering or... adoption.'

A mother who seeks psychiatric help and is hospitalised faces a lack of inpatient facilities that cater to the needs of women and their children, particularly older children.

Mothers in an inpatient setting have found that having mother-and-baby or mother-and-children units would be quite appropriate, and there just simply are not those facilities. There is a mother-and-baby unit only at NEMPS and one other unit, but for mothers with older children that is not possible.'

With such limited facilities, a mother's access to her children is very restrictive and of poor quality.

The only place for a visit or for access to take place is often a hospital office, often with staff present. It is not conducive to good access and it is certainly not conducive to good bonding between mother and child.'

Mothers living in the community have access problems too. One client of the Legal Centre was a mother who needed to travel to Shepparton to see her son.

She was too ill to organise the train to go, and Health and Community Services refused to assist by either bringing the child to the mother or assisting the mother to undertake the journey by providing a worker or provision of financial support."

This inflexibility denies the child access to the parent and the parent access to the child. It gives little recognition to the impact that this separation may have on the mental health of either.

Safety

The Inquiry heard disturbing allegations of sexual and physical harassment and assault upon women affected by mental illness.⁸⁹ These assaults took place within inpatient facilities or in mixed-sex accommodation. The Mental Health Legal Centre told the Inquiry that no real attempt is made to provide for the safety of women who are inpatients.

A young woman... had been raped twice whilst in certain accommodation on a psychiatric hospital grounds. The police were called in and it was quite clearly identified that the woman had been raped. There was no follow-up by the hospital of that woman's mental health or her counselling needs around those rapes or a safety net. She has since moved to another program, still in the same hospital, and was the week before last indecently assaulted.... No attempt was made to make that woman safe. She is not special. She said to me specifically: 'I feel very vulnerable, I am very afraid here.' She has every reason to be, given her experiences. No counselling has been made available to date.'

There were allegations of male staff colluding with male patients to create an unsafe environment for female patients.

A staff member, who is now on night duty, was sexually harassing the female members on that... program, and he was colluding with the male patients in that nudge-nudge-wink-wink way which means that the atmosphere on that ward is not very conducive to women feeling particularly safe.'

The risk of abuse is not confined to hospitals. Women with a mental illness living in mixed-sex accommodation are particularly vulnerable to sexual and physical assaults. One tenant who was also employed at a rooming house provided a number of disturbing case histories of violence.

'Leanne' is a middle-class women in her late thirties [who] takes up residency in the rooming house. She has travelled to hell and back..., suffered from a drug and alcohol problem and was constantly bashed and abused by both her husbands. Leanne is a strong, direct and outgoing person and she pursued several courses whilst living in the rooming house, so that she could attain employment. One male tenant ('Walter') was attracted to Leanne... Four weeks later this male attacked Leanne... she was almost raped... The police removed Leanne from the House and transported her to the police station... After

taking her home to my place there was an understanding that she should find other accommodation. Leanne found other accommodation and is now in full-time employment and has her own flat. Her attacker was not evicted at this time.⁹²

Later, Walter developed an attraction to another woman, 'Ruby'.

One evening Walter bashed Ruby, causing her teeth to break and fall out of her mouth, black eyes and other cuts and abrasions to the head. Walter was evicted and Ruby laid charges against him. After these horrific incidences we were informed that Walter had a history of woman-bashing. Ruby moved on to a safe house (women only). We were [later] informed that she.. .had fallen out of the system.'

Children and adolescents

The Inquiry heard that inadequate resources still seriously limit the availability and effectiveness of services for mentally ill young people, despite some positive developments in child and adolescent mental health services. Several innovative projects have been established to meet the particular needs of young people, such as the Early Psychosis Prevention and Intervention Centre (EPPIC) and the Homeless Youth Mental Health Outreach Project. A major review of child and adolescent mental health services was also under way at the time of the reconvened Inquiry.

A high proportion of psychiatric disorders have their onset in adolescence or early childhood. Yet the current resourcing of adolescent and child services does not reflect this fact.

We find it perplexing that the state only provides 5% of the mental health dollar to adolescent services when 70% of psychiatric illnesses begin during teenage years.'

Child and adolescent mental health workers said that the severe strain on resources in public and community mental health facilities undermines their ability to provide quality and effective services.' Issues of particular concern were the long waiting lists, lack of inpatient family facilities, inappropriate placements, shortage of day programs and the severe lack of services for young people living in rural areas and others with special needs.

Waiting lists for assessment

Witnesses expressed frustration over the delays for children and adolescents awaiting an initial psychiatric assessment, estimated at 5 to 15 months.⁹⁶ Because of this waiting time,

The trend has been more to crisis intervention and not taking children and families on for longer term work I think that is a very dangerous development, really, [because] these children often need very intensive specialist treatment over a longer period of time, much more than crisis intervention.⁹²

Child psychiatrist Dr Pia Brous stressed that the crisis intervention model is only appropriate for crisis cases. Entrenched and severe cases require careful assessment and often long-term treatment."

The Government's *Framework* document directs mental health professionals to give priority to children and adolescents with a diagnosed serious psychiatric disorder.' At the same time, the Inquiry was told that many clinics are severely under-resourced. As a result young consumers who are not considered 'serious' but who may be in an endangered or deteriorating state go on the waiting list. Dr Brous instanced the type of cases waiting for assessment on these lists.

The severity of a case cannot always be estimated on the presenting information and it is often only evident after a careful assessment. For example, I took a case after it waited for five months on the waiting list, of a violent 13-year-old boy. Assessment revealed that he was regularly attacking his mother and throwing his three-year-old brother head first on the concrete floor. Protective Services did not consider that notification was warranted despite numerous contacts by Community Police. The family were completely unable to take any action. I do not consider it appropriate for severe cases to wait on waiting lists at all. ¹⁰⁰

Inpatient family services

Families suffer considerable pressure and disruption during the course of a family member's mental illness. These families have a right to support and services. The Inquiry was told that services for families in Victoria are inadequate, particularly inpatient services that assess and treat children and adolescents within their families.

Currently there is only one family inpatient psychiatric unit in Victoria which admits whole families when they are in crisis... The aim of that program is to work intensively with the family rather than working with the child on their own. In other words, instead of admitting the child singly, to admit the whole family for anything between one to three or four weeks.'

However, according to researchers Lyn Allison and Robyn Campbell, the Child and Family Unit, which was the only family inpatient service operating in the State, was under threat.

[It must] constantly justify its existence because the whole family is accommodated and therefore [it is] an expense, whereas the only 'number' counted in terms of output is the child. This is in spite of it being a very successful program with proven long-term benefits.'

Placement in adult facilities

The original National Inquiry revealed the disturbing practice of mentally ill children and adolescents being placed in highly inappropriate settings, such as

adult inpatient psychiatric facilities.' Unfortunately, evidence submitted to the reconvened Inquiry suggested that inappropriate placements continue in Victoria.

Adolescents often have to be certified to adult facilities where they see the most severe, deteriorated and dangerous adult patients, which truly terrifies and traumatises them. I have worked in this field long enough to see the long-term effects this has in later adult life.¹⁰⁴

These facilities are unable to meet the special needs of young people with mental illness.

Adolescents in adult services are not treated by staff trained either in child and adolescent development, in a holistic psychosocial approach, or in adolescent clinical psychiatry... [And] adolescents certified to adult facilities for severe psychiatric disorders... are often discharged the next day, with very poor follow-up.¹⁰⁵

The principal reason why young people are placed in adult facilities is the shortage of beds.

There is a bed shortage, particularly for adolescent inpatient psychiatric beds. That will be addressed somewhat [in 1995] with the new ten-bed unit opening at Monash Medical Centre, but there still are shortages... No new children's units have been established for quite some time, and this does create problems with adolescents in crisis who need urgent admission.'

The inappropriate placement of young patients has become less apparent because of changes to the Department's definition of adolescence.

Adolescence has recently been redefined as ending at the 16th birthday. This does not fit with any developmental theory of adolescence, nor with clinical experience of working with disturbed adolescents. This policy ensures that disturbed older adolescents, and young adults who are *functioning* like adolescents, are inappropriately treated in the adult psychiatric system. However, the statistics for adolescent psychiatric disturbance in Victoria will improve because many will be counted amongst the adult members.^{m7}

Day programs

Outpatient or day treatment services can provide a disturbed young person with substantial care and treatment without the upheaval of admission to an inpatient facility. One expert witness told the Inquiry that there are too few day programs for adolescents.

There is a shortage of day programs, particularly rehabilitation programs for adolescents who have experienced their first onset of psychotic illness such as schizophrenia.¹⁰⁸

This witness was among several who referred to the Early Psychosis Prevention and Intervention Centre (EPPIC) as a successful program, incorporating day treatment programs as an integral component of its comprehensive care service. The Centre is regarded by mental health workers as an excellent model of care.

EPPIC is an integrated and comprehensive psychiatric service that addresses the needs of older adolescents and young adults (16 to 30) with emerging psychotic disorders in the Western metropolitan region of Melbourne. Its catchment population is around 800,000. Although a relatively new service, EPPIC has had significant success in reaching young people at an early stage of psychiatric illness. It also provides a comprehensive program of care with follow-up throughout the various stages of illness.' However, EPPIC is limited to one region and has only a small number of beds.

Assessment services in schools

Schools play an important role in the early identification and referral of young people with mental health problems. Evidence to the Inquiry suggested that education authorities in Victoria are eroding school-based psychiatric assessment services. According to one psychiatrist, children are being referred to outpatient psychiatric services for assessment and consequently face long waiting lists.

The Directorate of School Education has altered the psychology support services available to schools and considerably downsized those, so this has meant that a lot of children do not receive psychological testing or psychological assessment. In effect, that responsibility has been handed over to child psychiatric services. Most services are not really able to cope with that and they have got long waiting times for psychological testing and assessment — so in a sense it has really been changed from one ministry to another without any consultation between the two ministries.'

This situation particularly disadvantages children with learning disorders.

We are especially concerned about that group (children with learning disorders) because they are highly at risk of having other psychiatric illnesses; and if they could be effectively treated or assessed early it would prevent some later difficulties that those children experience.¹¹¹

Rural services

One expert told the Inquiry that psychiatric services for children and adolescents living in rural areas **are** grossly under-resourced. Mental health professionals in this area are under great pressure.

