



MENTAL ILLNESS FELLOWSHIP of Australia Inc

CONSUMER AND CARER SUPPORT— challenges for the future

Paper 2 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

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. 70.1% of respondents to the MIFA “Australians Talk Mental Illness” survey identified housing and housing support for people with mental illness as a key issue. This was followed by employment and employment support (60.1%), consumer and carer education and support (48.6%), the need for more research (45.8%) and issues pertaining to social security (45.5%).
2. In Australia, mental disorders had the highest burden of disease and injury for people aged 0- 44 years compared to any other causes.¹
3. For all age groups, mental disorders are the third highest cause of the burden of disease and injury in Australia (13%) with cancers (19%) and cardiovascular illnesses (18%) the two highest.
4. Most of the disease burden for a person with cancer or cardiovascular disease is due to premature death. However, for people with a mental illness it is the result of living for years with disability resulting directly from their mental illness, and associated physical disabilities, particularly those arising from lack of physical activity, poor diet and tobacco use
5. In Australia, it is estimated that of the 16 million people aged 16–85 years, approximately half (7.3m people) had experienced a mental disorder in their lifetime and one in five Australians (20% or 3.2m people) had a mental health disorder in the last 12 months.²
6. In Australia, mental disorders are more common in people who have experience of being homeless³, unemployed or in prison.
7. Unemployed Australians have high rates of mental disorder, a prevalence rate of 26% for unemployed men and 34% for women.
8. Estimates of the annual costs of the productivity losses attributable to employed people with a mental illness range from \$10 to \$15 billion.⁴
9. People with a mental illness are very frequent users of expensive hospital-based mental health facilities and are often caught in a cycle of readmissions and ongoing social exclusion,⁵ often leading to homelessness.⁶
10. It is estimated that 2.6 million people in Australia are providing 1.2 billion hours of care for people who need assistance due to physical, intellectual or psychiatric disability, chronic illness or old age, conservatively saving the economy \$16 billion dollars annually.⁷

CONSUMER AND CARER SUPPORT

Overview of issues

There is strong evidence that education and support for carers and consumers increases the capacity of people to self manage their illness thus reducing the risk of relapse and assists carers to better cope with their caring role and their own health within a recovery framework.

Having a family member or friend with a mental illness can have significant implications for the health and wellbeing of everyone concerned and the maintenance of the health and wellbeing of carers is as important and relevant as the health and wellbeing of the person experiencing a mental illness.

There are several examples of best practice models that offer education and support for consumers and carers. One proven example is the Well Ways Program, which is available through member organisations of MIFA.

Peer-based programs for consumers and carers offer a best practice model that operates on the basis that people are more likely to listen to someone that they can relate to because they have had similar experiences. Peer models offer the opportunity for consumers and carers to benefit from the wisdom and experience of trained Peer Educators working in effective partnership with clinical services where these are available.

Peer Educators also have an important role as expert providers of education directly to the community, which has proven to be an effective way in reducing stigma.

We need an increased commitment from governments to provide adequate funding for these successful models to be more broadly available on a secure and ongoing basis.

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

- **Ensure that consumer and carer education and support is embedded by the Department of Health and Ageing as a priority in the National Mental Health Plan.**
- **Ensure that current limited access to best practice peer-based educational programs become available nationally to increase mental health literacy and improve self-management.**
- **Fund ongoing de-stigmatisation campaigns that take consumers and carers directly to the community as trained public speakers.**

CONSUMER AND CARER SUPPORT IN THE NATIONAL MENTAL HEALTH PLAN

We need to embed consumer and carer education and support in all government policy and planning when considering mental illness.

Consumers

There is strong evidence that carer and consumer education increases the capacity of people to self manage their illness. As a consequence this reduces the risk of relapse and the overall cost to the health system.

The Fourth National Mental Health Plan⁸ refers to education in relation to:

- The need for a whole of government approach;
- The connection between education and employment for consumers;
- The training needs of workers (particularly front line workers); and
- The need to provide education to the community to raise awareness and reduce stigma.

The Plan discusses the need to link the health, education and employment sectors to expand supported education, employment and vocational programs. However, the Plan has more of a focus on employment outcomes rather than increasing education and support for carers and assisting consumers to learn the skills to self manage their mental illness.

