



MENTAL ILLNESS FELLOWSHIP of Australia Inc

MENTAL HEALTH RESEARCH— principles and priorities for the future

**Paper 5 in a Series of 5 Position Papers to raise
awareness of the needs of people with a mental
illness in Australia**

**For more information and a summary of all 5
papers, (40,000 people missing out on mental health
services) visit the MIFA website www.mifa.org.au**

JULY 2010

The Members of MIFA are the:

- *Schizophrenia Fellowship of New South Wales*
- *Mental Illness Fellowship of North Queensland*
- *Mental Illness Fellowship of Queensland*
- *Mental Illness Fellowship Victoria*
- *Mental Health Carers Northern Territory*
- *Mental Illness Fellowship of South Australia*
- *Mental Illness Fellowship of Western Australia*
- *ARAFMI Tasmania*

Combined, these organisations have fifteen thousand members, many of which are family or corporate members and therefore represent many more people than the membership number.

From the President

The Mental Illness Fellowship of Australia (MIFA) is a not-for-profit coalition of mental health organisations that supports people with serious mental illnesses, their families and friends. Such illnesses include schizophrenia, major depression, bipolar disorder, obsessive-compulsive disorders and anxiety disorders. MIFA is committed to maximising opportunities for recovery through hope, choice and improved capacity for decision making for all people affected by serious mental illness.

MIFA is the largest grass-roots organisation in mental health in Australia with in excess of 15,000 members within its eight member organisations. The majority of members are consumers and carers with approximately 20% of membership being organisations, mental health services, health professionals and others.

The role of community based service providers is to work with and support people with mental illness to self manage their illness and to be active in their own recovery, acknowledging that each person's journey of recovery is a personal process.

In 2007, MIFA undertook the "Australians Talk Mental Illness" survey. We received more than 2,000 responses from people with mental illness, family members and carers, other members of the State and Territory organisations and medical professionals.

The responses presented a compelling snapshot of the experiences, opinions and feelings that a variety of Australians have towards mental health issues. The key Federal issues identified included:

- **Appropriate housing and support;**
- **Consumer and carer education and support;**
- **Social security impacts on consumers and carers;**
- **Employment opportunities; and**
- **Research to develop evidence based service models delivered in the community.**

In 2010 MIFA has commissioned research to provide an update of the issues identified in the survey of 2007. The result is a series of 5 position papers which are available on the MIFA website.

The papers also seek to identify progress in these priority areas since the last federal election and those matters that require urgent action, some outstanding for many years.

We need fundamental reforms and increased investment across all sectors involved in supporting people with mental illness if we are to better meet the needs of Australians with a mental illness, their family members, friends and carers.

The Governments own estimates are that more than 50,000 Australians with severe and persistent mental illness urgently require support from community mental health services.

In the last three years, new funds obtained through the COAG initiatives appear to have reached 10,000 people, 40,000 Australians are still waiting.



ROB KNOWLES
CHAIRPERSON MIFA

THE FACTS

1. Almost half (45.8%) the respondents to the MIFA “Australians Talk Mental Illness” survey identified the need for more and better research into mental illness as a priority. Overall, it ranked fourth in importance, behind housing (70.1%), employment support (60.1%), consumer and carer education and support (48.6%).
2. Similar research undertaken in a poll of public opinion by Research Australia in 2009 indicates that 75% of the Australian community thinks there is not enough information available to youth about mental health. Only 4% think there is enough¹.
3. Research Australia’s 2008 poll indicated that the Australian public judged mental illness as their second most likely disease risk (39%), after arthritis (43%)². Australians have a strong appreciation of the prevalence and consequences of mental illness and the need for research into effective treatments and services.
4. Mental illness is one of the top three leading causes of burden of disease and injury. In 2003, mental disorders accounted for 13% of the total disease burden and 24% of the non-fatal burden in Australia³.
5. Mental illness accounts \$20bn per year in lost productivity to the Australian economy and for 19 million absentee days from the workplace⁴.
6. According to the National Survey of Mental Health and Wellbeing in 1997 mental health care was provided to 38% of people who experienced a mental illness over the preceding 12 months⁵. The 2007 Survey indicated this figure was 35%⁶. The past decade has failed to see Australia lift the rate of community access to mental health services. The reasons why people with a mental illness are not accessing care have not been researched.
7. According to the Australian Institute of Health and Welfare’s latest report into health expenditure, the total Australian recurrent health expenditure now tops \$104bn per annum⁷. Spending on health research accounted for 2.8% of total recurrent expenditure or \$2.73bn. Research has grown as a component of total health expenditure by more than 11% per year since 1997-98.
8. Of publicly-funded research, the Federal government funds around 80%, state and territory governments 14% and other sources the remainder⁸. Of Federal government funding for research, 90% is provided by the National Health and Medical Research Council (NHMRC).
9. In 2007 mental health received just over 8% of all NHMRC funding ranking it the fourth highest area funded after cancer (23.5%), cardio-vascular (17%) and diabetes (8.5%).