They often have to provide a model of crisis intervention because of lack of staffing, and there is usually very limited child psychiatry input into those teams. Most of the teams do not have — well, all the teams in fact in rural areas do not have — a child psychiatrist to lead those teams. There is quite low morale and high turnover. So I think the expectation placed on those services is really overwhelming for them.'

The witness suggested ways to attract child psychiatrists to rural areas, including encouraging more psychiatrists to specialise in child and adolescent psychiatry, providing incentives for work in rural areas and developing exchanges with metropolitan areas.

Homeless services

Some very positive and innovative services have been developed for young homeless people affected by mental illness. One major initiative has been the Youth Mental Health Outreach Project, co-funded by the Commonwealth and State health departments.' This project provides psychiatric services to homeless young people or those at risk of becoming homeless with mental illness or psycho-social disturbance. It aims to link the networks of psychiatric and youth homelessness services to improve both accommodation and mental health outcomes. The project operates in Footscray, Sunshine, Essendon, Williamstown and Altona. One supporter of the program said, however, that like its coverage its funding is limited.

These programs have generally been extremely successful but they only occur in some regions. There are still some metropolitan regions that do not have that facility and rural areas do not have that at all. The funding has not been taken over as yet by mainstream psychiatric services. So it is not recurrent funding, and programs will run out in the next..two to three year period.¹⁴

Adolescents with self-destructive behaviour

The Inquiry heard that adolescents with self-destructive behaviour in the welfare system are not receiving adequate attention or services.' These young people have generally experienced very severe forms of abuse and neglect in their lives. They repeat these experiences by self-mutilating or through other serious self-harm. One expert advised the Inquiry,

In child psychiatry we have a lot of concern [about] those adolescents being sent to secure welfare under legislation of the *Children and Young Persons Act*, where they can be contained for up to three weeks but no longer. These are often extremely disturbed adolescents... We are proposing that there needs to be joint management between the welfare and psychiatric sector of this group of population, that they often need longer term containment plus psychiatric treatment. Unfortunately, the way our system is structured has meant that they end up in one or other system but cannot actually be linked across those two systems.¹¹⁶

This problem needs to be addressed urgently. A lack of proper coordination and management of these young people's special needs by the welfare and psychiatric sectors perpetuates their experiences of neglect.

Elderly people with dementia

Dementia, most commonly caused by Alzheimers Disease, is the most disabling mental illness among the elderly. The loss of cognitive abilities and other impairments associated with dementia mean that affected individuals need intensive support.

The Inquiry heard evidence from two carers whose mothers have dementia. One described the enormous difficulty endured by carers who engage with 'the system' to find a suitable and safe place for a dementing relative to live.' The other witness, having found an ideal home for her mother, was about to lose it due to a funding shortfall."

Accommodation

The original National Inquiry highlighted the conundrum created by the funding formula for dementia-specific accommodation.' Most nursing homes and aged hostels are subsidised by the Commonwealth according to the level of the residents' disability. In the funding formula dementia is not considered to be a severe disability. This means dementia-specific facilities receive far less funding than nursing homes, which cater for people who are physically frail or bed-bound. However, good dementia care is expensive to provide because a high ratio of staff to patients is needed to cope with the associated behavioural disorders. Since the subsidy available for dementia-specific facilities does not cover this cost, there are very few of these facilities in operation. A witness said that Victoria is particularly poorly supplied.

In Victoria we have 17 compared with 52 in NSW, 60 in Queensland and 40 in South Australia. That is from the government's National Action Plan for Dementia report.¹²⁰

Dementia-specific facilities are similar to standard hostels or nursing homes but have staff trained in dementia care and a secure environment for people who have a tendency to wander. In addition, these facilities furnish the rooms with the residents' own possessions to provide the sense of belonging that is critical for orientation and self-esteem.

The Inquiry was told that finding appropriate accommodation for people affected by dementia is a frustrating and stressful experience for both the carer and the elderly person. Often the person is moved several times until something suitable becomes available. This instability can worsen the already frail mental health of a dementia sufferer. One carer, Rosemary West, noted the effect on her mother.

Each.. .move set her back, I think, mentally; and was extremely distressing and destructive to her and me.¹²¹

Carers go to great lengths to find the best facility for a relative who needs specialised care but in reality there is very little choice. Ms West described 15 nursing homes she visited that were highly recommended for their environment or dementia programs.

They were either clinical mini-hospitals where people were generally two to a room with lots of stainless steel, or else they were older-style places with anything up to six or eight

to a ward and they smelt of urine. The mini-hospitals smelt of disinfectant... When you move your mother into a nursing home.. .people say 'usually they do not last long once they get into a nursing home', and I think there are a number of reasons why that is true. ¹²²

Given a choice, most carers would prefer to place their relatives in facilities specifically designed for dementia sufferers rather than a generic hostel or nursing home. However, most dementia-specific homes require substantial up-front fees that are simply not affordable for many carers.

It is unfortunate that there seems to be a substantial fee disincentive, or fee incentive, to place people with dementia in nursing homes rather than dementia hostels — so as well as it being very difficult to find a dementia hostel, you actually pay a lot more... The newer places.. .cost \$80,000 up front to go into and \$400 a week. Other places had an up-front fee of around \$15,000 but some charged \$350 a week, which for most people would be beyond what they could afford.¹

Strathdon Lodge

The Inquiry was told that Strathdon Lodge, a Commonwealth-subsidised facility run by the Uniting Church, provided a best-practice model for dementia accommodation.

This facility.. .provides an atmosphere of love, compassion and peace for the residents who regard this as home, where their individuality is treasured, their needs are honoured and their dignity upheld. The staff are very special people. I spend 4-5 afternoons a week visiting and am very aware of the value of this accommodation which has special programs and social activities which satisfy and occupy. The building is designed to be like home, the environment is relaxed. It is the best care I could find for a very special person — my mother.'

Strathdon Lodge was described as a 24-bed unit within a larger complex that included independent living units, a conventional hostel and nursing home and a daycare centre funded by the State Government.' The Lodge was classified as a 'hostel', and received the same Commonwealth subsidy as standard hostels that do not provide specialist care — \$30 a resident a day. Nursing homes receive approximately \$80 a resident a day.¹²⁶

Repeated efforts by the Lodge's Council to secure funding to raise the subsidy by a further \$20 to 50 a resident a day had been in vain. So too had been attempts to have the Lodge reclassified as a nursing home to become eligible for the higher subsidy available under this category. ¹²⁷ As a result, the Lodge was closed in October 1995.

Closing the facility imposed extra costs on the Commonwealth, forced more people needing specialist care into mainstream facilities and increased pressure

on the Victorian Government to respond to the deterioration in dementia-specific elderly care.

As a consequence these patients must now be placed in nursing homes as that is the next most appropriate accommodation. The irony is that this relocation costs the [Commonwealth] Government twice the amount currently incurred and 50% more than the amount being sought by carers.'

Carers face the difficulty of finding alternative accommodation for their relatives, whose behaviour can be severely disruptive and difficult. One carer expressed concern about how a standard nursing home would manage her mother's difficult behaviour.

She has an obsession with her bowel which is a really difficult behaviour to handle. It means people do not particularly find her pleasant. She has faeces on her hands, on her clothes, she makes a mess everywhere with it. The staff have handled her extremely well. Her day is spent talking to the lady in the mirror who is her best friend. She spends a lot of time on the toilet or in the toilet. The staff have been absolutely wonderful. She is withdrawn with her behaviour but she is allowed to stay in her room, to be there if that is where she is comfortable... She does not know who I am; she has become my little girl. This facility is going to close and I cannot believe that it is being done.'

The Chair of the Strathdon Community Council, Bess McRae, told the Inquiry why nursing homes are inappropriate for this group of people.

They would not be comfortable in a nursing home. They would need to be restrained either physically or chemically, and at the same time the physically frail residents in that nursing home who are forced to co-habit with them would also be vulnerable. Their rights would also be infringed upon. So it is a devastating situation. We as a council are suffering as much bereavement as the relatives of the residents at losing this very special service.'

Insensitive treatment

Many professionals working in aged mental health are compassionate and committed to their clients' welfare. Evidence suggested, however, that elderly people affected by mental illness may also be subject to insensitive and patronising attitudes, as well as intimidatory behaviour in response to complaints.

Rosemary West complained to a nurse about a male resident who continually harassed her mother by groping her knee.

She came over to Mum and said, 'Mavis, you should be very flattered Peter likes you.' I said, 'Well, she's not flattered. She's feeling very upset and the word for it is sexual harassment.' And they said, 'Tut you surely wouldn't suggest that action should be taken against him?' I said, 'Well, no, of course not, but I think that my mother should be protected.'¹⁴

The safeguarding of residents' privacy and safety was a low priority in this facility. Ms West recounted another incident in which she found her mother in a distressed state when a male patient had 'wandered' into her room. The response from the nurse on duty was,

'...they're all demented so there's nothing to stop them wandering into each other's rooms.'
.132

When Ms West spoke to the facility's geriatrician, a sense of threat pervaded the conversation.

He said in his 20 years in the mental health system it was the first time anybody had suggested sexual harassment... In the same phone conversation he suggested that perhaps my mother no longer needed the service and I should look for another place for her."

As well as complaints about over-medication of elderly people with dementia, the Inquiry heard allegations about mismanagement of medication. Ms West told how one hostel, contrary to her protests and without consulting the geriatrician, decided to alter her mother's low-dose anti-depressant regime and place her on other drugs.

