Mental Health Council of Australia

Submission to the Senate Select Committee on Mental Health

May 2005

"NOT A FAILURE OF POLICY,
IT IS A FAILURE OF IMPLEMENTATION AND DELIVERY"

A Executive Summary

This Senate Enquiry is a timely opportunity to assess what is actually happening in mental health in Australia. Twelve years after the National Mental Health Strategy's inception and three years before a third review is due, studies carried out by the Mental Health Council of Australia and others reveal deeply disturbing gaps in planning, delivery and evaluation of mental health services. This is not a failure of policy; it is a failure of implementation and delivery.

The last five or six years have seen what was a significant policy initiative lose direction and show signs of stress and indeed crisis. Health consumers and their carers are losing faith in the system because of constant frustrations and inability to access proper care. The Australian community is growing increasingly uneasy with daily reports of death, suffering and abuse of human rights as a result of failures in the mental health care system. The people working in mental health services are struggling to cope with a lack of resources, support and direction which limits their capacity to do their job properly and can even put their own health at risk.

The Council submits that there are four major causes underlying these problems:

1 The burden of mental illness and associated disability within the community is not matched by the funding allocated to prevent, relieve and rehabilitate people experiencing mental health illness.

2 There is a significant mismatch between the community based mental health service model and the current system of still allocating funding largely on the old service model of 'beds and buildings'. Community based services, the key component of the National Mental Health Strategy, are unable to effectively perform their role.

3 The underlying and unmet need for mental health services in the community continues to put pressure on the mental health system and

soaks up any band aid funding measures without raising overall system effectiveness.

4 The failure to agree on and implement a national framework for accountability.

While total health funding has grown over the life of the National Mental Health Strategy, spending on mental health has remained static in comparison with overall health spending; yet mental health has grown as a component of the overall health burden. But simply throwing more money at the problem will not deliver the required outcomes for service consumers and the Australian community. There has to be a radical shift in funding to enable the original model of community based care to operate as a full continuum of mental health services linked in with other community supports. Management of the National Mental Health Strategy must also move from a focus on Commonwealth/State contributions and funding inputs to focus on outcomes for consumers, carers and service providers.

The full list of recommendations from the Mental Health Council of Australia to this Inquiry is at the end of this submission.

In summary, as leader of the national strategy to manage mental health in Australia, the Commonwealth Government, should:

1 Develop and permanently fund better models of primary and secondary care service delivery which better meets the needs of, and is more inclusive of consumers and carers

2 Address structural issues in the mental health care system such as lack of services, workforce issues, improving cross sectoral linkages, co-morbidity and protection of human rights.

3 Establish and monitor National Standards of forensic and restrictive care, especially in its own detention centres.

4 Increase expenditure on mental health by $1.1 billion per years over the next ten years, refocus funding on the full spectrum of service provision system and adjust existing funding mechanisms to bring them into line with the new funding (not the other way around as is more usual)

5 Establish a coherent set of health targets and goals which includes real 10 year targets for population mental health outcomes including that 60% of those with mental illness be provided with care in any 12 month period (currently this figure is 38%)

6 Establish regular, frequent and formal reporting mechanisms to Prime Minister and Heads of Governments on specific key indicators. Leadership

of this process should be vested in an independent, empowered national office or person, with direct access to the Prime Minister.

7 Restore the responsibility for the National Mental Health Strategy to a Cabinet-level Minister.

8 Reduce the social and economic costs of mental illness through investing in the services and supports to enable people with mental illnesses to optimally participate in the workforce.

9 Increase community support for mental health and reduce the stigma of mental illness through sustained social marketing, community education programs and health workforce training in mental health.

10 Significantly increase the percentage of research funding invested in mental health.

In this submission, we will outline the issues underlying these recommendations and the case for a substantial re-ordering of the mental health care system. Our main focus is on how mental health services are actually delivered and experienced by consumers, carers and service providers on the ground. We will examine the Strategy from our direct and relevant research and refer to the terms of reference as they become relevant in our examination.

B Introduction

1 The National Mental Health Strategy is the national vehicle for ensuring delivery of high quality, effective services to people requiring mental health care. It operates within a complex system for providing such services across State and Territories in public and private systems, using public, private, NGO, for-profit and not-for-profit service providers and professionals. These services are mainly funded through national health funding agreements, through public and private insurance funds and through specific mental health state/federal funding arrangements. In addition, some services for people with a mental illness may be provided by other programs entirely, eg aged care and detention services.

2 The National Mental Health Strategy has been evaluated 9 times since its inception in 1992 and new strategies and directions are developed and negotiated with State and Territory governments after each evaluation to fine tune the strategy to changing needs. Yet many of the innovative programs and additional funding initiatives being taken by the states and territories are not driven by the NMHS. It will become apparent to this Inquiry that we are awash with plans, strategies, policies, and guidelines in mental health but not results, evidence of impacts or outcomes.

3 Unfortunately, what has been lost in this complex model of funding and evaluation is effective service provision to the consumers, the people at the heart of the issue. The National Mental Health Strategy is not delivering mental health services effectively or efficiently because it focuses on the process of managing funds and statutory relationships, not on providing services to those people who desperately need them.

4 An indication of the seriousness of the failure of our current system is one of the recommendations which the MHCA makes to this enquiry:

That 60% of those with mental illness be provided with planned and appropriate care in any 12 month period (currently this figure is 38%)

What other health sector would accept a non-response rate of 62% in any 12 month period?

5 The implications of this statistic take on real meaning when it is applied to our population: the Australian Institute of Health and Welfare reports that mental illness account for nearly 30% of non-fatal disease burden and that mental health is third after heart disease and cancer in terms of disease burden. The Australian National Survey of Mental Health and Wellbeing (conducted in 1997 and not repeated) indicates that 18% of the population experiences a mental health problem each year. Such mental health problems include affective disorders, anxiety and substance abuse. The prevalence of mental health problems in children and adolescents in Australia is 14 % of the youth population, an estimated 217,000 young

people. Three percent of Australian adults experience severe mental illness such as chronic depression or a psychotic disorder. Yet national spending in mental health services was 6.4% of total gross recurrent expenditure on health care.

6 Over the last 2 years, the Mental Health Council of Australia has been collecting and publishing data and other material which has demonstrated a significant failure of the mental health system to meet these needs. This can no longer be tolerated in a prosperous, well governed country like Australia.

7 In 2002 the Commonwealth provided 64.9% of the total funds dedicated to mental health. It is not involved in day to day delivery of services and so has to rely on funding mechanisms and its leadership role in research, training and standards to contribute to the improvement of service delivery. We understand the considerable difficulties of dealing in a federated health system across a huge geographic space and across many different social, economic and cultural barriers. However, the Commonwealth has accepted a leadership role in improving mental health service for twelve years now. It is time to deliver on that challenge.

C The Mental Health Council of Australia

8 The Mental Health Council of Australia was established in 1997, as part of the Mental Health Strategy. Its brief is to bring together consumers, carers, non-government, government and private service providers in order to provide advice to governments; to represent the interests of its constituency in the public domain; and to monitor and analyse national mental health policy, resource allocation and outcomes. We are the independent, national representative network of organisations and individuals committed to achieving quality mental health for everyone in Australia.

9 This is not a matter of bringing a single voice to the table. Mental health is a very complex area; it includes many different illnesses, treatments, issues and views. The Council's role is to promote discussion and development of ideas among the consumers, carers, service providers - especially NGO's, private and public service deliverers, medical specialists, psychologists, nurses; mental health services staff. We don't always agree on how to go forward, but it is our very diversity which tests our assumptions, challenges our thinking and offers fertile ground for finding solutions.

10 We work together under the umbrella of the Council because of our common concern for a national health priority: mental health/mental illness.

Consumers, carers and service providers experience very similar problems in seeking services or providing it, that is a lack of support and resources, inadequate service systems, lack of understanding in the wider service community and, most importantly, a lack of leadership. We work in a continuum of prevention, early intervention, treatment and maintenance of health, involving all levels of care from primary to acute and all sectors of the mental health community.

11 We work in a wider community where the stigma associated with mental illness is still pervasive, even among general health and mental health workers. The community's mental health literacy (see Donovan report to Healthway) remains low. There is a dangerous lack of public understanding of mental illness which creates barriers to service and support precisely at the time when people with mental illness and mental health problems need help. Fear and ignorance often results in discrimination against people with a mental disorder and their carers so that those who need care and support are not able to access services which are available to others. It is also a significant factor in people's reluctance to seek assistance because of fear of being locked up, of the side effects of medication or of being labelled for life. The stigma of mental illness often makes it difficult for people to access information and services or to stay in touch with support services.