Research and Evaluation

Progress in achieving better consumer outcomes in mental health depends on the availability of adequate research into causes of mental disorders and evaluation of the effectiveness of various service interventions. In mental health, these research and evaluation issues are particularly complex, as they are grounded in knowledge from many fields, including the biomedical, psychological, and social sciences.

Mental health research has traditionally been given a low priority in gaining access to research resources.

As there has been no consistent collection of mental health data across the States and Territories, the application of a national policy approach has been limited, constraining mental health planning and making utilization review and quality assurance of programs difficult.

Objectives:

- *To promote basic and applied mental health research and its application in prevention and intervention programs.*
- *To institute regular review of outcome of service provided to person with serious mental health problems and mental disorders as a central component of mental health service delivery.*
- *To develop a national mental health data strategy*

**National Mental Health Policy
Australian Health Ministers
Canberra 1992**

MENTAL HEALTH RESEARCH IN AUSTRALIA

Overview of issues

Mental health advocates and reformers have been calling for a fair deal for mental health funding for some years⁹. The focus of such calls has largely been for more funding for services and treatments. This is not surprising given the statistics indicating that Australia has failed to lift the rate of access to care for people with a mental illness over the past decade¹⁰.

Such advocates often point to the significant gap between the burden of disease represented by mental illness and the amount of funding it receives in the health budgets of state and federal governments.

Just as mental health services struggle to achieve decent funding so too does mental health research. Despite the intent in the National Mental Health Policy back in 1992 and commitments made in subsequent national mental health plans, Australia lacks a substantive infrastructure to support quality mental health research.

This position paper outlines a range of challenges for the future. The top three priorities are:

- A commitment by Government to lift the level of investment in mental health research to a level commensurate with the burden of disease imposed by the illness and the development of Australia's first ever National Mental Health Research Strategy;
- The establishment of a national centre of mental health research excellence to carry out key functions not currently being undertaken such as:
 - Providing a clearing house function to take stock of the mental health research currently underway across Australia;
 - Establishing a framework for the prioritization of future mental health research with specific targeting of research into the experience of consumers and carers and the impact of social and community support services, not merely bio-medical approaches;
 - Developing a new mental health research workforce with particular emphasis on the establishment of consumer and carer research expertise; and
 - Improving coordination and dissemination of research to practice and policy and funding
- The establishment of an evidence-based, research-driven approach to mental health policy and program funding, including:
 - Nationally consistent benchmarks
 - Independence and transparency in service evaluation
 - A new national accountability framework for mental health in Australia
- An audit of all mental health related research, including that carried out by the National Health and Medical Research Council and more broadly. This audit would not only collate areas of research but also build a picture of those organisations currently (or potentially) working in the field.