A month later, [they] put her back on [anti-depressants] when her depressive symptoms were again apparent, but by then she was on two other drugs and she basically remained disturbed until, after seven months.. .I managed to get her restored to the original drug regime. There was one episode in that time when she actually was virtually in a coma, she was unable to walk or speak, and the psychiatrist said to me, 'Well, something's obviously happened. We're not sure whether it's a stroke or whether it's over-sedation, but we'll take her off the drugs and if she survives she can have her trial on the anti-depressant'... She did in fact recover and there was no evidence of a stroke in the tests they did.¹³⁴

Conclusion

Few specialist services exist for particularly vulnerable groups and where they do, access is limited. A number of innovative and successful programs exist, particularly within the adolescent mental health services area. However, the overwhelming experience of vulnerable groups attempting to use the mental health care system is marred by inadequate funding, inadequate provision of facilities, inadequate staffing, inadequate training of health workers, inappropriate inpatient care, inadequate aftercare, frequent abuse, lack of coordination between agencies and an inadequate commitment to preventive services.

- 1 Mental Health Legal Centre (submission), p6.
- 2 Isabell Collins, Victorian Mental Illness Awareness Council (submission), pl.
- 3 Margaret Hutson, (submission), p7.
- 4 Paul McDonald, Crossroads Housing and Support Network (oral evidence), p12.
- 5 *ibid*, p13.
- 6 Angela Incigneri, carer (submission), p2.
- 7 McDonald, pll.
- 8 *ibid*.
- 9 June Gay, carer (submission), p2.
- 10 Incigneri, p1-2.
- 11 John Beavis, consumer (submission), pl.
- 12 Rachel Martin, Inner South Community Health Service (submission), pl. A similar view was put by dentist Patricia Jeffries, Carlton Collingwood Fitzroy District Health Service (submission).
- 13 Kerry Punshon, North East Metropolitan Psychiatric Service (submission), pl.
- 14 Martin, pl.
- 15 Victorian Mental Illness Awareness Council (VMIAC) (submission), p10.
- 16 *ibid*.
- 17 *ibid*.
- 18 Christine Cleary, researcher (submission), p41.
- 19 For example, submissions from VMIAC; the Executive of the Statewide Senior Occupational Therapists in Psychiatry (ESSOTP); Cathy Dwyer, Victorian Deaf Society and Victorian Council for Deaf People; and Name withheld, Psychiatrist (oral evidence).
- 20 Jenny Gee, Mental Health Legal Centre (oral evidence), p84. Similar points were also raised in submissions by ESSOTP and Cleary.
- 21 Dr Julian Davis, psychiatrist (oral evidence), p40.
- 22 Nicholas Lennox and Robert Chaplin, Department of Public Health and Community Medicine, University of Melbourne (submission), p3.
- 23 Davis, p41.
- 24 Lennox and Chaplin, p14.
- 25 Davis, p43.
- 26 *ibid*, p42.
- 27 *ibid*, p43.
- 28 Cleary, p35.
- 29 Davis, p42.
- 30 *ibid*, p44.
- 31 Lennox and Chaplin, p14.
- 32 Davis, p49.
- 33 *ibid*, p51.
- 34 *ibid*, p50.
- 35 *ibid*, p47.
- 36 *ibid*.

37 Cleary, p41. This point was also made by Davis, p44.
38 Name withheld, carer (oral evidence).
39 VMIAC, p12.
40 Kaye Williams, Health and Community Services Union (submission), p4.
41 *ibid.*
42 Name withheld, carer (oral evidence).
43 *ibid.*
44 Gee, p82.
45 *ibid.*
46 *ibid*, p83.
47 *ibid.*
48 *ibid.*
49 Name withheld, carer (oral evidence).
50 Gee, p82-84.
51 VMIAC, p2.
52 At the time of writing this Report the amendments to the *Mental Health Act* were before Parliament.
53 Williams, p2.
54 Name withheld, carer (oral evidence).
55 Carol Jackson, Australian Association of Trauma and Disassociation (submission), p11.
56 *ibid*, p5.
57 *ibid*, p6.
58 Dwyer, p35.
59 *ibid*, p23, quoting a consumer.
60 *ibid*, p24.
61 *ibid*, p20, quoting a consumer.
62 VMIAC, p10.
63 Assoc Prof Harry Minas, Victorian Transcultural Psychiatry Unit (oral evidence), p179.
64 *ibid*, p178.
65 *ibid*, p177.
66 *ibid.*
67 Victorian Transcultural Psychiatry Unit (VTPU) (submission), p4.
68 Minas, p185.
69 VTPU, p3.
70 Anonymous, (submission), p2.
71 *ibid*, pl.
72 Minas, p185.
73 *ibid*, p187.
74 *ibid*, p178.
75 *ibid*, p180.
76 VTPU, p3.

77 Minas, p178.
78 *ibid*, p180.
79 VTPU, p4-5.
80 Minas, p177.
81 For example submissions by Gee and Brendon O'Hanlon, Association of Mental Health Social Workers.
82 Minas, p184-185.
83 VMIAC, p12.
84 Gee, p80.
85 *ibid*.
86 *ibid*. This point was also raised in the submission by VMIAC.
87 Gee, p81.
88 *ibid*.
89 Gee (oral evidence), p81-82. Also raised in submission by Shirley Rochow, consumer.
90 *ibid*, p82.
91 *ibid*.
92 Rochow, p3.
93 *ibid*, p4.
94 McDonald, p12.
95 For example submissions from psychiatrists Dr Pia Brous and Name withheld.
96 Brous, p7. Name withheld, psychiatrist (oral evidence).
97 Name withheld, psychiatrist (oral evidence).
98 Brous, p7.
99 Department of Health and Community Services, *Victoria's Mental Health Service, The Framework for Service Delivery*, March 1994, p21.
100 Brous, p7.
101 Name withheld, psychiatrist (oral evidence).
102 Lyn Allison and Robyn Campbell (submission), p24.
103 Human Rights and Equal Opportunity Commission, *Human Rights and Mental Illness*, Report of the National Inquiry into the Human Rights of People with Mental Illness (1993) vol 2, Ch 20.
104 Brous, p5.
105 *ibid*.
106 Name withheld, psychiatrist (oral evidence). The Inquiry was subsequently told that by September 1995 funding to Monash Medical Unit had extended the existing adolescent unit by 10 beds.
107 Brous, p6.
108 Name withheld, psychiatrist (oral evidence).
109 Assoc Prof Patrick McGorry, Early Psychosis Prevention and Intervention Centre (EPPIC), Western Region Psychiatric Services (submission), p11.
110 Name withheld, psychiatrist (oral evidence). This point was also made in the submission by the Australian Youth Policy and Action Coalition.

- 111 Name withheld, psychiatrist (oral evidence). This point was also raised by Sandra Oliver, carer (submission).
- 112 Name withheld, psychiatrist (oral evidence).
- 113 Anne Boscutti, Older Adolescent Service, Royal Children's Hospital (submission), pl.
- 114 Name withheld, psychiatrist (oral evidence).
- 115 *ibid.*
- 116 *ibid.*
- 117 Rosemary West, carer (oral evidence), p189-190.
- 118 Name withheld, carer (oral evidence).
- 119 HREOC, Vol 2, Ch 17, p 516.
- 120 West, p190.
- 121 *ibid.*, p189.
- 122 *ibid.*
- 123 *ibid.*, p190.
- 124 Name withheld, carer (submission).
- 125 Bess McRae, Chair, Strathdon Community Council (oral evidence), p203.
- 126 Bobbie Trembath, Strathdon Community Council (submission), p3.
- 127 *ibid.*, p5.
- 128 Graeme Wallace, Friends of Strathdon (submission), pl.
- 129 Name withheld, carer (oral evidence).
- 130 McRae, p206.
- 131 West, p191.
- 132 *ibid.*, p192.
- 133 *ibid.*
- 134 *ibid.*, p190.

CHAPTER 5

Administration of medication in non-specialist residential facilities

I have often placed clients [in accommodation] who need intravenous medication as well as oral medication on a daily basis, and they have had to rely on either the lady who is cooking the dinner that night to assist them with administering their medication, or it may be the husband of the lady who is cooking the dinner... In some cases other residents have assisted my clients to administer their medication — other residents either being intellectually disabled or suffering from mental illness themselves.

The original National Inquiry established that people affected by mental illness face a critical shortage of adequate, affordable, secure and supported accommodation. In this context support means the general provision of meals, laundry and other services and particularly the provision of appropriately trained staff to supervise medication and continuing psychiatric follow-up.

Boarding houses and Supported Residential Services

A large proportion of housing for people with disabilities in Victoria consists of boarding houses and Supported Residential Services (SRS). SRSs, also called special accommodation houses, provide accommodation, catering and assistance with personal care including medication. They are privately owned but registered and regulated under the *Health Services Act 1988*. The regulations under the Act contain standards covering matters ranging from record-keeping to the administration of medication. At the time of the reconvened Inquiry's hearings Victoria had 282 SRS, providing about 8500 beds or 25% of the state's residential care places. The Inquiry was told most residents in this type of housing depend on a social security benefit and almost 40% have a psychiatric, intellectual or other disability.²

In addition there are some 300 private boarding houses that often provide similar services but are not subject to registration. They are governed by two statutes. The *Rooming House Act 1990* establishes tenancy arrangements, while the *Health Act 1958* specifies certain public health requirements. The *Health Act* does not address issues associated with the care and support of people with disabilities in boarding houses, since these are not classed as health services.

These unregistered establishments house large numbers of people with mental illness. In fact patients are frequently discharged from hospital directly into a rooming house.' Residents themselves may not know whether they are living in a registered SRS or an unregistered rooming house. In any case they often have little choice.

The accommodation options for those individuals, given the lack of community-based residential services, has to be for sheer shelter; [it] has to be private hotels or boarding houses because there just does not seem to be the quality of stock around.⁴

Both types of accommodation are funded entirely by fees paid by residents. The Inquiry was told the fees charged by SRSs are higher than those in ordinary unregistered boarding houses, since it costs more to operate an establishment that meets the standards required under the *Health Services Act*. The cost of room and board in the cheapest SRS is around the same amount as the disability or age pension. This means that most SRS residents spend their entire income on supported accommodation, with no money left over for clothing, transport or personal items such as newspapers or toiletries.

The lack of disposable income for SRS residents has been raised as a major concern by the Community Visitors, who are volunteers appointed under the *Health Services Act*. Without any money the residents are unable even to buy clothes from an 'opportunity shop' but must rely instead on the charity of the SRS proprietor.

In one SRS, a resident was quite proud of the 'new' shoes he had on. He said that one of the [other] residents had died and the proprietor had given them to him.'