12 In this submission, we will address the terms of reference in two ways. It is important firstly to acknowledge the positive changes achieved under the National Mental Health Strategy under reference 1. However, our main focus is on how mental health services are actually delivered and experienced by consumers, carers and service providers on the ground. We will examine the Strategy from our direct and relevant research and refer to the terms of reference as they become relevant in our examination.

13 We submit that there are two major long term goals all sections of the health care system and the wider community should be agreed on:

- A supportive, educated Australian community which understands mental health issues and which provides a positive environment for promotion, prevention, early intervention, treatment and continuing care for people with mental illness.

- An accessible, high standard continuum of care for people moving through different stages of mental illness based on a step-up, step down model:

a. Firstly - family, GP, workplace and community focused service providers able to make an effective assessment and provide appropriate primary and secondary care;

b. Secondly - community services to support people with mental illness and their carers, operating within an overall framework which links related services eg housing, employment, drug and alcohol addiction, counselling, stabilisation and rehabilitation support services etc;

c. Thirdly - effective acute and emergency responses, including hospitalisation, which operates within the step-up, step-down model so that people can access appropriate care prior to entry and on leaving crisis care;

d. Individual case management providing long term patient-centred care and supervision of treatment, focused on individual recovery; and which recognises and incorporates the role of carers where appropriate;

e. Provision of appropriate care and support to prevent unjust and unnecessary incarceration of people with a mental illness;

f. Provision of appropriate processes, care and support for people on release from jail or detention who are affected by mental illness;

g. Appropriate long term care for prisoners and those who are considered a threat to the community, including forensic psychiatric facilities.

14 This submission will outline the strategies needed to realise those goals, for example new national targets and accountability mechanisms for mental health service provision and a renewed emphasis on workforce participation for consumers. Increased resources are essential and they should be carefully targeted to need and cost/benefit returns in order to achieve significant economic returns on new investment in mental health.

15 Provision of mental health services has been seriously held back by a top-down and crisis driven approach for years. We argue that it can only be made more effective and efficient through re-focusing our energy on the actual service provided to consumers and carers in a genuine partnership with them which actualises their right to fully participate in the planning and delivery of services. In the long run, that is the most important measure of success.

D Achievements of the National Mental Health Strategy

Reference a: The extent to which the National Mental Health Strategy, the resources committed to it and the division of responsibility and funding between all levels of government have achieved its aims and objectives, and the barriers to progress.

Reference b: The adequacy of care for people with a mental illness in particular: prevention, early intervention, acute care, community care, after hours crisis services and respite care.

16 The National Mental Health Strategy has made a significant contribution to the process of de-institutionalisation. Prior to this, de-institutionalisation, which commenced in the 1960's, was ad hoc and unplanned. The Strategy established broad directions of reform and attempted to put in place specific actions to support these reforms.

17 Data published in the National Mental Health Report charts the Strategy's achievements on a number of levels:

- the number of stand alone psychiatric beds has decreased by 60% since 1993;
- national spending on mental health has grown by 65%, and mental health "has maintained its position but not increased its share of the health dollar." (p2 NMHR);
- community based care has grown from 29% of total expenditure in 1993 to 51% by 2002 (p5 NMHR); and
- NGO funding rose from 2% of total expenditure on services in 1993 to 5.5% by 2002.

18 There has been an increase of awareness in the community, some service improvement and an increased understanding of the mental illness through research and epidemiology. The current situation we find ourselves in is not a failure of policy but a failure to implement orderly and integrated care and support systems which meet the needs of consumers and their carers.

19 Reduced reliance on stand alone psychiatric hospitals was the major policy driver for the first National Mental Health Strategy. This was to be made possible by the expansion of community based and primary mental health care to provide support for consumers within their own communities and build a focus on primary and preventative health care. The strategy has been successful in achieving the first objective to the point where dedicated, stand alone mental institutions are regarded as a last case resort. However, even here the Council has serious concerns that, while the institutions themselves have closed, institutionalisation of people with a

mental illness has in fact been transferred to prison and detention systems or replaced with isolation within the community, for example through homelessness.

20 The broad underpinning strategies for the transfer of services to mainstream health services and community based care were:

- to build increased capacity in the workforce to deliver care within these altered service models;
- to build increased capacity in the community and non-government sector to provide care;
- the empowerment of consumers and carers to participate in the planning, delivery and evaluation of care ; and
- to use data collection and evaluation to monitor change and plan effectively.

Thus the Strategy developed sound policies with achievable strategies underpinning them. Its greatest success has been in building them into the espoused values of mental health service provision.

21 Actual achievement of the strategies has been varied. Workforce reforms have achieved a reported 25% increase in clinical workforce size between 1993 and 2002, although this represents an increase in numbers of staff, not necessarily full time working hours available to the system. There has been a shift in staffing mix to nursing and psychiatry and workforce training standards have been agreed. However, psychologists are significantly under-utilised in the provision of mental health services, due to issues related to affordable, government-supported access. They could make a significant contribution to evidence-based interventions and to relieving the burden on the psychiatric workforce within the public health system. Providing access to the Medicare FPS items established under the Better Outcomes initiative to well trained psychologists for rebatable psychological services would immediately ease the mental health burden.

22 Community based care has expanded to 51% of total spending on mental health. This included both NGO and public services, including outpatient clinics, specialised community residential services and support services including accommodation, rehabilitation, recreational and social support and advocacy programs. However, making community based care actually work required an increased focus on intersectoral linkages. The National Mental Health Report 2004 does not report on this crucial strategy but consumers report a consistent lack of access to these broader community services which impairs their ability to maintain their health and operate effectively in the wider community. The lack of concrete data about actual service provision and, more importantly, consumers' access to mainstream

health, housing, employment, education and social activities is a distinct weakness in the National Mental Health Strategy.

23 There has been an expansion of the role of non-government service providers with the recognition they could deliver some services more efficiently or more effectively than the government or private sector. Data quoted above shows a 250% increase since 1993. However, this figure reflects the exceptionally low level of initial funding and conceals a significant and continuing under resourcing of the NGOs and the community based sector. In addition, these figures conceal some significant differences across jurisdictions, always a problem with broad national data The lack of funding for non-government services is one of the major factors in the under performance of the Strategy.

24 The Strategy has established consumer and carer participation in service planing and delivery as a desirable goal, though there is little evidence it has progressed into a practical reality. It has established consumer rights as an accepted part of service delivery, though again there is considerable evidence that the exercise of such rights is weakened by a lack of support for consumers and carers. There is inadequate and patchy funding to train and support carers and consumers to enable them to participate fully in this role, and what is available often does not address mental health issues specifically. As importantly, a change in service culture and practice by the mental health workforce is required so that they recognise the rights of and work effectively with consumers and carers. This is a fundamental and urgently needed element of workforce training and service.

25 The practice of collecting and reporting on selected data has been firmly established. The National Mental Health Report is published each year giving an analysis of data collected against the milestones, targets and performance indicators established by the National Mental Health Strategy. This provides some public accountability for achievement of some of the strategy's goals, for example with the establishment of the National Minimum Data Set – Community Health Care which included 95% of private hospital sector and 60% of public hospital sector by 2003.

26 This data enables us to say with some confidence that provision of private psychiatric services is growing, from 14% in 1993 to 23% in 2002 (W p8). Health insurance funding of private psychiatric hospital beds grew from 17% to 38%; patient days grew by 59% and separations 270%. However, there is no evidence that this has relieved pressure on public hospitals as data is not collected on unmet need or people who fail to access appropriate services. The National Survey of Mental Health and Wellbeing should be a regular survey conducted on at leats a three year cycle to provide monitoring of community needs.

27 Some researchers report greater access to mental health services for non-psychotic illnesses, child and adolescent mental illnesses and low

prevalence illnesses. However, state and territory governments report this is a continuing problem and consumers report considerable difficulties in accessing such services in research (see *Not for Service)*. Without specific data on accessibility, it only safe to say that these services have been established and have grown over the life of the Strategy.

28 A major concern of Commonwealth administrators at the start of the Strategy was to maintain state and territory funding to mental health over the life of the Strategy. In fact, spending by state and territory governments has increased by 40% since 1993 and spending by the Commonwealth has increased by 128% in the same period. However, combined spending increases only paralleled overall health spending increases over the same period of time and include a significant increase in PBS costs due to increased import costs.

29 The overall trend of evaluations of the Mental Health Strategy to date has been to say that the Strategy will start to work soon, just give it time. There is a sense in some jurisdictions that the structural changes are in place, we don't need to tinker much more with them. In this scenario, consumers and carers who experience difficulties accessing appropriate services appear to be asking for the moon. Only unsupportable levels of funding – preferably from another jurisdiction - would solve everybody's problems. The nominal successes of the Strategy to date have encouraged the assumption that only time and more money will fix the problems.