We need to embed consumer and carer education and support as a priority in the National Mental Health Plan. This should include increasing the level of best practice programs across Australia such as:

- Peer education programs;
- Peer networks;
- Programs that utilise consumers and carers to educate the general community.

Carers

Current policies rely heavily on the availability and willingness of families and friends to provide care.¹⁰ However, the many relatives and friends that provide the majority of support and assistance for the person they are caring for are often doing this with limited training and support of their own.⁹

With more people now living in the community, it is carers that are at the centre of community-based mental health care and they are increasingly required to manage the complex health and care needs of their loved one.

There is a breadth of knowledge and diversity of skills required to fulfil the caring role.¹⁰

WHAT AUSTRALIA NEEDS

- **Ensure that consumer and carer education and support is embedded by the Department of Health and Ageing as a priority in the National Mental Health Plan.**

REINFORCE PEER-LED PROGRAMS

Research has shown that the use of peers in a variety of roles, including education provides beneficial outcomes.¹¹ This is due in part to the fact that people more likely to listen to someone that they can relate to because they have had similar experiences.

Peer educators can make a significant contribution to the quality of life of people with a mental illness by assisting consumers to:

- Better understand their illness;
- Explore various coping skills;
- Become more effective self-advocates and partners with service providers;
- Access and share information about community resources; and
- Engage more fully in their recovery.

Peer education programs for consumers assists carers through providing a brief time of respite and, with the increasing ability of the person to self manage their illness, a reduction in the burden of care.

Carers report that one of the most debilitating aspects of being a carer of a person with a mental illness is the sense of isolation and helplessness.¹² Peer education models for carers offer the opportunity for carers to benefit from the wisdom and experience of other carers that are trained Peer Educators.

Having a family member or friend with a mental illness can have significant implications for the health and wellbeing of everyone concerned. Yet the knowledge of how to care for someone with mental illness is rarely available.¹²

“Carers have the lowest collective wellbeing of any group...”. They experience higher rates of depression and are at risk of experiencing medical and psychological conditions compared to the general population.

Unfortunately, they do not seek treatment, as they have no time or cannot afford the treatment.¹³

We need a workforce that accommodates both consumers and carers as expert providers.

The National Mental Health Plan does refer to increasing the proportion of consumer and carer workers and developing a peer specialist workforce, which is welcomed by MIFA. However, there is no detail of how this will be achieved and no mention of the importance and benefits of peer-based educational programs.

Peer Educators can also play an important role in reducing stigma amongst the general community. There is strong evidence that training consumers and carers as public speakers to address groups of people in the general public about mental health is contributing to de-stigmatising mental illness.

MIFA members are leading the nation in recruiting consumers and carers who then become valuable members of staff.

Peer based education programs need to be made available across Australia to improve the outcomes of people with mental illness, the better support carers and to contribute to reducing stigma amongst the community.

An example of best practice models that offer education and support for consumers and carers is the **Well Ways Program**, which is available through member organisations of MIFA. The program aims to increase the capacity of carers to cope with the impact of caring for a person with a mental illness upon themselves and other family members.

Well Ways also supports people with a mental illness by increasing their focus on the person's strengths, personal goals, wellbeing and personal change to assist the person to re-discover and start to achieve their hopes and aspirations.

An evaluation of Well Ways showed a statistically significant positive change in the level of psychological distress and the health of participants when compared to levels prior to undertaking the program.¹⁴

In addition, self-help groups have been shown to improve a person's self-management of their illness as the mutual benefit of helping others helps oneself.¹¹ There is a misconception that self help programs do not require funding or external support. Our experience is that with professional staff providing ongoing support and expertise self help groups not only survive but they flourish if resourced properly.

We need an increased commitment from governments to provide adequate funding on a secure and ongoing basis for these programs.

WHAT AUSTRALIA NEEDS

- **Nationally available peer-based programs for people with mental illness and their carers that seek to increase their mental health literacy and improve self-management skills.**
- **A funded de-stigmatisation campaign that enables trained consumers and carers to share their experiences with groups in the general community.**

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