The Community Visitors' 1994 Annual Report stressed that this level of poverty undermines the already fragile independence and self-esteem of these vulnerable individuals and leaves them open to exploitation or coercion. The Visitors pointed to the contrast with residents of nursing homes, which are funded and regulated by the Commonwealth. The Commonwealth guarantees that all nursing home residents have some disposable income by fixing the standard resident contribution at 87.5% of the combined age pension and rent assistance. The disposable incomes of residents in Commonwealth aged care hostels are also protected through a sliding fee scale which ensures that all residents retain at least 15% of the combined maximum age pension and rent assistance.

Faced with the high cost of living in an SRS, many people affected by mental illness choose instead to live in a boarding house or a caravan park, simply because the fees are lower. The Inquiry was told that discharge officers in the mental health system often place people directly into unregulated accommodation for the same reason. This is despite the fact that the support available in these places is almost always inadequate or non-existent.'

The principle behind the SRS regulatory scheme is that, if a dwelling houses at least two people on pensions and provides accommodation, catering and 'personal care' for a fee, it must register so that the care it provides will be subject to standards. An SRS can be inspected by the Department of Health and Community Services and prosecuted if found to be in breach of the standards.

A witness from the Department said that the standards were policed quite seriously. A number of SRSs had been deregistered, others were forced to make improvements and nine proprietors had been convicted of over 200 breaches.' SRSs are also able to be inspected by Community Visitors.

The scheme's limitation is that it only gives the Department power over houses that are registered. A boarding house that provides care to mentally ill residents is technically in breach of the law if it fails to register as an SRS. However, as long as it is not registered, the Department has no power of entry to determine whether in fact care is being provided and whether the boarding house should be registered as an SRS. While it is not registered, it commits no offence by failing to meet the standards of care. The scheme is effectively voluntary, with proprietors choosing whether or not they wish to be regulated.

I guess it is the old attitude, people who are relatively honest are subjected to the law. Those people who want to distort the law will do it anyway; and if I wished to contrive to set up a residential care establishment outside of the *Health Services Act* I could do it without any great problem.'

There is no incentive to register as an SRS. In fact there is a financial disincentive, as the cost of registering and meeting the standards can be significant. The Department does not promote registration and, despite its record of prosecuting breaches by registered SRSs, seems reluctant to bring more boarding houses into the scheme.

The Department.. .does not encourage landlords or proprietors of rooming houses or boarding houses to provide in-house support services, as this would change the nature of the housing and then require such houses to be registered as Supported Residential Services.'

It appeared to the Inquiry that this system works against the interests of people with psychiatric disabilities in two ways, discouraging the provision of services they need and discouraging registration. By adopting this approach the Department may be minimising its own regulatory workload at the expense of the vulnerable individuals it should be protecting.

The appalling conditions in boarding houses and private hotels documented in the earlier report continued to be reflected in evidence.

One man was talking to me about a boarding house in Hawthorn where the toilets and showers are cleaned only once a week, although there are upwards of 20 residents using those showers and toilets. He said the smell is — well, you can imagine, and the bathrooms are really very unhygienic. There is no privacy, shared bedrooms, it is very cramped, very lacking in space.¹⁹

Even in a registered SRS living conditions can be poor. The Community Visitors have reported that most of the SRSs they visit 'are run well and provide a good standard of care and accommodation' but 'a significant minority' are failing in this regard." Problems reported by the Community Visitors included overcrowding, an absence of privacy, residents performing unpaid labour and residents having to go 14 hours without food between dinner and breakfast. At least in these cases there is some chance the breaches will be detected and followed up, which is virtually impossible in an unregistered boarding house.

A particular concern to the Inquiry was the circumstances in which medication is provided.

There is undoubtedly reason for concern about medication management for persons who suffer chronic mental illness in any residential premises. These concerns [are] exacerbated when the accommodation option selected by or for the individual is an unregulated facility. There must therefore also be grave concern for the welfare of people who are discharged from the supportive environment of psychiatric facilities into the unassisted surrounds of the local caravan park, flat, hotel, or boarding house.'

Evidence presented on the provision of medication revealed two main areas of concern. The first related to the administration of medication by people who are unqualified or under-trained, including staff and fellow boarders. The other area involves the deliberate over-servicing of residents' medical needs, either to 'manage' their condition or to exploit the Medicare system for personal gain (in other words, Medicare fraud).

Unqualified administering of medication

Almost all boarding houses, private hotels and SRSs have some contact with the health system. Arrangements are often made with local general practitioners or nursing and other services to assist residents on a regular or ad hoc basis with their medication or to provide on-call back-up for proprietors. However, the task of supervising and dispensing medication generally falls to a person with no relevant qualifications or training.

Whilst many of the residents are responsible for their own medication and others are supervised by case managers from the local Community Mental Health Clinic, there were other consumers whose medication was supervised by the cook of the residence... He is clearly not qualified nor trained to be supervising psychotropic medications for people. 13

The Inquiry was told that the supervision of medication by unqualified staff of residential settings is not new. It has long been a side-effect of deinstitutionalisation.

In the 1960s and 70s the majority of long-stay patients were directly discharged to rooming houses, boarding houses, hostels and 'rest homes'... It was customary for many

proprietors of these places to retain and administer medication... It was seen to be the most effective method of ensuring that a resident would take prescribed medication.'

Some witnesses to the Inquiry pointed out that, since boarding house operators have no legal responsibility to look after their residents' medication, those who do are acting positively by filling a gap in the health and welfare network.

If medication is kept in the rooms of the residents, often it can be the subject of theft by other residents. So the management and the resident often agree mutually that medication be kept in the office under control of the management.'

The hotel manager is not dissimilar to the community sector 'unattached worker' in a single program, except there is not a management committee, colleagues to provide back-up and support, de-briefing, professional development opportunities, holidays nor a 40-hour week.¹⁶

However, a submission from the regulated sector insisted that mere kindness cannot be the basis of care.

[We are] perturbed by the extensive and inept placement of these persons, perhaps recovering from an acute episode of illness, into un-supportive accommodation where no provision for assisting them with their medication regime is 'officially' possible. Where such assistance is 'unofficially' given as an act of goodwill by the operator or their staff, there is no means of holding them accountable for any maladministration or other variations from the prescribed regime.'

Appropriate care

Witnesses giving evidence about medication agreed that there are widespread problems associated with unqualified care. However, some suggested that formally qualified care is not necessarily better and in some cases is not even preferred by people who depend on it.

Many residents, regardless of why, trust hotel management before they trust community sector representatives... Many.. were concerned that community workers were going to start to come in and tell them what to do.'

People with a mental illness who need to maintain a medication regime often prefer to rely on a familiar person rather than a support service offered by people they do not know.

It does not require a qualified psychiatric nurse to administer medication. VICSERV is aware that a number of participants in NGO psychiatric disability support services have nominated people they trust, such as neighbours, fellow residents, friends and family, to provide them with their medication during the times when they feel at risk of not taking it regularly.'

The question is how to protect from abuse people who prefer this informal assistance.

The real question concerns whether or not such administration is handled responsibly. The use of dosettes is a good way of ensuring that correct amounts are available for each time medication is due. The extension of clinical outreach services and availability of Continuing Care Teams and Mobile Support and Treatment Teams should ensure that non-clinical staff are properly instructed if such practices continue to occur. The ultimate aim should be to ensure that residents themselves are able to make their own decisions regarding who should administer medication.'

The witness from the regulated accommodation industry told the Inquiry that the level of staff training is likely to be higher in SRSs because a high proportion of proprietors are former nurses. The industry association has also helped design a new TAFE certificate course in residential care. This course is aimed at SRS workers but is not compulsory.²¹

In the regulated sector, the standards require SRS proprietors to take responsibility for the storage, distribution and administration of residents' medication. Generally oral medication is given from dosette boxes filled for each resident by a local chemist, so that SRS staff only have to follow instructions. There is no requirement that staff have any particular training, though there is usually some contact with health services. The Inquiry was told that these informal arrangements can lead to dangerous neglect.

Some special accommodation houses will have a nurse come in two times a week, or they will contact a GP to come and assist — but in many cases, we found that clients have run out of medication [for] up to five days because nobody has known how to get the medication filled. Or special accommodation houses are too frightened to bring themselves to our attention to say that they forgot to get the medication filled, because they are then afraid we are going to go and take action against them.'

This evidence indicates that the regulated SRS sector is not immune from problems relating to the incompetent administration of medication. In 1994 the Community Visitors reported several alarming situations, including one where medication was placed on residents' spoons on the dining table at 3pm each afternoon, creating a risk of people taking each other's medication.'

Reliance on medication

Another concern of the Community Visitors was the practice of SRS proprietors over-medicating residents with sleeping tablets. This was also raised in evidence to the Inquiry.

[Some] managers of special accommodation houses [make] unilateral decisions to alter the levels of medication according to their assessment of a resident's mental state. These same managers have been known to medicate and lock residents in their rooms for days. [Residents] absences from local psychiatric disability support services.. .have alerted their key workers who have then visited their participants at home, only to find them semiconscious.'

Proprietors face pressure because of the severe shortage of housing and services for people with mental illness. Evidence to the Inquiry suggested that the increase in homelessness among people with a mental illness and/or psychiatric disability has put enormous pressure on proprietors to manage the demand for housing.

A submission from the St Kilda Project, a non-government accommodation agency, referred to a review of the four largest private hotels in St Kilda. Up to 80% of residents had some form of mental illness and up to 90% of those had multiple or dual disabilities, as the use of alcohol and other drugs is prevalent.

25

Management has freely acknowledged that it is increasingly difficult to cope with the needs and demands of residents. As private hotels of some 10 years ago, they experienced a stable population group, often employed or otherwise occupied and who lived in privacy and managed their own needs. As a sole worker/operator 10 years ago, the demand on their time and the tasks they were expected to perform were manageable and more predictable.²⁶

The Crossroads Housing and Support Network also conducted a survey of five private hotels in the city and inner south areas of Melbourne. It estimated that in the last six months of 1994 there had been an increase of 30 to 60% in the number of individuals with psychiatric illnesses presenting for accommodation. This meant that up to 75% of residents in these facilities had a mental illness, forcing proprietors to turn away people in this group because 'it would be too many to handle.'