30 We submit that, while significantly more funds are needed to deliver acceptable mental health care, on their own they will not fix the problems, merely deliver the same sort of services more widely. The Strategy has got the broad policy right but continuation of its present approach will waste money and lives. What is needed is:

- leadership,
- accountability,
- governance, and
- investment in research and innovation.

E Things Not Working in the Strategy

31 The failure of the implementation of the National Mental Health Strategy has to be looked at against a pattern of:

- increasing demand,
- lack of effective monitoring, out-dated systems, and
- a continued dependence on crisis driven management of care.

Reliance on previous funding models is holding back the wider implementation of best practice care regimes and efficient use of

resources. Prejudice and lack of support are preventing positive economic and social returns to the community by way of consumers' participation in employment, family responsibilities and community participation.

32 Although funding has been maintained at comparable levels, service delivery is not meeting the needs of people with a mental illness and their carers and yet, at the same time, it is placing an unacceptable strain on the mainstream health services themselves. Three things have gone wrong.

33 First, and most significantly, what has undermined the Strategy from the beginning is that the service model has not matched the funding model. The new strategy allocated mental health funds into the general health system according to the old institutional funding model of "beds and buildings" so that many hospitals, clinics and services retained funding for service relationships and treatment principles which did not draw on the new community based services. For example, re-institutionalisation still occurs but now takes place in a general hospital setting; access to treatment is still rationed according to highest need as determined in a crisis and the stigma of mental illness still operates in both the general and mental health systems.

34 At the same time, the success of the Strategy relied on implementing a service delivery model which required much more flexible funding so as to build capacity in community based care. However, funding has failed to flow to early intervention, primary and secondary care sectors, public and non-government organisations so that they could relieve the pressure on the acute care component of the system.

35 This has resulted in:

- Failure to provide effective and sufficient early intervention, primary and secondary care in the community.
- Increasing severity of individuals' symptoms until they finally require acute or crisis care.
- A continuing emphasis of funding on acute care beds and crisis services.
- Continuing under-funding of community based care, early intervention and recovery/rehabilitation.
- Restriction of prevention and early intervention services to the better resourced areas and to demonstration funding rather than on-going funding.

- Lip service to consumer and carer participation in the planning and management of resources.

- Lack of integration of mental health services into the broader community support system.

36 Secondly, the Strategy took an ad hoc approach to building the extensive network of support services in the community required to manage mental illness at the primary and secondary levels. Clinical services, housing and community support, employment, adequate access to appropriate justice support systems and drug and alcohol support have all been patched into the system on a fairly random basis which has left the services themselves struggling to build their own local and regional networks and to cope with demand. Large areas of Australia are still serviced poorly or not at all. In addition, the Strategy did not acknowledge the burden it was placing on carers through this approach and ensure that they had sufficient support to carry out their difficult and emotionally draining role, often over many years.

37 Thirdly, the NMHS did not recognise the levels of unmet need already in the community, nor did it anticipate the growth in demand for mental health services which the past decade has witnessed, estimated at a 62% growth in 2002 over the 1993 demand levels. Recent discussions with State/Territory mental health services also indicated 'unprecedented growth in demand placing even more pressure on services'.

38 As a result of these failures in implementing the Strategy, the system is in crisis. New funding is drawn down by an increasingly overloaded acute care system and primary and secondary care systems remain constricted. Consumers and carers struggle to gain access to the wider community service networks. People who would benefit from being actively engaged in work cannot access the help they require to obtain and maintain employment.

39 These are large claims to be making but the evidence is irrefutable. Two major pieces of work done by the Mental Health Council of Australia over the past three years offer overwhelming evidence that structural reforms have not delivered the level of service which would meet national expectations in any other health area. *Out of Hospital – out of Mind*, released in 2003 and *Not for Service*, to be released in June 2005, both offer convincing evidence that people with mental health problems at all levels and from all walks of life experience unacceptably low levels of service. These reports do not stand alone. They are supported by a wide body of research as cited in this submission and a number of auditor-general, critical incident, ombudsman and coronial reports.

40 The MHCA reports show that the key driver for quality improvement in the mental health system, the National Standards for Mental Health Services,

is failing in the experience of the people who use them. Consumers and carers report consistently experiencing frustration, fear, stigmatisation, failure and abuse of human rights in seeking adequate care and support. Some jurisdictions dismiss such reports as 'coming from a small minority and not representative of the general experience'. The facts do not support this view. Over half of all public mental health services had not even reviewed their performance against these standards by June 2003, some seven years after they were agreed to by all governments. This is a very clear example of the lack of accountability and commitment to mental health by all Australian governments. The reality of the reports of consumers, carers and providers is that they put flesh on the difficulties of a system struggling to cope with the human cost of the huge gap between policy and its implementation.

F Funding

41 The last four or five years of the National Mental Health Strategy have seen a loss of momentum instead of a consolidation of service planing and delivery. The most recent opportunity to establish an integrated and effective plan for mental services was lost when the 2003-2008 National Mental Health Plan focused on the wording rather than putting a proper financial management plan into place. This plan fails to define specific targets for increased investment in mental health; it fails to develop a plan for growth of the community service sector; and maintains the evaluation of funding inputs rather than service outcomes. Such a flawed approach has resulted in ad hoc funding increases which can only patch up parts of the system and which does not address the core priorities, problems and needs.

42 It is clear to all those working in the mental health system that its problems can no longer be resolved simply by providing more money which to date, has only been in line with overall growth in health care funding. The issue now is a matter of how to leverage new money to achieve systemic change. The first step must be to commit substantial new funding to build the comprehensive integrated service delivery system envisaged by the National Mental Health Strategy. At the Commonwealth level, at least $1.1 billion in additional funding is needed every year over the next ten years, applied at key points across the whole spectrum of care, in order to meet identified needs and leverage existing state/territory mental health funds into achieving sustainable outcomes.

43 The recent funding increase announced by the Commonwealth Government of $110 million over four years is a step in the right direction but only one tenth of the funding required from the Commonwealth to put the system on a sound footing. But the next step is the most important: to use this funding to build and strengthen the community based primary and secondary care systems which will then take the pressure off the acute and crisis care services. For example, the additional $180 million over four

years announced by the Victorian Government in its 2005 Budget for new services needs to be leveraged by increased Commonwealth funding for additional GP services under the Better Outcomes program. Thus the additional services created would be able to work within an accessible, effective early intervention system available to all Victorians, not just those lucky enough to live in the right areas.

44 We estimate that an additional $500 million a year would fully implement the Better Outcomes in Mental Health Care initiative and achieve substantial savings in other government programs. A fully operational Better Outcomes program would provide sufficient training, access to specialist support and funding to build effective early intervention and primary care services across Australia through the existing GP network. If it is put in place in conjunction with appropriate referral and specialist systems, including greater access to allied health professionals working in collaboration with the accredited GPs, primary mental health care would be able to cover the full spectrum of interventions for most mental health consumers.

45 There are real savings to be made by this sort of investment. Effective treatment can make savings, firstly against the Disability Allowance by enabling higher rates of workforce participation; secondly against overall health costs by reducing calls on high cost crisis and inpatient care; and thirdly by reducing per patient costs against the Pharmaceutical Benefit Scheme by reducing long term dependency on drugs. This last area is worth special note because it is already subject to worrying cost escalation. Increased access to and use of early intervention and non pharmaceutical strategies would help to contain such costs as well as providing better long term outcomes for consumers and carers. Treatment programs that use appropriate combinations of drug and non-drug therapies such as Cognitive Behavioural Therapy (CBT) have been shown to be more effective than drug therapies on their own.

46 Other new funds should be allocated to services providing primary care for young people; for funding services providing stepped care; and for specialised recovery programs.

47 New funding for acute care should be limited to 25% of any new funding in order to avoid the mistakes of previous funding arrangements and dedicated funds should be made available for research and for addressing public mis-information about mental health.

48 The focus on commonwealth/state responsibilities has too often clouded effective discussion on funding. From the outset, the NMHS did not address differing service levels caused by pre-existing funding differences between states and territories. So the Strategy continues to reference spending in each jurisdiction against other jurisdictions instead of against consumer need. This is a common error. Our federated system of health

care means that we are often content to ask states and territories to bring their standards up to the level of the best performing state/territory. But it is not a particularly useful measure in the current circumstances.

49 The National Mental Health Report shows that state/territory differences decreased marginally between 1993 and 2002, but not enough to lift services to a comparable level across all jurisdictions. So the question of "how are we doing in comparison to others?" has not lifted spending in those states which are behind the national average. A more effective approach would be to ask "what level of funding is actually required to meet consumers' needs?" Measurement of jurisdictional funding levels should be secondary to measurement of consumer service levels. Assessment of States' and Territories' compliance with the National Mental Health Strategy should be made primarily on levels of service and secondly on percentage of funding growth.