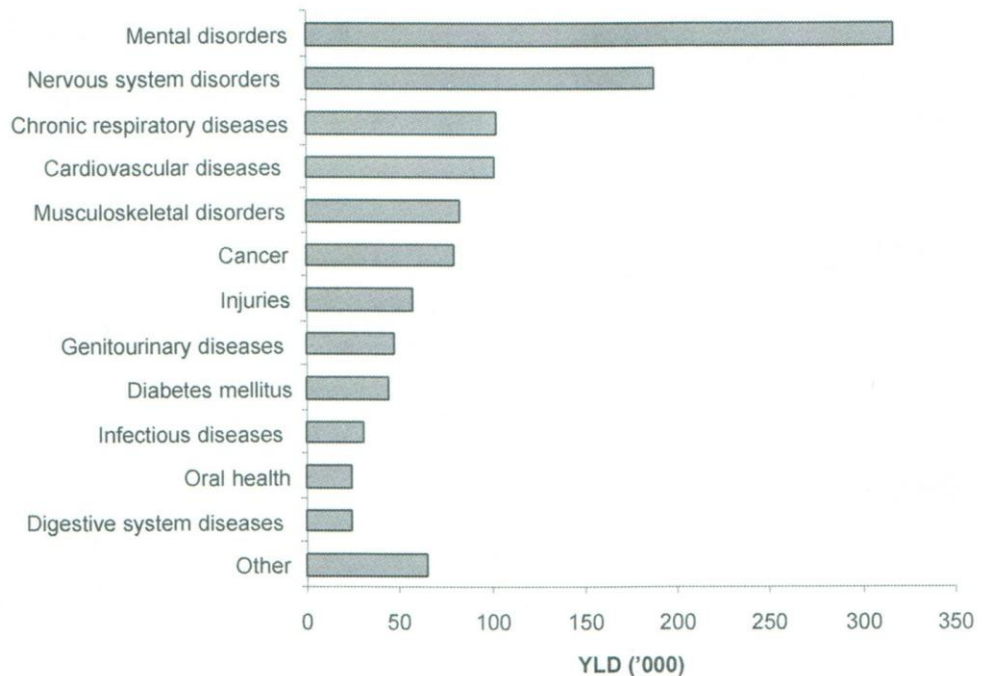
THE NATURE OF MENTAL ILLNESS AND IMPLICATIONS FOR RESEARCH

The nature of mental illness has implications for how best to shape Australia's mental health research efforts. Other diseases like heart disease and cancer may take more lives, but no other illness causes as much ongoing suffering and disability as mental illness. The level of health burden caused by disease is often expressed in terms of disability-adjusted life years (DALYs), years of life lost (YLL) and years of life lost due to disability (YLD).

The majority of all mental illness manifests before the age of 25, meaning the overwhelming burden of mental illness falls on the young who, unlike those with cardiovascular disease or cancer, can face many years of varying degrees of disability for many years of their lives¹¹. This is particularly true for psychosis with three quarters of lifetime prevalence occurring before age 25.

Figure 1 shows more clearly the contribution of each disease to the non-fatal burden of disease and injury in Australia in 1996¹². The non-fatal disease burden presents a substantially different picture than that provided by traditional mortality statistics: mental disorders are the leading cause, accounting for nearly 30% of the non-fatal burden (YLD) in Australia.

Figure 1 Non-Fatal Disease Burden



The nature of the disease means that many people with a mental illness, particular chronic or severe illnesses, may need contact with a range of supports over a prolonged period. Research into mental health therefore needs to move beyond bio-medical approaches and treatments to also focus on evaluating community, psycho-social services and support mechanisms so we can be sure vulnerable groups of citizens are getting access to quality health care and support over the course of their lives.

The types of research questions to be asked of all services are:

- Is the service delivering a positive outcome as assessed by the person using the service and their carers?
- Does the service represent good value for money?
- Can the service demonstrate new ways of helping people with mental illness more effectively or efficiently than existing services?

These questions are almost never asked of any mental health service, government, non-government, public or private, anywhere in Australia. While data is available with regards to simplistic measures of activity such as patient numbers or occupied bed days, key elements reflecting the quality of Australia's mental health service system go unmeasured. In this context, research and evaluation can play a critical role in sponsoring service reform and quality improvement.