Another source of pressure on proprietors is the fact that mental health services often refuse requests for help. The Inquiry heard these two examples from hostels run by Catholic agencies.

[A man] who is now deceased, was observed to be extremely disturbed and needing psychiatric intervention, according to the staff of Avonsleigh [Hostel]. On 10 March [1994], Royal Park Hospital was approached but refused treatment, referring to the Alfred Hospital. The Alfred Hospital refused treatment, suggesting that Royal Park would be more suitable. On 11 March, the gentleman was placed in an ambulance by staff of Sacred Heart Mission and sent to the Alfred. The Alfred returned him to Avonsleigh by taxi. On 13 March, he was again sent to the Alfred by ambulance at 5.30 in the morning. The Alfred again sought to return him, but Avonsleigh refused; and finally he was admitted to Royal Melbourne on 14 March.

Ozanam community, an organisation of the St Vincent de Paul Society.. .reports similar experiences in getting seriously mentally ill people hospitalised when they are very seriously disturbed. They suggest that there is a need for a more effective intervention system before the crisis occurs. Royal Park Hospital will often refuse admission on the basis that no beds are available... Eventually the matter proceeds to more serious

situations where another resident or member of staff is assaulted, sometimes by a weapon.'

Hospital discharge practices are a further factor. Hospitals commonly discharge patients directly into a boarding house or SRS, regardless of whether appropriate care is available there. Sometimes the hospitals will not even provide case files or a discharge plan to assist hostel staff or the local general practitioner in caring for the mentally ill person.'

The attitude amongst 'Professionals' seems to be summed up in this comment — 'give them a handful of tablets and discharge them and let nature take its course.' The prevalent approach to discharge planning appears to be 'discharge and be damned'.'

Some people discharged from hospital are obliged to live in a specified place as a condition of a Community Treatment Order (CTO). The place specified in a CTO is often an unregulated accommodation facility. These CTOs are based on a fundamental contradiction. The discharge staff have recognised that the patient is so seriously ill as to justify a treatment order with a compulsory residential provision. Yet the place where they compel the person to live is exempt from any standards of care. The Mental Health Legal Centre told the Inquiry this frequently results in placements that are extremely inappropriate, both for the individual under the CTO and for the accommodation proprietor. It also leaves the proprietor in an impossible position if the resident ceases to pay rent or behaves badly enough to justify eviction, since the person is legally obliged to live there.³¹

Legislative reform

Calls for legislative reform in this area featured repeatedly in evidence to the Inquiry. Some witnesses, however, warned of the potential side effects of new legislation. The executive director of VICSERV observed that 'a blanket ban on non-clinically trained persons administering medication to residents would be both undesirable and unworkable'.³²

The danger is that stricter regulation could result in the deregistration or closure of SRSs that do not meet the training requirement, exacerbating the housing shortage. This is already a consideration in the minds of public servants enforcing the existing law.

We cannot really afford to be taking action against them, because if we move them out of there, we have got nowhere else to put them. So we tend to have to close our eyes to a lot of things that we would not otherwise tolerate, because of the fact we absolutely have nowhere else to put people. It is a bit of a revolving door syndrome.'

Deregulation of nursing homes

Nursing homes house considerable numbers of people affected by mental illness. Nursing homes were previously also regulated under the *Health Services Act*, which gave the residents the same range of protections applying in an SRS. In 1994 the Act was amended to remove nursing homes and hostels from its coverage, thereby completely deregulating the provision of aged care services in Victoria. The Australian Nursing Federation (ANF) told the Inquiry that Victoria is now the only state or territory which does not have legislation requiring any nursing qualifications among the staff of a nursing home. While Commonwealth funding of nursing homes prescribes that a proportion of staff be qualified, it is not a legislative requirement. The only recourse for the Commonwealth if a nursing home breaches the requirement under funding arrangements is to withdraw funding. This does not address the problem of providers operating without qualified staff.

There are now no regulations arising from either the state or Commonwealth [law] requiring qualified staff. The premise on which this is based is that patients/residents with permanent disabilities are not 'sick' but merely disabled and therefore do not need care based on the medical model, but rather require assistance with 'personal care' and with 'activities of daily living'. The effect of this is to put residents at risk and displace nurses from legitimate employment.'

In one particular nursing home affected by the legislative change,

There is a list of residents who require nursing interventions on a daily basis... Things such as the administration of morphine, numbers of residents who suffer from manic depression and are often suicidal, the giving of blood, frequent episodes of epileptics who have had fits and require medical and nursing treatment, numbers of residents who suffer from the giving of incorrect medication — all by unqualified staff. "

The ANF listed the number and severity of mistakes made in the nursing home, including one person being given another person's medication, in some cases repeatedly."

Over-servicing

The practice of a general practitioner overseeing medication in boarding houses has been common for many years. In the absence of organised support services, a local doctor often provides clinical back-up for residents through informal arrangements with proprietors or managers. The Crossroads survey of five inner-city private hotels showed that all the proprietors canvassed saw local doctors as their sole supports. Ambulances, police and occasionally the CAT teams were sometimes involved but the general practitioners were the only regular contact the residents had.'

Evidence to the Inquiry emphasised the importance of general practitioners maintaining contact with mentally ill residents. However it also suggested that the informal arrangements between accommodation proprietors and general practitioners can provide an environment conducive to over-servicing, leading to over-prescribing and possible Medicare fraud.'

Over-prescribing

There is a lack of understanding on the part of the medical profession where dual disability is concerned. The tendency is to over-medicate.'

Doctors not trained specifically in treating mental illness may tend to over-prescribe, on one hand as a precautionary measure and on the other hand to assist proprietors and managers in coping with particularly difficult residents.

There is an excessive reliance on drug usage to pacify and moderate the behaviour of Alzheimers patients who are residents of hospitals and hotels. This seems to be done to reduce the need for staffing for residents who naturally have a high dependence...A patient's boredom, restlessness and inactivity tend to be 'medicated away. 40

The Crossroads survey also highlighted the practice of over-medicating.

Further evidence [suggested] over-servicing and over-medicating the residents in private hotels by two GPs operating in the inner south and CBD area.'

Even where specialist support is available to residents, the informal arrangements under which it is provided can attract practitioners who operate negligently or improperly.

A psychiatrist who had a large caseload of dual disability [patients] was deregistered recently as he was not even qualified.. .He had caused some horrific damage to some of our clients.. .by mis-medicating.'

Medicare fraud

The other category of over-servicing involves Medicare fraud, where unscrupulous practitioners take advantage of a vulnerable population, often with the complicity of proprietors who benefit from having a more manageable establishment. Several submissions gave evidence of this.

An Inner South GP...had, in the past, visited special accommodation houses and rewarded residents with chocolates and cigarettes if they signed the requested number of Medicare forms.'

There is also evidence of doctors visiting residents, bulk-billing and providing no care.'

One manager recalled having to ask a GP to stop visiting the residents as they were being doubly medicated.'

Conclusion

Some of the most disturbing evidence to the Inquiry related to the standards of care for mentally ill people living in boarding houses and SRSs. The protection intended in the *Health Services Act* is not always afforded. Nevertheless, the Inquiry concluded that conditions of care, including those relating to medication, are more likely to be acceptable in an SRS than in an unregistered boarding house or hostel. In addition, abuses are more likely to be discovered in regulated accommodation.

The existence of the regulatory scheme is an acknowledgement by the Government that people with severe psychiatric and other disabilities need legal protection. Yet the Department of Health and Community Services routinely places patients who are being discharged from psychiatric wards into unregulated private hotels and rooming houses. It has no responsibility for what occurs in these houses because they are in the private sector, but at the same time it discourages upgrading into registered SRSs. This approach to the care of vulnerable individuals is unacceptable from both a clinical and a human rights perspective.

The price structure of accommodation services leaves impoverished mentally ill people an invidious choice between cheaper but unregulated, unsupportive accommodation and accommodation in an SRS with no disposable income. The inequity is highlighted by a comparison with nursing home and aged care hostel residents, who are guaranteed by the Commonwealth to retain a percentage of their pension as disposable income. Supported accommodation is intended to allow people with mental illness to live relatively normal lives in the community, but the absence of any disposable income diminishes their dignity and makes them as dependent on the proprietor as they would be in an institution. It is not surprising that many people choose an unpleasant, unregulated rooming house when faced with these options.

Hospital social workers deciding where to discharge patients may also be influenced by this financial consideration. They frequently discharge consumers directly into unregulated accommodation out of concern for their finances, even though they know the conditions will be detrimental to mental health. The Inquiry considers that discharge staff should not have to compromise on quality of support to allow a patient to retain enough money for expenses such as clothing and transport. It is not acceptable for a mental health care plan or Community Treatment Order to impose such a limitation on the patient.

1 Name withheld, public servant (oral evidence).
2 Patrick Bowden, National Association of Nursing Homes and Private Hotels (oral
evidence), p260.
3 Paul McDonald, Crossroads Housing and Support Network (oral evidence), p18; William
Moon, Citizen Advocacy Program Western Region Inc (submission), p4-5.
4 McDonald, p18.
5 *Annual Report of Community Visitors 1994*, Office of the Public Advocate, p40.
6 Bowden p267-268; Name withheld, public servant, (oral evidence).
7 David Green, Department of Health and Community Services (oral evidence), p299.
8 Bowden, p263.
9 Green, p300.
10 Belinda Thurlough, Victorian Mental Illness Awareness Council (oral evidence), p72.
Similar evidence and submissions came from VICSERV, the St Kilda Project and Name
withheld, public servant (oral evidence).
11 *Annual Report of Community Visitors 1994*, p2.
12 National Association of Nursing Homes and Private Hotels (submission), p6.
13 Victorian Mental Illness Awareness Council (submission), p9.
14 Dr Lyn McKenzie, VICSERV (submission), pl.
15 Peter Norden, Melbourne Catholic Social Services (oral evidence), p96-97.
16 Marg Welsh, St Kilda Project (submission), p3.
17 National Association of Nursing Homes and Private Hotels, p6.
18 Welsh, p3.
19 McKenzie, p3.
20 *ibid*, p3-4.
21 Bowden, p266-267.
22 Name withheld, public servant (oral evidence).
23 *Annual Report of Community Visitors 1994*, p103.
24 McKenzie, p4.
25 Welsh, p1.
26 *ibid*, p3.
27 Crossroads Housing and Support Network (submission), p4.
28 Norden, p97.
29 *ibid*, p96; McDonald, p18.
30 National Association of Nursing Homes and Private Hotels, p6.
31 Mental Health Legal Centre (submission).
32 National Association of Nursing Homes and Private Hotels, p4. A similar point was made
by Lyn Allison and Robyn Campbell, Australian Democrats (submission), p13-14.
33 Name withheld, public servant (oral evidence).
34 Australian Nursing Federation (submission), p14.
35 Jill Clutterbuck, Australian Nursing Federation (oral evidence), p271.
36 Australian Nursing Federation, p6-11.
37 McDonald, p10.