G Community Based Services

50 The second most significant failure of the National Mental Health Strategy has been its inability to build the extensive network of support services in the community required to manage mental illness at the primary and secondary levels. Such support include clinical services, housing and home care services, community support, employment support services and timely access to appropriate justice support systems.

51 One of the most important tasks now is to build sufficient capacity within the community service sector to provide clinical services, early intervention and primary care to mental health consumers. Strategies such as workforce training and implementing service standards were tagged as essential from the very start; however, there is little evidence that the required levels of knowledge, skills and capacity have been even remotely approached at any point in the life of the Strategy. Funding for these programs remains grossly inadequate.

52 The 2004 National Mental Health Report shows some growth in community services but sheds little light on their capacity to fulfil their functions. It states that its figures "do not tell us about the ambulatory care workforce levels required to meet priority community needs nor the amount of care actually provided." The report admits the distribution of services is uneven and it is the view of the Council that many rural and remote areas and particular sectors of the community such as CALD, Aboriginal and young people have little or no access to such services. We need to start now on capacity building in the community – that is developing NGO, public and private facilities and staff at a real, substantiated growth rate of 10% over the next five years. Start-up costs and workforce training need to be given high priority in additional funding mechanisms.

53 In addition, there is very little data available on the extent to which early intervention is playing the role it should. Programs for early intervention are critical both in terms of interrupting the establishment of mental illness and in reducing the burden of disease. Such programs need to work within the existing range of health settings and use risk assessment tools to assist with the identification of important behavioural indications of anxiety, withdrawal, social inappropriateness and poor socialisation. For example, such programs used within the community based services such as infant welfare centres, school systems, GPs and other primary care settings, could enable the identification of at-risk families and children. Provision of timely, appropriate referrals to appropriate programs and services could reduce the establishment of mental illness.

54 Even if such services are available to all who need them, there is no capacity to ensure the high standards of care which the Strategy aims for are met. The process of setting service standards has been cumbersome and slow and there is little prospect of using them to improve service delivery before 2008. The 2004 National Mental Health Report anticipates that all jurisdictions would have completed **the first round** of assessment against service standards by 2008. The Council submits that this type of delay in a critical part of the national strategy is simply unacceptable and goes a long way towards explaining the loss of faith in the system by consumers and carers.

Reference e: The extent to which unmet need in supported accommodation, employment, family and social support services, is a barrier to better mental outcomes.

55 The community care model of service delivery is further undermined by inadequacies in cross-sectoral care. Generalist housing, education and employment services are reluctant to undertake service provision for mental health clients without additional support. There is inadequate emphasis within the existing system on providing funds for these services to help consumers and carers to access existing services. In many areas, formal pathways between services are virtually non-existent and there are no formal supports, agreements or protocols to make them work. Individual case managers are left to argue the rights and wrongs of an individual's access to services which, in a well-run system, would be automatic.

56 States and territories are slowly addressing these problems and have implemented some programs which show how cross sectoral co-operation could work. "Project 300" in Queensland and, more recently, the HASI agreement in NSW demonstrate the benefits which formal agreements and planning could produce if implemented effectively. Project 300 commenced in 1995 which assisted some 200 people to move from long stay psychiatric hospitals to community based accommodation. It involved collaboration between Queensland Health, Department of Families, Youth and Community Care and the Department of Public Works and Housing. It

continues today with an annual recurrent funding of $9.2 m to support 190 people.

57 HASI (Housing Accommodation Support Initiative) is a more recent initiative to provide supported accommodation services for people with a mental illness. It is a formal agreement between the NSW Departments of Health and Housing and NGOs which will also be linked with other non-acute and acute care inpatient services of the Centre for Mental Health. It works within existing housing services for people who require a high level of support to participate in community life. Project 300, HASI and other similar state and territory programs demonstrate that intersectoral support for people with mental illness is critical to their stabilisation and rehabilitation.

58 Even where a consumer, carer or support service is able to access other community services, their problems are not over. The Strategy does not make adequate provision for funding education and training to enable staff in other health and community sector services to work effectively with mental health consumers. Having won the lottery of access to appropriate support, consumers often find continuing difficulty in dealing with service providers who are untrained in dealing with people with mental illness.

H Unmet Need

59 The third great failing of the NMHS is that it did not adequately plan for the increase in demand which is such a significant feature of mental health care at the present time. While the focus was on de-institutionalisation of mental health services, proper allowance was not made for an increase in mental illness among young people; for increasing incidence of mental illness brought about by family breakdown, decreasing participation in community and recreational networks; and increased drug and alcohol abuse.

60 Population-based estimates of mental illness also document an unmet need for mental health services. The Australian Bureau of Statistics estimates that in 1997, 2.4 million people aged 18 years and over (18% of all adults) had experienced a mental problem or illness in the previous twelve months. Adults with mental problems or illnesses were on average more likely to be disabled than adults in general. They were more likely to live alone and more likely to be unemployed. Professor Gavin Andrews estimates that at least half of those with affective disorders in the general population do not get access to professional help for their mental health problem. Of those that do seek help, barely half receive treatment that could be regarded as minimally adequate. Regrettably no on-going measures of demand are undertaken and the Council must rely on anecdotal reports on the rising levels of demand. A number of State Mental Health directors have reported unprecedented growth in demand in the recent discussions this year with the Council.

61 Dr Sev Ozdowski, acting Australian Human Rights Commissioner and Disability Discrimination Commissioner, put it this way in an address to the National Press Club in 2004: "The statistics on sanity are that one out of every five Australians this year will experience some form of mental illness. Think of your four best friends. If they're okay, then it's you."

62 The nature of this unmet need varies. Most of the unmet need for interventions is among those with common problems like depression, anxiety and substance misuse. At the other end of the spectrum, there is restricted access to emergency services for psychotic or other enduring illnesses because of the lack of discharge places and support systems. Consumers are often discharged without any rehabilitation plan or even reference to appropriate places because the discharging services knows these services have no capacity to accept further referrals. As a result, their carers and family bear the brunt. Access to care during prolonged rehabilitation is also restricted, creating further demand on services as consumers suffer a relapse and seek acute care.

Reference f: The special needs of groups such as children, adolescents, the aged, Indigenous Australian, the socially and geographically isolated and of people with complex and co-morbid conditions and drug and alcohol dependence.

63 A further urgent dimension in unmet need is the categories of people who are unable to access appropriate care: children, adolescents, the aged, Indigenous Australians, people from different cultural and linguistic backgrounds; people in rural and remote areas and people with complex and co-morbid conditions and alcohol and drug dependence.

I Children and Youth

64 The Council is especially concerned about access to appropriate mental health care for children and adolescents. The Australian Infant, Child, Adolescent and Family Mental Health Association, in a position paper for the MHCA Board in 2004, estimated that between 14% and 18% of children and young people aged 4 – 16 years experience mental health problems of clinical significance. The AIHW put the actual figure at 217,000 young people aged between 12-17 years in 1998. This figure takes on added significance when you consider that this is also a critical time for building the mental resilience and personal strategies needed to cope with the stresses of adult life. Many young people continue to suffer the effects of this early exposure to mental illness throughout their lives.

65 Early intervention programs are particularly important for children and young people both in terms of interrupting the establishment of mental illness and reducing the burden of disease. It is important that such programs work within existing systems, eg GPs, schools and children and

youth services where risk assessment tools can be used within normal interactions with parents, children and young people.

66 However, when dealing with mental illness in young people, specialist children and youth services, which are designed specifically to address their developmental needs, are required. An example of an effective and evidence-based youth service model is Orygen, which has attracted international attention. This youth-specific mental health services combines area-specific clinical services, including outreach and some accommodation services, with research, education and consultation services available to the wider mental health sector. This combination allows Orygen to work directly with young people and at the same time to work for a change in the conceptual framework and clinical practice for young people which is acceptable and easily accessible for them.

67 Some children also bear the burden of caring for an adult with mental illness. This is an especially difficult task given the social isolation often associated with mental illness and can in turn affect the mental health of the child. These needs cannot be met by increasing capacity within the general service sector. Young carers and young people in families affected by mental illness should be identified as a priority target within children and youth services.

J Culturally and Linguistically Diverse Consumers

68 For consumers from culturally and linguistically diverse backgrounds there are significant gaps in service. Despite the release in 2004 of the *Framework for the implementation of the National Mental Health Plan 2003-2008* under the National Mental Health Strategy, which documents the key issues in multicultural mental health and provides a framework for addressing these, there has been no resource allocation for the implementation of this framework. It appears that once again another document and framework has been published under the National Mental Health Strategy without any strategic direction or mechanism for engaging the states in the delivery of its intent.

69 This means that the inequity that currently exists in relation to the delivery of mental health services will continue. Multicultural Mental Health Australia (MMHA) notes that culturally and linguistically diverse (CALD) consumers continue to:

- Be excluded from any major planning initiatives, (eg. National surveys, mental health outcome measures research) on which decisions are made about allocation of resources;

- be underrepresented in mental health services due to access barriers;

- experience higher rates of involuntary admissions, and

- experience inappropriate service delivery due to lack of cultural competency of mental health workers and lack of flexibility or capacity of service models to address cultural issues.