WHAT AUSTRALIA NEEDS

- **The establishment of a national centre of mental health research excellence to carry out key functions not currently being undertaken such as:**
 - **Providing a clearing house function to take stock of the mental health research currently underway across Australia;**
 - **Establishing a framework for the prioritization of future mental health research with specific targeting of research into the experience of consumers and carers and the impact of social and community support services, not merely bio-medical approaches;**
 - **Developing a new mental health research workforce with particular emphasis on the establishment of consumer and carer research expertise; and**
 - **Improving coordination and dissemination of research to practice and policy and funding**

MENTAL HEALTH AND RESEARCH FUNDING IN AUSTRALIA

As stated, the vast majority of government funding for mental health research in Australia comes from the NHMRC. Australia has seven identified National Health Priority Areas

(NHPAs), of which one is mental health. NHMRC spending on the NHPAs over the past years is shown at Figure 3 below.

Figure 3 Funding Trends - 2000 to 2007, NHMRC Expenditure by National Health Priority Areas

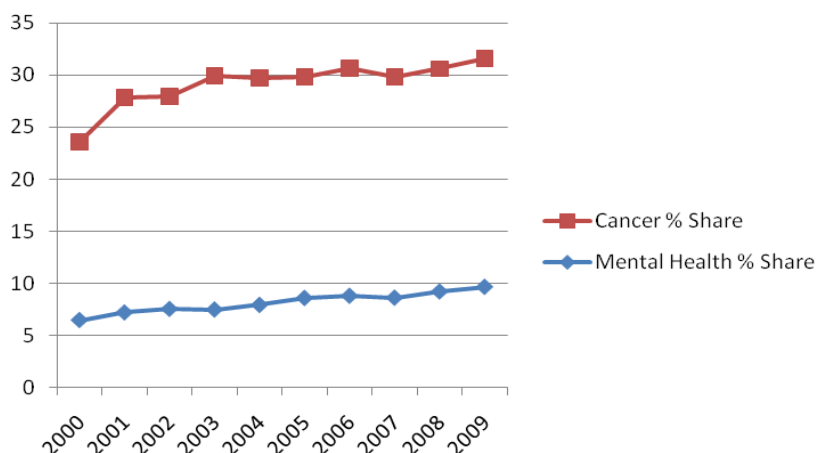
National Health Priority Area	2000	2001	2002	2003	2004	2005	2006	2007
	\$m	\$m	\$m	\$m	\$m	\$m	\$m	\$m
Asthma*	4.2	6.8	7.9	8.1	8.9	11.8	12.6	14.8
Arthritis and Osteoporosis*	4.5	7.9	9.9	11.7	14.0	16.9	18.1	20.1
Cancer *	27.8	40.5	52.0	68.1	72.6	87.5	99.1	118.6
Cardiovascular Disease*	31.6	38.5	41.0	47.2	52.8	65.9	77.9	84.6
Diabetes*	10.4	14.0	18.4	19.8	21.6	27.2	34.7	42.3
Injury	4.0	9.6	7.7	9.1	11.0	15.5	19.6	21.0
Mental Health #	10.9	15.9	21.3	24.5	27.2	33.4	38.3	42.1
Total NHPA	93.5	133.2	158.2	188.4	208.2	258.2	300.4	343.5
Total Expenditure	171.1	207.8	264.1	313.0	343.7	410.4	452.9	503.5

NB. Total expenditure includes NHMRC-funded research in areas other than NHPAs.

The disparity between mental health and the other areas is more starkly shown when considering the NHMRC's funding of cancer by

comparison in isolation, as is shown in Figure 4. Mental health funding has come from a low base and has increased slowly.