- 38 ibid; Name withheld, public servant (oral evidence); McKenzie (oral evidence), p275;
 Allison (oral evidence), p118; Welsh, pl.
- 39 Name withheld, public servant (oral evidence).
- 40 Ted Bryan, carer (submission), pl.
- 41 McDonald, p10.
- 42 Name withheld, public servant (oral evidence).
- 43 McKenzie (submission), p4.
- 44 Allison (oral evidence), p118.
- 45 McDonald, p10.

CHAPTER 6

Other significant issues raised in evidence

Who is 'the community'? In my case it's me and when things get beyond me, the police — or if you're lucky enough, a close-knit community of local shopkeepers and doctors who are aware of the problems and try to help where they can.'

The inadequacy of the mental health system has forced an enormous burden of care onto individuals and organisations lacking the skills or resources needed to deal with people who are severely disturbed. Chapter 5 outlined the consequences of this burden falling on the proprietors of boarding houses and Supported Residential Services. Evidence to the Inquiry also highlighted the role played by two other groups of 'service providers', family carers and the police.

Burden on families

Anyone who has had to use (or has tried to use) our mental health system talks of the utter frustration of trying to get the help they know their children need.'

The failure by the mental health system to meet the needs of people with severe mental illness is largely hidden because families take responsibility for their care beyond their ability to cope. Family carers who gave evidence to the Inquiry expressed the frustration, isolation, bewilderment and fear experienced by those at the 'frontline' dealing with chronic or acute mental illness.

I have been trying to get the CAT team to attend when my son is at home smashing the house literally to pieces, breaking every window and pouring his blood all over the house.. unbelievable scenes at home and I am expected to cope with it.³

Family carers generally have no training, no funding, no respite, very little information and often no back-up from professional mental health agencies. Yet they are frequently required to provide basic services to mentally ill people in need of professional assistance. These services include accommodation, rehabilitation, counselling, 24-hour supervision, administration of medication and often physical restraint of a person who is severely disturbed. Apart from the practical difficulties involved, filling this role is particularly distressing for a family carer who lacks the professional detachment of a qualified mental health worker.

We, the parents must have some sort of back-up. In my case, I'm a 64-year-old parent and the only parent he has, but it still gets too much at times for me to handle on my own when a crisis situation occurs.'

The load on family carers would be far less onerous if they felt it was shared with mental health professionals whom they could call on for assistance.

Evidence to the Inquiry suggested that family carers feel very much on their own. For example, one mother described her isolation in seeking help for her son.

I was ignored by everyone I turned to for help. I was left, always feeling that I was a raving lunatic myself... From the age of 16 years old I watched my son totally self-destruct and felt so hopeless.'

Several carers referred to the extremely restrictive eligibility criteria that prevent them from getting help from mental health services until their loved one's condition deteriorates into a crisis. These criteria include the 'serious mental illness' threshold and the exclusion of people with dual disabilities from services designed for individual disabilities. The harmful consequences suffered by mentally ill people as a result of these criteria are discussed in Chapter 3. Witnesses pointed out that the criteria also inflict great suffering on carers, who are left to deal with the spiralling mental state of patients considered not yet sick enough to qualify for assistance.

This failure to give help early on in the development of the illness is leading to all the sorts of terrible trauma that our families experience, and often to the development of violence in a person who would not normally be violent.'

Another theme in family carers' evidence was frustration that when a mental health service does intervene their insights as primary carers are trivialised or ignored.

My experience this year.. .has been that whilst some of [the CAT team] are good and caring, most of them tried to shut me out, as a carer, concentrating mainly on medication and my son's physical feelings and reactions to the medication. I was a nobody.'

Police involvement

The police are here to protect us against dangerous criminals, not psychiatric patients. Although sometimes it can seem like the same thing, given that they're not given proper care for long enough and no proper aftercare.'

Many witnesses and submissions to the Inquiry stressed the urgent need to improve the skills of police officers in dealing with seriously mentally ill people.' This issue was especially topical at the time of the hearings because a report had recently been released by the task force on police shootings.'

The Inquiry was told that the task of coping with acute psychiatric episodes had been imposed on police because of the lack of resources for community mental health support. This occurred in two ways. Large numbers of people with a mental illness came into the criminal justice system when, due to lack of treatment, they became so disturbed that they committed an offence. In addition, carers reported that the lack of early intervention or crisis support meant they

must often phone the police for assistance in dealing with a disturbed family member.

One carer recounted to the Inquiry his experiences with police during his son's acute episodes of mental illness. He said he had found many police to be 'excellent, caring and considerate'.

Many is the time when police intervention has saved my son's life, and saved my sanity probably when there was no-one else .¹¹

However, he said that at other times 'police involvement has been frightening and inappropriate'.

Many is the time I have pleaded with the police that my son does not need a pistol waved in his face, what he needs is proper management... Because I [have] learned how to manage him and not to confront him, but to act towards him with love and care and concern, and then he is manageable.

So I have pleaded with the police not to use any threat of violence or any firearms with my son. One policemen said to me, 'If he rushes us.. we are going to shoot him.' Another policemen, when I begged him, 'If you are going to shoot my son please shoot him only in the leg,' and I thought, what am I saying? The policemen pointed to the space between his own two eyes and said, 'I shoot here if I shoot.' I just again had to pray that my son would not misbehave with the police there because I was worried they would shoot him.¹²

Evidence such as this clearly shows the need for education of police officers, who may lack not only conflict resolution skills but also understanding of people affected by mental illness and their families.

The Inquiry was also told that procedures for dealing with mentally ill people in police custody are unacceptable.

My son has been locked up in these monkey cages that are called police cells on several occasions, and if you are psychiatrically disturbed or whatever and you get stuck in one of those monkey cages, it is a really good reason to hang yourself — because there could not be many places more depressing than some of those police lockups.

[At] one police station.. I said to the head policeman, 'My son is very suicidal, please watch him.' He said to me, 'Look mate, if he hangs himself that is one less we have to worry about.' That is an exact quote.¹³

One mother called the police because she was afraid of what her son might do. She told the Inquiry,

The officer in charge listened to me and.. promised my son would see a police doctor that night. This promise was repeated to me two or three times before he left my home. It was two weeks later before my son saw a doctor... My son spent those two weeks in three different city cells before his condition was noticed by anyone and a doctor called

in.... While in the city cells my son was beaten, which I presume was an attempt to make him conform. I am well aware that the way my son was treated is common and happens more than one would like to believe.'

In August 1995, nine months after his mother made her submission to the Inquiry, this young man was shot dead by police.

Witnesses called for better police training.

There is a serious concern, long recognised by the wider community and only now being recognised by police command, that police have been inadequately trained to deal with persons with severe behavioural disturbance. Police cannot be expected to act as psychiatric professionals, but there is clearly a greater need for police to be trained to recognise the symptoms of mental illness.'

The need for training was also the focus of recommendations from the task force on police shootings. However, several witnesses to the Inquiry pointed out that police can never be expected to replace professional psychiatric workers. The director of the Mental Health Legal Centre stressed that mental illness is a health issue, not a criminal justice issue, 'and we need to have a health team responding with the police to those emergencies' ¹⁶ This view was echoed by a carer who said,

Don't blame the police force... It [should be] fairly and squarely on the Health Department's agenda."

The Inquiry approached the Victorian Health Department on this matter in preparation for this report and was told that a protocol between Victoria Police and Psychiatric Services had been established in October 1995. The Inquiry was also told that the Department provides training sessions for police on understanding mental illness.

Conclusion

Large numbers of people affected by mental illness are cared for by family members or close friends. These carers are essentially providing a safety net for those individuals who fall between services. This may be acknowledged by the Government, but little or no support is provided to the family carers. In fact, the mental health system aggravates carers' feeling of abandonment by turning them away when they seek assistance. The role of carers in mitigating the pressure on government and community sector resources should not be underestimated. The Government should recognise this by resourcing back-up, respite and crisis services more adequately.

Better resourcing of services to assist carers would also ease the pressure on police to respond to crises involving people with mental illness. Training police to handle such situations better is clearly of paramount importance.

Collaborative response teams combining police and psychiatric services should be further developed and adequately resourced as a fundamental element of deinstitutionalisation. These are, however, reactive strategies that do not address the source of the problem. The Government is responsible for the shortcomings in mental health service delivery and must address the detrimental aspects of its reform agenda.

- 1 June Gay, carer (submission), pl.
- 2 Angela Incigneri, carer (submission), p2.
- 3 Name withheld, carer (oral evidence).
- 4 Gay, pl.
- 5 Colleen Simon, carer (submission), p2.
- 6 Dr Margaret Leggatt, Schizophrenia Fellowship of Victoria (oral evidence), p55.
- 7 Gay (attachment to submission).
- 8 *ibid*, p2.
- 9 For example Gay; Simon; Name withheld, carer (oral evidence); Margaret Bayliss, carer (submission); Penny Drysdale, VMIAC (oral evidence); Peter Norden, Melbourne Catholic Social Services (oral evidence); Jenny Gee, Mental Health Legal Centre (oral evidence); Name withheld, public servant (oral evidence).
- 10 *Police Shootings — A Question of Balance*, Report of Task Force Victor, 21 October 1994.
- 11 Name withheld, carer (oral evidence).
- 12 *ibid*.
- 13 *ibid*.
- 14 Simon, pl. The inadequate procedures for dealing with people in police custody were also raised by Lyn Allison, Australian Democrats (oral evidence), p116.
- 15 Norden, p98.
- 16 Gee, p86. This point was also raised by Norden, p98.
- 17 Gay, p2.