Over the years a number of initiatives have been funded to address culturally appropriate service models but these have not been integrated into sustainable program delivery models due to lack of resources.

70 CALD carers of people with a mental illness also need special assistance, including enabling carers to use their own community language; the availability of information admission forms and other documents in community languages; and the availability of community care services and other personal support services which are culturally appropriate.

K Services in Rural and Remote Areas

71 People in rural and remote areas are especially hampered in seeking appropriate care and support for mental illness. While this may be to some extent understandable in remote areas, the lack of services in well populated rural areas is unacceptable. Standard early intervention strategies cannot work without proper referral systems. Community based primary and secondary care, including the work of GPs, is hampered from the start.

72 Even where a diagnosis can be made and a plan of care developed, the required services are usually not available or over subscribed and understaffed. Regional health services report a consistent inability to attract specialist mental health staff. The National Mental Health Report 2004 notes that little change has occurred in the distribution of private psychiatric services since the beginning of the Strategy in 1993. *Out of Hospital, Out of Mind* quotes a respondent "Country areas need more psychiatrists desperately. Bendigo has only one full time private psychiatrist – her books have been closed for three years!!!"

Similar stories of no care or long waiting periods were reported across Australia in the more recent public consultations for the preparation of the *Not for Service* Report. In many rural areas it is more than just a lack of specialist services; people often suffer exclusion from general community and health services because of the stigma of their mental illness. Training and support for health professionals on appropriate treatment and response to disorder-related behaviour is urgently required to make these generalist health services more accessible to people with mental illnesses. Training and support services should also be more available for consumers and carers.

L Aged People

73 Dementia is excluded from the National Mental Health Strategy on the grounds that it is covered by aged care programs. This is yet another indication of the inability of the Strategy to address issues of co-morbidity and cross sectoral service provision. This is not to suggest that the Strategy should take responsibility for funding of services dealing with dementia, but there is no benefit from ignoring the impact of dementia across the range of mental health issues for the elderly.

74 The Strategy needs to address three major issues in the provision of good mental health care for elderly people:

- Provision of appropriate mental health care for elderly people in general hospital facilities where successful treatment of physical conditions is hampered by poorly understood mental illnesses such as depression and anxiety.

- Improvement of standards of mental health care in aged care facilities and systems where misuse of psychotropic medication, restraints and inappropriate response to mental illnesses is often a result of poor training and lack of access to specialist services.

- Provision of mental health care to the elderly in the community who are already disadvantaged by loss or incapacity of carers, fragile housing and community isolation. Dementia often operates to alienate family and friends and to isolate elderly carers of dementia sufferers.

75 Elderly homeless people who suffer mental problems may be one of the most disadvantaged groups in the mental health sector, but even those in stable and supportive living arrangements have difficulty accessing appropriate mental health treatment. The present aged population are more likely to feel the stigma of mental illness than their children and grandchildren and to suffer from high prevalence illnesses such as depression and anxiety without seeking assistance. Elderly war service veterans provide a good example of people who may have chronic affective disorders but who are unwilling to seek help. There needs to be an increased emphasis on information and education programs for the elderly and their carers and on access to appropriate treatment through GPs and aged care services.

M Indigenous People

76 There are well documented difficulties faced by Indigenous communities in addressing mental health issues. Indigenous people have higher rates of exposure to events related to onset of mental stress and illness. They are more likely to be exposed to grief, loss and trauma than non-indigenous people. They have higher rates of exposure to family separation,

imprisonment and violence and there are higher rates of death in young indigenous people due to suicide, self-harm, injury and violence.

77 The Social and Emotional Wellbeing of Children and Young People, published in 2005, demonstrates the intergenerational nature of mental illness in indigenous communities. The children of Aboriginal carers who were forcibly separated from their natural family by a mission, the government or welfare were 2.3 times more likely to be a high risk of clinically significantly emotional or behavioural difficulties. While over 16% of children aged 12 to 17 years had seriously thought about taking their own lives, this proportion was higher (22%) in children exposed to family violence.

78 However, there are two initiatives which offer some promise:

- the Social and Emotional Well Being Framework for 2004-2009 which establishes a coherent and integrated framework for the delivery of services to indigenous communities; and

- the recent COAG Agreement which establishes a national framework of principles for delivering services to indigenous Australians.

79 The Social and Emotional Well Being Framework for 2004-2009 is a comprehensive strategy for building mental health in indigenous communities as part of an integrated approach. It draws connections between the physical health of people and their mental health and sets out to address the two in tandem. The strategies set out by the Framework to achieve improved community health and wellbeing include: community based services, run by the community, with staff trained in both the community and cultural needs of consumers and in the specialist skills needed to deliver professional a and effective services; strengthening families to raise healthy, resilient infants, children and young people; providing effective response to grief, loss, trauma and anger; strengthening Aboriginal Community controlled health services; and effective implementation, monitoring and evaluation processes.

80 The COAG agreement establishes the basis for a much needed simplification and streamlining of funding and service delivery which will focus on providing communities with the services they need rather than trying to fit community needs into artificial funding categories. In fact, if this agreement is able to demonstrate its effectiveness in cutting through red tape and the slicing and dicing approach to funding, it may well provide a model for mainstream, community based mental health funding.

81 For Indigenous Australians, achieving health and wellbeing requires a holistic and whole-of-life view of health which refers to the social, emotional and cultural wellbeing of the whole community. In some respects, this Framework is well ahead of non-indigenous mental health

strategies in that, right from the beginning, mental and generalist health services are planned to be part of a wider community well-being approach. The Council strongly supports the innovative approaches being adopted to address mental health in indigenous communities. That the learning from such approaches is quarantined from the National Mental Health Strategy is one of its great weaknesses.

N People in Custody

Reference j: The overrepresentation of people with a mental illness in the criminal justice system and in custody, the extent to which these environments give rise to mental illness and the adequacy of legislation and processes in protecting their human rights and the use of diversions for such people.

82 The Strategy established in its first set of National Standards for Mental Health Services, respect for human rights, dignity and safety but it does not measure human rights abuses within the mental health system itself, despite the evidence that people with a mental illness are one of the most vulnerable groups in society. Anecdotal evidence is sufficient to warrant this being given priority in reporting on service standards within the mental health system.

83 What the Strategy also does not do is establish the responsibility of the mental health system to protect those rights for people with a mental illness who are not accessing mental health services. There are three main challenges here:

- To prevent people getting caught up in the criminal justice or detention systems because of their mental illness.
- To train custodial staff to recognise and respond appropriately to mental illness so that human rights abuses do not occur through misjudgement, ignorance or prejudice.
- To deliver effective, appropriate mental health services to people in prisons and detention centres.

84 People with a mental illness are overrepresented in all types of custody, including the criminal justice system and the immigration detention system. This over representation is, in part, a factor of the failure of the mental health system to provide adequate support for consumers at risk of incarceration. It is a result of the failure to build sufficient intersectoral links, as previously discussed, and to provide adequate crisis care which does not have to rely on police and private security to handle situations where there is abusive or violent behaviour.

85 The symptoms and behaviour of people with mental illness, once they are in custody, are frequently misunderstood by untrained custodial officers to the extent that human rights abuses are a common occurrence. A failure to notify the family or carer of a person with a mental illness of their detention has resulted in the inappropriate detention of consumers. Where consent to talk to family or primary carers is refused by acutely ill consumers, custodial services rely on the ability of a vulnerable consumer to represent their own histories accurately and advocate for their own needs. This is compounded where the person is from a different culture or speaks a different language.

86 People with a mental illness often do not have the resources to cope with the discipline, routine and regimented behaviour required in custody. More explicit legislation providing harsher penalties for abuse of human rights is not the best way to address this issue. Keeping people with a mental illness out of custody in the first place is the most important. The Thomas Embling Hospital in outer Melbourne provides an example of alternate models of secure care based on innovative treatment and rehabilitation. Training and education for custodial officers will also help but it is worth noting that where reforms in the prison system are being introduced, for example Queensland and South Australia, they are not being driven by the NMHS.

87 The critical factor in preventing human rights abuse in custody is the provision of sufficient, appropriate specialist mental health services within prisons and detention centres. These specialist services cannot be contracted out to providers who operate outside the mainstream health care services. They need to be part of the spectrum of care; they need to be staffed by professionals trained in forensic mental health who met professional standards and regulations. They need to have regular and timely access to those in custody. They should conduct regular assessments of people at risk at least on a fortnightly basis in an appropriate setting conducive to making an effective assessment. In light of these requirements for professional assessment and care, the placing of prisons and detention centres in remote locations itself mitigates against appropriate treatment.