Figure 4 - % Share of NHMRC Research Funds, Cancer and Mental Health



On behalf of the Australian Society for Medical Research, Access Economics carried out a detailed investigation of the projected benefits of Australian health research and development from the year 1993 to 2042. From this investigation, it was clear that that current levels of spending on health research reflect a dominant focus on mortality. Access Economics state that areas such as mental illness have far greater significance to morbidity in the community rather than mortality and that:

...current Australian R&D spending in [mental health] is not sufficient to outweigh the expected increase in these disorders and as such, the burden of disease will be greater in the future than in 1993. Even though these disorders do not have a large burden due to mortality, they do have a large burden due to morbidity, and it is expected that this burden will apply to a larger proportion of the Australian community in the future. This highlights the need to also direct health R&D to areas where morbidity is a dominant burden¹³.

WHAT AUSTRALIA NEEDS

- **A commitment by Government to lift the level of investment in mental health research to a level commensurate with the burden of disease imposed by the illness.**

A FRESH APPROACH TO THE CONDUCT AND APPLICATION OF MENTAL HEALTH RESEARCH IN AUSTRALIA

In the absence of an agreed National Mental Health Research Strategy, priorities for research in mental health are established by means of a mixture of explicit and implicit means¹⁴, including:

- the personal scientific interests of researchers
- the priorities of those who serve as reviewers for grants and the philanthropic interests of those who privately fund research
- the availability of researchers or institutions who specialise in a subject area
- government policy
- stakeholder lobbying
- media interest
- the potential profit of the research.

In this crowded environment it is perhaps not surprising that recent evidence has shown a massive disconnect between the research priorities established by researchers and those of mental health consumers¹⁵. This research compared the research priorities identified by consumers with depression and bipolar disorder relative to the frequency of published Australian literature in these areas and the startling results are shown in the tables below.

Top Three Topics for Depression Research as Rated by Consumers with Depression versus percentage of Depression Literature

Consumer Priorities	Published Literature
Matching the individual and treatment – 95.9%	0.06%
Effective coping strategies for living with depression - 95.6%	0.27%
Evidence on effective therapies – 93.7%	2.04%

Top Three Topics for Bipolar Disorder Research as Rated by Consumers with Bipolar Disorder versus percentage of Bipolar Disorder Literature

Consumer Priorities	Published Literature
Long-term effects of medication – 95.4%	1.83%
Matching the individual and treatment – 95.4	0%
Effective coping strategies for living with bipolar disorder - 95.6%	0.61%

The top three topics identified for both depression and bipolar disorder by consumers were amongst the lowest ranked topics in the literature.

Comparison of published Australian literature with consumer priorities suggests that to date, little research has been conducted on topics consumers consider of high importance.

There are exciting, nascent developments seeking to engage consumers and carers more formally in the design and conduct of mental health research, in units such as the Consumer Research Unit at the Australian National University¹⁶.

There are also several new pilot projects aimed at gathering consumer and carer experiences of care in a systematic and validated manner such as the MH-COPES Project - Measuring and Responding to Consumer Perceptions and Experiences of Adult Mental Health Services in NSW¹⁷.

Perhaps the most highly developed of these pilots is that run by the Consumer Research and Evaluation Unit at the Victorian Mental Illness Awareness Council¹⁸. The Victorian Unit has developed a psychometrically-tested survey tool based on a set of issues and outcomes assessed as critical by consumers and carers. Computer-assisted telephone interviews are then undertaken with recent users of area mental health services across Victoria to survey perceptions of quality of care. Consumers and carers have determined the questions in the survey and are responsible for collecting the information, its analysis and reporting. They then feed information back to the area health services for the purpose of quality improvement.

While still in its infancy, this type of consumer involvement in research and evaluation is a contemporary advancement in mental health system research, reform and improvement, which contributes to building the knowledge of mental health with a consumer-centred approach.

The feedback from consumers and carers is also identified as a crucial element of the model of mental health research as supported by the Australasian Society for Psychiatric Research (ASPR)¹⁹.

The ASPR make three critical points:

1. Mental illness is not a single disease entity but encompasses several. It would make sense to at least distinguish between high and low prevalence disorders when considering research funding;
2. The targets of neuroscience, treatments, preventive and services research are interdependent but different. Mental health research needs to be designed accordingly;
3. Mental health research must be collaborative in order to cover these different aspects.