CHAPTER 7

Findings and Recommendations

General findings

- Victoria's mental health system is not meeting the demands placed on its services. Although Victoria still has the highest per capita spending on mental health, overall mental health expenditure has declined. Mental health workers, advocates, consumers and carers describe the service delivery as severely overstretched. This is the case particularly for prevention and early intervention services.
- The predominant medical model places an over-reliance on clinical labels to the exclusion of psychosocial and environmental factors in the diagnosis, care and treatment of people with a mental illness.
- Service over-loading and clinical labelling have produced narrow eligibility criteria for treatment based on an abstract definition of 'serious illness' rather than functional need.
- The changes in the mental health system have been accompanied by fragmentation of mental health services, a lack of coordination in service delivery and demands on the community sector that it has been unable to meet.
- Large numbers of people affected by mental illness are cared for by family members or close friends. These carers provide a safety net for those individuals who fall between services. They are often forced to provide care beyond their ability to cope.
- Carers, consumers and their advocates say they have been marginalised in the policy making process. They report that their views are consistently ignored or rejected by the Deputy latent of Health and Community Services (the Department) and by service providers.
- Witnesses spoke of a climate of intimidation that has inhibited mental health workers and advocates from voicing their concerns about the mental health system.

General recommendations

- Specialist services which have been absorbed by mainstream services should be resourced at a level that guarantees effective service delivery.

- The Government and non-government service providers, in consultation with specialists, community workers, consumers and carers, should develop an effective referral system between services. The focus should be on ensuring continuity of care for vulnerable people at the points of entry to and exit from hospital.
- More flexible and responsive service delivery is required for particularly vulnerable people who have a mental illness. Service providers, carers and consumer groups should develop a joint strategy to address the limitations of the medical model approach to treatment and care.
- The Commonwealth should vigorously pursue the project of developing national standards for mental health services, as outlined in the National Mental Health Strategy.

Intimidation of those advocating on behalf of the mentally ill or criticising the adequacy of services (Chapter 2)

Findings

- Some professionals and other mental health workers who have criticised the adequacy of the mental health system have been punished or dismissed. Others are afraid to speak out. Some individuals and organisations advocating on behalf of the mentally ill have also suffered retaliatory and intimidatory treatment.
- The Department's defensive response to criticism has eroded staff morale, harmed the quality of clinical care and prevented the Department from receiving important feedback about problems in mental health service delivery.
- People without clinical skills or experience are increasingly responsible for mental health policy and services.

Recommendations

- The Department should establish and promote effective processes for mental health workers to voice their concerns. These should include consultation processes, complaint and review mechanisms and procedures for investigating allegations of intimidation.
- Independent complaints authorities such as the Ombudsman and Public Advocate should be adequately resourced and staffed with officers whose independence is well accepted by community organisations and health care professionals.

- The Department should consult urgently with clinical professionals, service providers and their associations, carers and consumer organisations about the best way to resource the mental health system.
- The Department should ensure that people with experience in psychiatric services, particularly people with clinical skills, are placed in positions with direct input into policy making and coordination.

Consultation with non-government agencies, consumers and carers (Chapter 3)

Findings

- Consumer and carer advocacy groups are legitimate and important participants in the mental health policy process, independent of non-government service providers.
- The views of consumers and carers, who are central figures in the mental health system, are not adequately taken into account in government decisions about the system.
- Advocacy groups feel their criticisms of the mental health service are not considered on their merits but rather are perceived as an attack on the Department.
- Consumers have been denied the care and treatment they need due to ineligibility, inaccessibility or unavailability of services.

Recommendations

- The Victorian Government should broaden its advisory committees on mental health services to ensure more effective consultation and representation. In particular:
 - the major consumer advocacy groups should have membership on all advisory committees;
 - the membership of all advisory committees should be made public, as well as each member's organisational affiliation; and
 - mental health advocacy groups should be able to find out what decisions have been made by advisory committees and how to contact their members.

- The Department and service providers should base criteria for treatment on the individual's functional need, rather than simply on a narrow medical diagnosis of 'serious mental illness'.
- The Department should fund a project to examine ways of ensuring that carers are informed about their mentally ill relative's condition, and how information provided by carers can be taken into consideration in assessment and treatment decisions, while still respecting the rights of patients to have maximum control over their own lives.

Adequacy of services for especially vulnerable or disadvantaged groups (Chapter 4)

Homeless people

Findings

- Mental illness is extremely prevalent and largely untreated among homeless people. They encounter a severe lack of community support services and a shortage of appropriate and affordable accommodation.
- Hospital discharge practices often do not include organising accommodation or aftercare.
- Because of their circumstances, homeless people with mental illness have special needs which can be particularly costly to meet. For example, being discharged too early from hospital has extremely serious consequences for homeless people, and their need for aftercare is especially acute. In addition, they need more intensive support and monitoring in their treatment. They are often transient, which can exacerbate mental illness.
- The lack of appropriate accommodation and aftercare for people discharged from hospital is placing the burden of care on family members for relatives who would otherwise become homeless.

Recommendations

- The Government should ensure better coordination of resourcing of mid-to-longer term supported accommodation for people discharged from institutional care. It should provide funding incentives and other initiatives for this purpose. The Departments of Housing and of Health and Community Services should cooperate in this.
- The Government should direct additional funding to community mental health services so that they can respond effectively to the demands made

on them as a result of deinstitutionalisation. This funding should be directed to achieving specified outcomes.

- Discharge plans and summaries should include consultation with local accommodation providers and informing community mental health centres of people discharged into local accommodation. Confidentiality should also be safeguarded in this process.

People with dual or multiple disabilities

Findings

- Very large numbers of people affected by mental illness also have another disability.
- There are very few crisis support or other mental health services available to assist people with dual disabilities. This is exacerbated by the fragmentation and under-resourcing of general mental health services.
- People with dual disabilities are particularly vulnerable to inappropriate diagnosis and treatment, prolonged or compounded mental illness, as well as abuse and degrading living conditions.
- Specialist psychiatric training in the diagnosis, care and treatment for people with a dual disability is rare. Consequently the understanding of the needs of this group of people within mental health and other services is very poor.

Recommendations

- The Government should direct additional resources to mental health, disability, drug and alcohol services to encourage better coordination of service delivery and allow for a broadening of eligibility criteria. Alternatively, resources should be directed towards establishing services specifically for people with dual disabilities.
- The Department should ensure equality of delivery within services. For example, where deaf patients are placed with hearing patients, appropriate equipment and interpreters should be available to ensure an equal range of treatment options.
- The Commonwealth and Victorian Governments should fund research and training initiatives to further the sub-specialties of psychiatry concerned with dual disability. Universities and other institutes should accord greater priority to research and training in these areas.

People from non-English speaking backgrounds

Findings

- Mentally ill people from non-English speaking backgrounds are more likely to be acutely ill when they first come into contact with the mental health system.
- Mainstream services tend to under-use interpreters or not use interpreter services appropriately. As a consequence there is an over-reliance on medication in treating people from this group.
- Current reforms to the mental health care system exacerbate the low usage rates by people from non-English speaking backgrounds because of stricter catchment areas which limit referral options.
- The lack of appropriate mental health services for people from non-English speaking backgrounds places inordinate strain on general practitioners.
- Very little is known about how mental illness manifests and impacts on members of different ethnic communities.

Recommendations

- Staff who are multilingual and have training in cross-cultural issues should be recruited in departmental areas responsible for mental health policies, program planning and service delivery.
- The Commonwealth and Victorian Governments should ensure adequate resourcing of interpreter services (including sign language interpreting) for hospitals, community mental health services and doctors' surgeries. Interpreters should receive training in mental health issues and terminology.
- Where appropriate the Department should allocate bilingual case managers to mitigate the effect on people of non-English speaking backgrounds of rigid area divisions imposed by regionalisation of mental health services.
- The Victorian Government should develop incentives for doctors from non-English speaking backgrounds to specialise in psychiatry.
- The Commonwealth and Victorian Governments should continue to encourage investment in research on the incidence, treatment and impact of mental illness on non-English speaking background communities.

Women

Findings

- Women who have a mental illness are at risk of losing custody of their children if they seek treatment.
- There is a shortage of inpatient facilities that can accommodate women and their children, especially older children.
- Women with mental illness are particularly vulnerable to sexual and physical abuse in inpatient facilities and mixed-sex accommodation.

Recommendations

- The Department should provide education about mental illness and parenting to social workers, lawyers and other staff of child protection services and children's courts.
- The Department should fund the establishment of a residential facility suitable for women with children, especially older children, in association with a major psychiatric service.
- Major psychiatric facilities should establish women-only wards for vulnerable female patients in hospital.
- Psychiatric facilities should adopt better measures to ensure the safety of women in mixed-sex wards, including effective complaint mechanisms, staff training and, where appropriate, referral to police.
- Women-only Supported Residential Services should be established to enable more appropriate placement of women discharged from hospital.

Children and adolescents

Findings

- Due to a lack of appropriate services, adolescents and children are being placed in services designed to cater for adults with a mental illness.
- For large numbers of people the onset of mental illness occurs during adolescence, yet adolescent mental health services are one of the areas most poorly served.

Recommendations

- The Department should fund adolescent services as the best preventive and early intervention programs.

- Major psychiatric facilities should guarantee adolescent-only settings staffed by appropriately skilled professionals.
- The Government should vigorously support model services such as EPPIC and similar initiatives.
- The Department should re-adjust its definition of 'adolescence' to increase the age limit from 16 to 18 years.
- The Government should restore funding to school-based assessment services to ensure early detection and intervention of mental illness in young people and enable effective referral and follow-up.