88 As importantly, there is no capacity to gather together any material which would give an overall picture of the extent of human rights abuses in prisons and detention centres. Critical incident reports and occasional inquiries by Auditors-general, ombudsmen and the like, are no substitute for a systematic reporting and analysis. Without such reporting and follow-up these systems will continue to exacerbate the condition of people with mental illness through inappropriate, often inhumane treatment. It is only when we are confronted with cases such as that of Ms Rau, that government agencies are forced to look at the level of human rights abuse within these facilities. Starting with a single incident, the numbers of people in a predicament similar to that of Ms Rau has risen to over 30.

89 Nor is the extent of human rights abuse of people with mental illness in the wider community measured, despite the fact that, where people with mental illness are isolated and unsupported, they are vulnerable to abuse in every aspect of their lives from housing through to their social activities. Many survive in the community because they don't make trouble but are ignored by the mental health system - and its data - when it comes to their right to access health, education, employment and participation in the community.

90 It is clear of the high number of people who are in prisons with mental illness that many are from CALD backgrounds. It is the experience of members of the MMHA consortium that many people from Middle Eastern, Pacific Islander and various Asian backgrounds are over represented in this group. An alarming trend has also been that newly arrived refugees from African countries with mental health problems are increasingly in contact with the juvenile and criminal justice systems. Many of these could have been prevented with the availability of early intervention and prevention programs for CALD young people at risk. Unfortunately the few such programs in Australia are usually one-off funded projects rather than ongoing funded programs.

91 Detention and incarceration are also factors in an increased incidence of mental illness among refugees and immigrants who are detained. The experience of the MMHA consortium members who are involved in the delivery of clinical services is in line with what is now a growing body of research and literature condemning the impact of immigration detention on the mental health of detainees. The issues of prolonged detention, lack of safety and security, uncertainty about the future and past traumas has meant that many of those who have been released into the community have required specialised mental health treatment and services.

O The Impact of Incarceration on Children

92 *A last resort?* the Human Rights and Equal Opportunity Commission's report on children in immigration detention documented the serious detrimental impact of detention on children. It found that detention inherently circumvents a normal family environment, contributes to anxiety, distress and self-destructive behaviour including self-harm. While the report recommended that children in detention have access to the mental health care services they need, it is in no doubt that in fact "the only effective way to address the mental health problems caused or exacerbated by detention is to remove them from that environment."

P Protecting Human Rights in Mental Health Facilities

Reference k: The practice of detention and seclusions within mental health facilities and the extent to which it is compatible with human

rights instruments, humane treatment and care standards and proven practice in promoting engagement and minimising of treatment refusal and coercion.

93 The abuse of human rights within mental health care facilities is associated with the failure to implement the National Mental Health Strategy appropriately. This failure is manifested under three general areas of concern to the Council:

- Re-institutionalisation of people with a mental illness in mental health facilities in the general hospital system and in the community; and the abuse of human rights which can occur as a result;

- Use of police and security staff instead of trained mental health workers where there is a threat of violence or self harm in mental health services; and

- Application and monitoring of service standards within secure mental health facilities.

94 It is clear to the Council from its work with consumers and carers that one of the first casualties of an under-resourced mental health system is human rights. This is exacerbated by using staff who may be untrained or inappropriate, overworked or unsupported, to manage people who are exhibiting the often extreme behaviours associated with mental illness. There is a tendency in untrained staff to associate such behaviour with defiance, a challenge to authority or even a lack of morals and to respond within a long standing practice of meeting violence with force, threats with abuse and misbehaviour with punishment and withdrawal of remaining rights. Detention and seclusion are too often used within this punishment regime instead of alternate strategies of care and restraint.

95 Many consumers report such responses from staff within mental health facilities in both in *Out of Hospital, Out of Mind* and in *Not for Service* so we do not intend to repeat them here. They also report a failure of the grievance system designed to prevent or reduce such incidences but again, there is no comprehensive data available. There can be no doubt though, that there is insufficient funding, training and support for staff working in such facilities. There is constant pressure on them to accept more placements and because of rationing of care, patients more often present with more extreme behaviours. The Council considers, once again, that all the right policies are in place. It is the implementation and funding of strategies to prevent human rights abuse that is still missing.

Reference d: The appropriate role of the private and non-government sectors.

96 The Strategy placed some reliance on the belief that private services would move in to supplement inadequate public mental health services, as happened in the aged care and child care sectors. According to figures in the 2004 Mental Health Report there has been a 38% increase in beds in private hospitals since 1993 and the private sector has increased its shifted its overall pattern of care towards community based outpatient care, with 75% of total private admissions on a same day care basis. This increasing extension of the role of private hospitals to community based care is welcome. However, there has been a fall in services provided by consultant psychiatrists and access to such services remains limited in the main to large population centres, thus reducing the effectiveness of primary and secondary care services in rural and remote areas.

97 The 2004 report shows that 37 private psychiatric hospitals, or 95% of private sector psychiatric hospitals, were participating in the introduction of consumer outcome measurement. There are no details on what the outcomes were, and the major focus in the report is on the uptake of private services. The impact of this uptake on public services is not documented. It is therefore very difficult to make any determination on the impact of private services on the overall Strategy.

98 Expectations that an increase in private services would take pressure off public services have yet to be proven but it is clear that private services do rely on significant public funding to operate. For example, the 50% reduction in MBS rebate (after 50 private consultations in 12 months) was associated with a decrease in private psychiatric consultation and 2-3% decline in government funding each year since 1996/97.

99 The role of non-government sector is a little clearer, if only because NGO's are more visible in community debate about the quality of mental health services. The NGOs provide a wide range of services and are often best placed to provide essential links into the community and between services. They are to some extent the engine room of reform because of these links and because of their capacity to run flexible and consumer-centred care.

100 However, in some instances, shifting service provision to NGOs is seen as a cost cutting measure and this is completely counter-productive to the intent of the NMHS. NGOs need to be formally acknowledged as full partners with governments in service provision. This must include open negotiation in fixing the actual costs of service provision in accordance with national mental health standards including indexation of salary and operating costs, and the cost of appropriate staff recruitment and training. They have to have the same capacity to access and use the planning and management tools, for example data collection, which other providers of mental health services have. This is essential to the integration and improvement of services across the mental health system.

Q Data and System Improvement

Reference o: The adequacy of data collection, outcome measures and quality control for monitoring and evaluating mental health services at all levels of government and opportunities to link funding with compliance with national standards.

101 Despite the best efforts of governments and service providers alike, the failure of the Strategy to deliver on its policy promises is in large part a result of the Strategy's inadequate data and system improvement strategy. Data is collected, analysed and reported on, but its weakness is that it tests the policy, not service levels. It measures the amount and placement of current funding against the Strategy's goals, but does not yet report on consumer outcomes. It does not collect data which could improve reporting and accountability, for example consumer, carer and provider data on their direct experiences of service provision. The data systems are presently good at measuring what is being done instead of showing what has been achieved in outcome terms and what should be done.

102 A further failure of the data system is that its use across specific elements of the NMHS is not effective. Firstly, recent data is not available – 2001-2002 is the most recent data quoted in the National Mental Health Report 2004. What information there is, is not being applied to resource allocations, system management nor at patient levels to improve service delivery and outcomes because it is not relevant at these levels and the quality of the data is simply inadequate. Most importantly, there is no culture of using data as major aids to decision making.

103 The Strategy does not rely on its data collection and reporting to drive service improvement in because, in its original design, it relied on service standards to drive change. However, service standards are not delivering sufficient change in the system to improve service levels because the sector is slow to implement these standards and even slower to audit them. This is probably another sign of under-resourcing. It took until June 2003 for almost 90% of all public mental health services to have commenced a service review and to date only 47% had completed their first review against these standards.

104 The National Practice Standards for Mental Health Workforce training has yet to be implemented so there is still a huge gap in the system improvement strategy there. There are no standards set for consumer and carer participation and no standards set for community-based services working with people with a mental illness.

105 In addition, standards don't work on their own to bring about service improvement where there is no accessible data measuring their effectiveness and impact, or process for using data-based assessments to improve behaviour and systems. For any standards to work properly, they

need to have public independent auditing, robust process improvement methodologies and public reporting on the implementation of improvement. The National Mental Health Report is only collecting data on whether the standards are in place or not. There appears little chance it will be able to report on whether these standards are actually met.

106 Consultations with all jurisdictions in March/April this year by the Council show there are initiatives to put in place some direct surveys of experiences of care. However none of these were independent of the state mental health branches.

R Consumer and Carer Participation

Reference g: The role and adequacy of training and support for primary carers in the treatment, recovery and support of people with mental illness.