With Australia's mental health research infrastructure so underdeveloped, it is no accident that some of the key publications which have influenced mental health reform in Australia have not been produced by governments. Special research reports by organisations such as the Mental Health Council of Australia, the Mental Illness Fellowship of Australia, SANE Australia, the Human Rights Commission, the Australian Senate and various statutory officers among others have often been more the catalyst for reform, change and improvement of Australia's mental health system.

Research and evaluation is probably the most neglected area of mental health policy development and implementation. High staff turnover in government departments means the officials originally involved in policy implementation will almost certainly have left by the time an evaluation is due.

For an evaluation to have credibility it must be as transparent and independent as possible....Policy development, adoption and implementation is often seen as a political and bureaucratic exercise. However research can impact on all these levels by providing options which are scientifically validated and data which allow decisions to be made more on the basis of fact and less on the basis of political expediency and ideology.

Professor Harvey Whiteford
Can Research Influence Policy?

It is time for a fresh approach to mental health research in Australia.

WHAT AUSTRALIA NEEDS

- **The development of Australia's first ever National Mental Health Research Strategy designed to coordinate and foster Australia's research efforts across treatments and services. A central goal for this strategy must be to enable greater understanding about the impact of bio-medical, pharmacological and psycho-social services and treatments as assessed by people living with a mental illness using these services and treatments**
- **The establishment of an evidence-based, research-driven approach to mental health policy and program funding, including:**
 - **Nationally consistent benchmarks**
 - **Independence and transparency in service evaluation**
 - **A new national accountability framework for mental health in Australia**

REFERENCES

- ¹ <http://researchaustralia.org/content/documents/Research%20Australia%20Public%20Opinion%20Poll%202009.pdf>, accessed 14 May 2010
- ² <http://researchaustralia.org/content/documents/Poll%20FINAL%20WEB.pdf>, accessed 14 May 2010
- ³ *The Burden of Disease and Injury 2003*, Australian Institute of Health and Welfare, Canberra, 2007.
- ⁴ *Improving Mental Health Outcomes in Victoria, The Next Wave of Reform*, Boston Consulting Group, 2006
- ⁵ *National Survey of Mental Health and Wellbeing*, Australian Bureau of Statistics, Canberra, 1999.
- ⁶ *The 2007 National Survey of Mental Health and Wellbeing, Summary of Findings*, Australian Bureau of Statistics, Canberra, 2009
- ⁷ *Health Expenditure Australia 2007-08*, Australian Institute of Health and Welfare, Canberra, 2009.
- ⁸ AIHW, 2009
- ⁹ *Not for Service*, Mental Health Council of Australia, Canberra, 2005
- ¹⁰ ABS, 2009
- ¹¹ P McGorry, *Making Sense of Orygen Youth Health*, accessed at www.orygen.org.au, 14 May 2010
- ¹² C Mathers, T Vos, C Stevenson, *The Burden of Disease in Australia*, Australian Institute of Health and Welfare, Canberra, 1999
- ¹³ *Exceptional Returns II*, Report prepared for the Australian Society for Medical Research, Access Economics Canberra, 2008.
- ¹⁴ A Jorm, K Griffiths, H Christensen, J Medway, *Research Priorities in Mental Health*, Department of Health and Ageing, Canberra, 2001
- ¹⁵ Banfield M, Griffiths K, Christensen H and Barney L, *Study of Consumer Priorities for Research on Depression and Bipolar Disorder*, ANU Centre for Mental Health Research poster presentation to Australasian Society for Psychiatric Research Conference, Canberra, 2009
- ¹⁶ <http://cmhr.anu.edu.au/cru/>, accessed 14 May 2010
- ¹⁷ http://www.health.nsw.gov.au/pubs/2006/mhcopex_stage1_rprt.html, accessed 14 May 2010
- ¹⁸ <http://www.vmiac.com.au/research.php>, accessed 14 May 2010
- ¹⁹ <http://www.aspr.org.au/pdfs/ASPR%20submission%20senate%20mental%20health.pdf>, accessed 14 May 2010