Elderly people with dementia

Findings

- The severe shortage of dementia-specific services makes people with dementia vulnerable to inappropriate and at times abusive treatment.
- Carers of elderly people with dementia require more respite and other support services, such as home help and day care.

Recommendations

- The Commonwealth Government should lift the level of funding for dementia facilities to that of nursing homes.
- Through Home and Community Care funding, the Victorian Government should increase and improve services for people affected by dementia to:
 - make it possible for them to be accommodated at home for as long as possible, where appropriate;
 - enable carers to receive appropriate levels of assistance; and
 - provide more psychogeriatric services in mainstream accommodation.
- The Victorian Government should ensure top-up funding for facilities where it is needed.
- Any aged accommodation facility that includes people with dementia among its residents should ensure its staff have psychogeriatric training.

Administration of medication in non-specialist residential facilities (Chapter 5)

Findings

- Medication is handled better in Supported Residential Services than boarding houses because registration imposes statutory standards. For the same reason, the standard of accommodation and support is also likely to be better in SRSs.
- Large numbers of unregistered boarding houses accommodate people who have a mental illness and require assistance with medication.
- Some Supported Residential Services currently charge 100% of the pension for food and accommodation. This price disincentive pushes many people with a mental illness into unregulated boarding houses where fees are lower but conditions are worse.

Recommendations

- The Victorian Parliament should extend the Health Department's statutory powers to allow inspection of boarding houses to determine whether they should in fact be registered.
- To make registration effective, the Department should allocate funding specifically to monitor and enforce registration requirements and standards.
- The Victorian Government should pay a subsidy to Supported Residential Services for each resident referred by the Health Department. In return for this subsidy, SRSs should be required to limit the fees charged to these residents to ensure that they retain an adequate proportion of their pension as disposable income.
- While it is not feasible to require every Supported Residential Service to have a qualified nurse on staff, registration should require that a percentage of staff have a minimum level of training in dealing with mental illness and specifically in the use and administration of medication.
- The Department should encourage better protections for individuals residing in boarding houses and other unregistered accommodation by resourcing hospitals and community mental health services to coordinate discharge plans.

- The Department should ensure that people discharged under a Community Treatment Order are not placed in an unregistered facility under any circumstances.

Other significant issues raised in evidence (Chapter

6) Findings

- The burden of providing services to people with a mental illness is increasingly falling on non-medical service providers, such as families, police and accommodation providers, who do not have adequate training or support.
- There are not enough services that can provide the necessary information, support and respite to carers.

Recommendations

- As part of the new protocol between Victoria Police and Psychiatric Services, the Government should ensure adequate resourcing to enable psychiatric teams to accompany police attending all emergencies involving a person with mental illness.
- The Department should rigorously evaluate the effectiveness of training given to police about the needs of people with a mental illness who come into contact with the criminal justice system.
- As part of the process of deinstitutionalisation, the Government should ensure adequate resourcing of community support services to enable consumers and carers to receive appropriate levels of assistance.

APPENDIX

WITNESSES APPEARING BEFORE THE RECONVENED INQUIRY

MONDAY 5 DECEMBER 1994

Lyn Allison	Researcher, Australian Democrats
Michael Cully	President, Australian & New Zealand College of Mental Health Nursing, Victorian Branch; Lecturer in Nursing, University of Ballarat
Dr Julian Davis	Psychiatrist, St Vincent's Hospital; Lecturer in Psychiatry of Intellectual Disability, Melbourne University
Penny Drysdale	Coordinator, Victorian Mental Illness Awareness Council (VMIAC)
Jenny Gee	Director, Mental Health Legal Centre
Dr Margaret Leggatt	Director, Schizophrenia Fellowship of Victoria; Secretary, Schizophrenia Foundation of Australia
Paul McDonald	Program director, Crossroads Housing & Support Network, Salvation Army
Peter Norden, SJ	Associate director, Melbourne Catholic Social Services
Belinda Thurlough	Advocacy worker, Victorian Mental Illness Awareness Council (VMIAC)
Rosemary Webster	President, Schizophrenia Fellowship of Victoria

TUESDAY 6 DECEMBER 1994

Patrick Bowden	Executive director, National Association of Nursing Homes & Private Hospitals
Stan Capp	Chief executive, Morningson Peninsula Hospital
Jill Clutterbuck	Australian Nursing Federation, Victorian Branch
David Green	Director, Aged Care Division, Department of Health & Community Services
Dr David Leonard	Director of Clinical Services, Morningson Peninsula Hospital
Dr Lyn McKenzie	Executive officer, Psychiatric Disability Services of Victoria (VICSERV)
Bess McRae	Chair, Strathdon Community Council
Assoc Prof Harry Minas	Director, Victorian Transcultural Psychiatry Unit, University of Melbourne
David Plant	Executive officer, Australian Psychiatric Disability Coalition
Rosemary West	Carer
Jennifer Williams	Director, Psychiatric Services, Department of Health & Community Services

PRIVATE HEARINGS

Name Withheld (Nine witnesses)

SUBMISSIONS

Anonymous	Concerned psychiatric worker
Anonymous	Relative
Anonymous	Carer
Anonymous	Carer
Anonymous	Service provider
Anonymous	Consumer
Access Employment, Mildura	
Rev Julian Ahem	Minister
Lyn Allison and Robyn Campbell	Researchers, Australian Democrats
Australian Nursing Federation, Victorian Branch	
Australian Youth Policy & Action Coalition (AYPAC)	
Malcolm Barr	Consumer
Margaret Bayliss	Carer
John Beavis	Consumer
Graeme Bond	Carer
Anne Boscutti	Older Adolescent Service, Royal Children's Hospital
Phyllis Bourke	Carer
Patrick Bowden	National Association of Nursing Homes & Private Hospitals Inc
Dr Pia Brous	Child/adolescent psychiatrist
Heather Brown	Consumer
Ted Bryan	Carer
Alex Bums	Director, Psychiatric Care Consultants Pty Ltd
Prof Graham Burrows	Royal Australian & New Zealand College of Psychiatrists
Chris Campbell	Victorian representative, Citizens' Commission on Human Rights
Christine Cleary	Researcher (student), Monash University
Isabell Collins	Victorian Mental Illness Awareness Council
Tony Creedon	Mental Health Lobby Group
Crossroads Housing & Support Network, Salvation Army	
Michael Cully	President, Australian & New Zealand College of Mental Health Nursing, Victoria Branch; Lecturer in Nursing, University of Ballarat
Barbara Denton	Researcher, La Trobe University

Disability Action Network (Sunraysia Branch)	
Carolyn Dixon	Chair, Mental Health Issues Group
Neville Dusting	Consumer
Cathy Dwyer	Researcher, Victorian Deaf Society and Victorian Council of Deaf People
Executive of the Statewide	Senior Occupational Therapists in Psychiatry
June Gay	Carer
Pamela Fitzpatrick	Member, Mental Health Issues Group
Warren Fraser	Industrial officer, State Public Service Federation (SPSF)
Jenny Gee	Mental Health Legal Centre
Dr FW Graham	Associate, Department of Psychological Medicine, Monash University
Paul Hill	Consumer
Gerry Hoogenboom	Psychiatric nurse
Margaret Hutson	Carer
Angela Incigneri	Carer
Carol Jackson	President, Australian Association of Trauma & Dissociation
Patricia Jeffries	Carlton Collingwood Fitzroy District Health Service
Valerie Jenkins	Consumer
Victor Kardasz	Consumer
Valerie Laszlo Dr	Consumer
Margaret Leggatt	Executive director, Schizophrenia Fellowship of Victoria; Secretary, Schizophrenia Foundation of Australia
Dr David Leonard Dr	Director, Clinical Services, Mornington Peninsula Hospital
Nicholas Lennox and Dr Robert Chaplin	Department of Public Health & Community Medicine, University of Melbourne; and St Georges Hospital, London
Bronwyn Leschke	Health worker
Margaret Manno	Group convenor, Mill Park Family Support Group for Schizophrenia
Rachael Martin	Dentist, Inner South Community Health Service
Timothy Martin	Consumer
Assoc Prof Patrick McGorry	Director, Early Psychosis Prevention & Intervention Centre (EPPIC), Western Region Psychiatric Services
Dr Lyn McKenzie	Psychiatric Disability Services of Victoria (VICSERV)
Melbourne Catholic Social Services	
Sherrill Meredith	Carer
William Moon	Coordinator, Citizen Advocacy Western Region Inc
Angela Murphy	Town clerk, City of Stawell Council
National Association of Nursing Homes & Private Hotels	
Sandra Oliver	Carer

Gordon Ortmann	Carer	
Br Trevor Parton	St Augustine's Adolescent and Family Services	
Dr Christopher Percival	Psychiatrist	
Neil Plueckholm	Consumer	
Dr Bill Pring	Australian Medical Association	
Kerrie Punshon	Dentist, NEMPS	
Judith Rainbow	Consumer	
Jacklyn Richardson	Consumer	
Shirley Rochow	Consumer	
Julian Rollins	Consumer	
Myra Ryan	Health worker	
Gary Samuels	Public servant	
Colleen Simon	Carer	
Phil Spencer	Honorary president, Property Owners' Association of Victoria	
Judy Stellato-Pledge	President, Allergy & Environmental Sensitivity Support & Research Association (AESSRA)	
Elsie Teer	Chair, Citizen Advocacy Western Region Inc	
John Thwaites	Shadow Minister for Health, Victorian Opposition	
Bobbie Trembath	Director of Nursing, Strathdon Community Council	
Denis Vardon	Carer	
Dr Ivo Vellar	Surgeon, St Vincent's Hospital	
Victorian Government		
Victorian Mental Illness Awareness Council (VMIAC)		
Victorian Transcultural Psychiatry Unit, University of Melbourne		
Graeme Wallace	Friends of Strathdon	
Marg Welsh	Project worker, St Kilda Project	
Rosemary West	Carer	
Kaye Williams	State secretary, Health & Community Services Union (HACSU)	
Name Withheld	Health worker	
Name Withheld		
Name Withheld	Concerned citizen	
Name Withheld	Carer	
Name Withheld	Carer	
Name Withheld	Psychiatrist	
Name Withheld	Hospital administrator	