107 The NMHS is still not adequately including consumers and carers in formal planning and evaluation processes. At the moment their involvement is designed for them by others and will, of necessity, meet the needs of system managers rather than their needs. This moderates their ideas through managerial eyes; their problems and understandings of the system, new ways of looking at things, are unnecessarily filtered by others.

108 Consumers and carers nominated to committees and working groups lack sufficient on-going administrative support, hence their ability to both develop well-based input and communicate outcomes is severely restricted. They are presented with complex business systems and asked to provide meaningful comment without any support. Senior bureaucrats can and do rely upon information systems and statistical experts. The mental health system needs to recognise that consumers and carers currently bear the burden of the financial cost of capacity building, training and time in order to contribute as much as they do at present. In order to contribute more fully, this activity needs to be properly resourced. Some governments are working to fill his gap, for example, the West Australian Government has very recently announced funding for a panel of trained carer representatives who are available to participate in forums and committees that steer community involvement in mental health policy.

109 The National Mental Health Strategy has also lost step with changing community expectations in terms of support for carers in their personal responsibilities. The majority of funding for carer training and support is only available through generic carer support programs where the NMHS does not have a role. The generalist programs have little ability to focus on the specific needs on mental health carers, even if they had the funds to do so. Some of the identified differences are the stigma of mental illness, the course and onset of the illness, financial impacts, dual diagnosis and the rejection of the carer. *Out of Hospital, Out of Mind* documents the

experiences of many carers who struggle to cope without support, information or training to help them in this role.

110 Again, there are some areas where this support is available and effective. The Victorian Government has funded an extensive network of carer peer support workers who work closely with the social worker, nurses and other staff in a range of facilities including aged persons mental health faculties and psychiatric services. The Carers NSW Mental Health Project has developed a framework for carers of people with a mental illness which seeks to normalise what is often a frightening and isolating role.

111 Of particular importance to carers is their access to information about treatment, medication and discharge planning. Where this access is denied at the request of the consumer, it places the carer in a very difficult situation. The NMHS should coordinate the development of a nationally consistent process which recognises the role of carers as a critical factor in successful community-based care and clarifies the interactions of the right to privacy for the consumer and the right to know for the carer so as to promote the best outcome for the consumer and carer.

Reference n: The current state of mental health research, the adequacy of its funding and the extent to which best practice is disseminated.

112 The folding of mental health research funds from RADGAC into the NHMRC was presented as an opportunity to build links with other research programs and to improve the overall standard of research, but it has in fact had a seriously adverse effect on the NMHS. It has focussed research funding on clinical and scientific research when the Strategy was designed as a continuous improvement process, a process in which applied research and investigation is needed to determine better ways for delivering service.

113 It is important to understand the multi-disciplinary nature of mental health research and that the consumer experiences and perspectives are integral to developing effective interventions.

114 What is needed is NMHS specific research funding focused on improving services to mental health consumers and an increase in mental health research funding from its current level of 3% to 10% if it is to cover all necessary aspects. In addition there is very little funding for disseminating the results of relevant research through the increasingly diverse mental health service sector. Disseminating findings from the research settings into clinical and non-clinical practice is essential to change the experience of care for consumers and carers.

115 Multicultural mental health continues to be an area where there is limited research. The study on Research Priorities in Mental Health in 2001 found

that trans-cultural comparisons figured in only 0.6% of articles and 0.04% of research funding. (MMHA)

S Things Outside the Strategy's Scope

116 The previous comments reflect on the National Mental Health Strategy, which has of necessity, limits to its scope. The funding, evaluation and management of the Strategy is unable to address issues which lie outside this scope and this is the reason often cited for an inability to respond to criticism.

117 Our chief concern about the Strategy is that, while it does not report on its ability to meet unmet demand, it has no capacity to generate planned and sustainable responses to that need.

118 There are other issues here however, which reflect badly on the Strategy's capacity to lead or direct effective responses to the crisis in mental health. It has not implemented sustained population measures to address public ignorance and distrust. While some work is being done here with BeyondBlue and state and territory initiatives such as VicHealth's Promoting Mental Health and Wellbeing, this is presently ad hoc and piecemeal. Broad population measures which impact upon the community as a whole must be implemented if real change is to be achieved. For example, school bullying is a key contributor to youth and adolescent depression, yet the Mind Matters program in schools is limited in its scope and application. While its impact has not yet been assessed, there are some doubts that a limited program of this type can have any long lasting impact where it is not supported by broader community strategies.

119 What is required is a sustained, ongoing public information and education campaign with a variety of carefully planned, long term strategies designed to dissolve the stigma attached to mental health issues; to encourage a positive approach to and promote active treatment of high prevalence illness such as depression, anxiety and personality disorders; and to promote support for long term, community based treatment of people with low prevalence illnesses. Over the past twenty five years state, territory and federal governments have funded long term campaigns on drug and alcohol abuse, HIV prevention, domestic violence and reducing the road trauma, all of which have achieved documented changes in behaviour and public opinion. In some instances Australia has developed the world's leading social marketing programs. It is time to apply similar strategies and resources to change how the Australian population manages their mental health and wellbeing.

120 The Strategy does not address the exclusion of people with a mental disorder, from the workplace because of lack of support or ignorance and fear in the workplace. By not addressing these issues, the Strategy fails to provide pressure, impetus or leadership for the necessary changes in

support services and the average workplace. It is an essential part of early intervention, primary and secondary care for people to maintain engagement with work if at all possible and to be able to achieve an orderly and successful return to work where their illness has required them to leave.

121 But there are more than personal health outcomes at stake in improving the rate of employment for people with mental illness. By increasing the participation in work of those on disability support pension for psychological reasons, from the current 29% to 60% would create sufficient savings in social security costs to fund many of the other initiatives proposed in this submission. Simple and effective measures for achieving this goal include targeted workplace support programs, workplace education initiatives, providing meaningful re-training and employment options and improving workplace practices.

122 The current barriers to returning to work such as health cost disincentives and the impact of supplementary benefits need to be addressed so that people would be able to return to work without putting their mental health care plan in jeopardy. The long term benefits of a higher rate of return to work for consumers, cares and the community make this a high priority in immediate mental health planning.

123 The Strategy does not address cross-border relationships and the difficulties caused in border communities by a jurisdictional-based funding model. Again, *Out of Hospital, Out of Mind* and *Not for Service* document the impact of being 'locked out of' a nearby mental health service because it is located across a state or territory border. Even at regional levels, there is evidence that services are withheld from consumers in need because of their location. While the planning and resourcing of health systems depends on regional allocation of resources and services, this should not be an excuse to deny service to someone in need.

124 Despite its focus on what mental health services cost the Australian community, it does not track the cost of lost education, employment and community participation. About 27% of disability costs are due to mental health problems and illness; less than 30% of people with a mental illness participate in the workforce, despite the evidence that for many of them, working would contribute to their recovery. 15% of total disability allowances are paid to people with a mental illness, again an area for considerable savings if the proper care and support could be provided to assist people back into the workplace. In addition, it does not count the cost of crime, policing and financial impacts on households in assessing the cost of mental health.

125 It does not address the shift in the mental health sector to police and security services which are filling gaps in crisis care when there is a threat of violence or community concern about a mentally ill person. The Police

Association of NSW, in its submission to the 2002 Inquiry into Mental Health Services in NSW, documented direct police experience of being used inappropriately in the detention, transportation and supervision of people with a mental disorder. "We are often required to transport these people but they are not criminals, they are ill," a police officer told a MHCA forum. At times the police officers themselves have been locked up with the patient and the staff have refused to release them. It is noteworthy that when people became concerned about Ms Rau's safety they called the police, not a mental health team. This is cost-shifting at its worst, where under funding reveals a dangerous gap in services.

126 It does not address the inequalities that are emerging in the shift toward private sector provision of services. It is difficult to establish that the growth in private sector services relieves any pressure on demand for public services. At best, it is meeting unmet need in the private sector which would, in all probability have never impacted on public services. The concept of the private sector delivering services to relieve public pressure is largely unattainable, given the economic impact of mental illness on most consumers and the range of services required across the community service sector.

T Formal Recommendations

In the light of its extensive research and consultations over the past few years, the Mental Health Council of Australia makes the following recommendations.

1 That the National Mental Health Strategy develop and permanently fund better models of service delivery including:

   a. Rapid expansion of youth friendly mental health and primary care services and development of new models to meet emerging needs at a cost of approximately $50 million per year.

   b. Increased development and implementation of 'stepped care' programs.

   c. Increased use of non government organisations, where appropriate, in the delivery of care.

   d. Increased use of early intervention programs within the broad spectrum of community based services.

   e. A new spectrum of acute care programs which work better with the community care model of service delivery.

   f. Increased funding for education, employment and participation of people with mental health problems.

   g. Specialised recovery and workforce participation programs.

   h. Specialised support and service modules within the prison and detention systems.

2 That the NMHS increase and more effectively fund consumer and carer participation:

   a. New funding should be allocated to educate, support and assist consumer and carer participation in the mental health care system.

   b. Real consumer and carer participation in policy, planning and implementation of services to people in Australia with mental health problems based on world's best practice.

   c. Establish the system wide use of consumer and carer consultants as an essential component of the mental health workforce.

3 That the National Mental Health Strategy address mental health workforce issues to resolve shortages of suitable staff through funding for:

a. Better use of the skills and services of trained psychologists to relieve the pressure on psychiatric services.

b. Subsidised training in areas of need.

c. Faster implementation of workforce standards.

d. Proper grievance and dispute resolution procedures to ensure high workforce standards are maintained.

4 That the National Mental Health Strategy improve cross-sectoral linkages for example:

a. Developing strategies to address co-morbidity, particularly in the aged, young people and in indigenous communities.

b. Using models such as HASI to develop better access to housing, education and general health care for people with a mental disorder.

c. Direct involvement of the Department of Prime Minister and Cabinet in co-ordinating Attorney General, Immigration, Human Services, Education, Employment departments to improve treatment for mental health illness in people in detention and incarceration.

d. Direct involvement of Premier's departments in improving state/territory linkages in treatment for mental health illness in people in detention and incarceration

5 That the National Mental Health Strategy establish national standards of forensic and restrictive care and ensure that services provided in the prison and detention systems are operated within those standards.

6 That the National Mental Health Strategy, in conjunction with Attorneys-General in Commonwealth, state and territories, develop safeguards to ensure people in Australia with mental health problems have the same access to human rights protections as all other people in Australia and the same guarantee of respect by health care professionals.

a. As part of this process, the NMHS should coordinate the development and application of nationally consistent guidelines which balance the right to privacy for consumers and the need to share information with carers and other service providers.

7 That the Commonwealth Government commit to bringing mental health expenditure to the level where it better reflects the actual burden of disease. To do this, the Commonwealth needs to:

a. Commit to an increase in Commonwealth funding of $1.1 billion per year over next ten years, commencing in the 2006-07 Federal Budget.

b. Commit to further funding increases, tied to State and Territory funding increases, to bring national mental health funding up to a level commensurate with the burden of disease over the next ten years.

c. Commit the bulk of new funding to community services to address primary and secondary care needs.

d. Commit specific new funding to increasing services which assist people with mental health problems to participate in employment, education and the community.

e. Commit specific new funding for population measures designed to remove the stigma associated with mental illness and to promote prevention and early intervention.

f. Commit specific new funding to provide education and support, including CALD specific initiatives, for consumers and carers which enables them to participate more fully in:

   - planning and implementing their care; and

   - in contributing to the overall planning, delivery and evaluation of mental health services

g. Adjust existing funding for acute care beds to:

   - distribute beds in accordance with population densities and address unmet needs eg in rural areas and in growth areas

   - work more closely with step-up/step-down services rather than a stand alone response to crisis.

   - distribute beds in accordance with population densities and address unmet needs eg in rural areas and in growth areas

   - work more closely with step-up/step-down services rather than a stand alone response to crisis.

h. New funding for acute care should refocus on delivering a seamless service provision system which links primary, secondary and acute services to best meet the needs of individual consumers.

i. New funding should be ongoing and tied to a "reform/perform" independent assessment and reporting system which is administered along the lines of the National Competition Council

j. Existing funding mechanisms should be adjusted to bring them into line with the new funding (not the other way around as is more usual):

- National funding agreements should better reflect the more stringent "reform/perform" reporting requirements

- The Medical Benefits Scheme (MBS) should allow for a more effective use of GP and psychologists' services by providing benefits which reflect the added time and cost of servicing patients with mental health problem.

8 That the National Mental Health Strategy establish real 10 year targets for mental health outcomes including but not limited to:

a. That 60% of those with mental problems or illnesses be provided with care in any 12 month period (currently this figure is 38%).

b. Disability costs due to mental problems and illnesses be reduced from 27% to 20%.

c. Disability costs among 15-34 year olds attributable to mental illness be reduced from 60% to 40%.

d. Participation in work rates among those on disability support pensions for psychological reasons be increased from 29% to 60%.

e. A real reduction in the rates of suicide for persons with a mental illness.

f. Suitable population health outcomes.

g. That the NMHS establish a more independent and rigorous accountability process, more closely aligned to practice and service delivery and more directly informing the continuous improvement process on a perform/reform basis. New performance indicators should be based on consumer, carer and service provider outcomes, rather than Strategy processes. The MHCA is the appropriate independent, national body to undertake routine national surveys of the experiences of care of consumers, carers and providers.

9 That the Commonwealth Government establish regular, frequent and formal reporting mechanisms to the Prime Minister and Heads of Governments on specific key indicators including an annual public report

to the Prime minister, "The State of our Mental Health", with data which reflects user and carer experience, not just system measuring indicators. Leadership of this process should be vested in an independent, empowered national office or person with direct access to the Prime Minister.

10 That the day-to-day responsibility for the National Mental Health Strategy within the Commonwealth Government rests with the Cabinet level Minister.

11 That the Commonwealth Government increase workforce participation for people with mental health problems to participate in the work force in real jobs, through its existing social services structure and through:

a. A coordinated, jointly funded Federal-State government commitment to implement a clear pathway for people with mental health problems to participate in the work force in real jobs.

b. Specific allocation of funding under the Disability Review to specific strategies to assist people with mental health problems to access and retain employment.

c. Ensuring re-entry to welfare safety nets is readily accessible if and when it is required due to ill health.

d. Providing programs to increase employer participation and deal with workplace stigma.

12 That the National Mental Health Strategy increase community support for mental health by increased funding for community education in mental health and reducing the stigma of mental illness to $20 million per year over the next five years.

13 That the National Mental Health Strategy investment in medical research and innovation reach 10% of all health research funding by 2010 with:

a. Specific funds allocated through a non-medical organisation such as the Australian Research Council, to supporting research and investigation into effective care and improvement of outcomes for people with a mental illness.

b. Specific funds allocated to communicating the outcomes of this research to the wider mental health sector and training service providers.

U Glossary

Note: this glossary indicates the usage applied to the following terms in the Mental Health Council of Australia's submission to the Senate Select Committee on Mental Health. It draws on the glossary in the National Mental Health Plan 2003-2008 but also reflects preferred usage within the membership of the MHCA.

Acute care: specialist psychiatric services for people who present with acute episodes of mental illness. Such episodes may be characterised by recent onset of severe clinical symptoms of mental illness that have potential for prolonged dysfunction or risk to self and/or others.

Carer: A person who provides unpaid support and care, usually a family member or friend whose life is affected by a close relationship with a consumer.

Community based services: government and non-government agencies providing services within a community setting, including mental health clinics, outreach services, case management and support services, advocacy and access to inter-sectoral services such as housing, education and income support.

Consumer: a person who is currently using, or has previously utilised, a mental health service. This term may also include potential consumers who have not yet accessed services, often because of accessibility issues.

Disease burden: the impact of mental illness on the psychological, social and economic wellbeing of consumers, carers and their families, caused by premature mortality and disability.

Early intervention: timely interventions which target people displaying the early signs and symptoms of a mental health problem or a mental disorder. Early intervention also encompasses the early identification of patients suffering from a first episode of a disorder.

Forensic services: mental health services provided within the context of legal and/or prison systems to people with mental illness.

Mainstream health services: services provided by health professionals in a wide range of agencies including general hospitals, general practice and community health services.

Mental health: a state of emotional and social wellbeing in which the individual can cope with the normal stresses of life and achieve his or her potential.

Mental health problems: a disruption in the interaction between the individual, group and the environment, producing a diminished state of mental health.

Mental illness: a clinically diagnosable disorder that significantly interferes with an individual's cognitive, emotional or social abilities.

Morbidity: the incidence of disease within a population.

Non Government Organisation, NGO: private, not-for-profit, community managed organisations that provide community support services for people.

Outcome: a measurable change in the health of an individual or group of people within a population, which is attributable to interventions or services.

People with mental health problems: people whose emotional and social wellbeing is at risk because of a diminished state of mental health.

People with a mental illness: people with a clinically diagnosable disorder, which may or may not be recognised, who are experiencing significant interference with their cognitive, emotional and social abilities.

Prevention: individual or population based measures which address potential mental health problems or illnesses and which can help address the problem or illness, prevent its escalation and minimise its impact on individuals, their carers and their community.

Primary care: the detection, diagnosis and treatment of mental illness and mental health problems in the general health and community sectors.

Rehabilitation: interventions aimed at reducing functional impairments that limit the independence and participation of consumers in family, community and vocational life.

Secondary care: specialised mental health services which provide stabilisation and rehabilitation, usually as part of a long term care plan and within a community setting.

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