President: The Hon Rob Knowles
Vice President: The Hon Frank Walker QC
Executive Director: Margaret Springgay
PO Box 844
Marleston South Australia 5033
web: mifa.org.au

Submission to the Senate Committee Inquiry in to Mental Health

A Call to Action

May 2005

Members:
Mental Illness Fellowship Victoria, Mental Illness Fellowship of South Australia, Mental Illness Fellowship of North Queensland, Mental Illness Fellowship of Western Australia, Schizophrenia Fellowship of Queensland, Schizophrenia Fellowship of New South Wales, Canberra Schizophrenia Fellowship, Northern Territory Association of Relatives and Friends of the Mentally Ill.

Introduction

The Mental Illness Fellowship of Australia (MIFA) calls on the Federal Government to take action to alleviate the neglect and distressed state that many people affected by mental illness are experiencing. People affected by mental are among the most stigmatised and disadvantaged group in the community.

Australia has had over a decade of reform in mental health initiated by seminal reports such as the Human Rights and Equal Opportunity Report in 1993 "Report of the National Inquiry into the Human Rights of People with Mental Illness". The Inquiry by HREOC commenced in 1990 and was a prime mover in prompting Australia to develop model mental health plans and policies. Despite obtaining state and territory agreement to those plans, achievement of reforms has been hampered by a failure by the Federal Government to adequately fund and promote structural and service changes, and by variable compliance by some states and territories in actioning the changes.

The failure to provide adequate mental health care to Cornelia Rau has resulted in acute embarrassment to the Australian government and a tragic dislocation in her life. While the findings of the investigation into that case are yet to be released, MIFA members deal on a daily basis with many other people who are not receiving the level of support they need to cope with severe mental illness. There are many studies pointing to the high numbers of people with severe mental illness who are homeless or living in sub-standard housing; or who are in the criminal justice system; or living with families because they unable to obtain the level of housing and other supports they need.

MIFA acknowledges that many reforms have been introduced in the past 12 years since the first Mental Health Policy. Too little has been done however to enable the reforms set out in subsequent plans to achieve their goals. This is both a failure to provide adequate funds and a failure to hold states and territories to count in the introduction of reform. In particular, there has been a general failure to resource community services to be able to meet the demand from people affected by a severe mental illness.

The inadequate community service infrastructure results in increasing demand across the entire public sector. There is an over-representation by people with a mental illness in the criminal justice system, among the homeless, being attended by police, seeking housing assistance and presenting at accident and emergency services. The increased demand on mental health services is indicative of an increase in incidence of mental illness, an effect being experienced by many services and practitioners.

Care for people affected by mental illness must be spread across the whole spectrum of public service jurisdictions, the private and NGO sector as well as targeting the whole course of the illness and any subsequent disability. For many people who develop mental illness, the effects of that illness continues across their lifetime with episodic periods of an increase in symptoms requiring treatments followed by a more stable period with minimal or no need for service interventions.

The incidence of mental illness is presently 1 in 5 of the population, and an increasing rate of disability is predicted by the *Burden of Disease* studies. It is imperative, therefore that Australia address mental illness needs in all age groups and plans services to cover the continuum of needs from diagnosis and onset to continuing care, depending on an individual's course of illness. Failure to do so will result in an increasing social and economic burden across multiple service sectors.

About the Mental Illness Fellowship of Australia [MIFA]

MIFA is a non-government, incorporated, benevolent organisation with member organisations in states and territories. MIFA grew in the 1970s and 1980s from a grass roots movement of carers and consumers whose lives were shattered by disabling mental illness. Today MIFA represents over 15,000 people in Australia whose daily lives have changed forever because of severe mental illness. To address the deficits in available services, Fellowships at state and territory level began to provide the non-clinical, community-based services so desperately needed to address residual disabilities which remain present following acute clinical intervention. Such services today include a broad range of interventions aimed to provide support, enhance individual skills, optimise rehabilitation and recovery and enable individuals to catch up on interrupted education and career planning. These services include:

- Information and referral – fact sheets
- Telephone and face-to-face help-line
- Education to consumers, carers and the broad community
- Vocational programs including Clubhouse and Social Firm employment models
- Individual and system advocacy
- Day programs – with activities aimed at re-connecting people into communities, and to increase personal skill development
- Specific courses – eg Well Ways for carers, stop smoking, hearing voices groups, weight management etc
- Rural and remote education programs
- Accommodation support
- Residential services
- Newsletter with latest findings, diary of events

MIFA members continue to operate within a disconnected and poorly resourced mental health service system in one of the wealthiest countries in the world. State and territory members have variable government support at state and territory level and rely heavily on volunteer support to achieve their aims. MIFA members deal on a daily basis with consumers and carers in various stages of mental illness. The services provided focus in the main on those with a psychiatric disability.

A call to action for the Federal Government to require service accountability

Federal government needs to lead states and territories in the implementation of reforms and increase the funding allocation for mental health and allied services. Australia spends less than 7% of the health budget on mental health. This sum places Australia well down on comparable amounts spent by OECD countries. Despite the low funding allocated to mental health, it is the leading cause of disability. Australia is falling behind the investment and achievements of its neighbours in the OECD in many areas relating to services to people affected by mental illness. For example New Zealand increased its funding to mental health services by 128% between 1993/94 and 2002/03. New Zealand allocation of funds differs considerably from Australia's. Funding for community services represents 69% of total funds and in-patient services receive 31% of total

funding. In New Zealand NGOs receive 28%[1] of funding compared to an average of 5.5% in Australia. That 5.5% represents a wide dispersement across states and territories reflecting the under-utilisation of NGOs in the provision of services for which they are often well-equipped .

Each National Mental Health Report has provided evidence of state and territory inequities across Australia in the delivery of reforms set out in the national mental health plans. Such service inequities should not be occurring in a modern democratic state like Australia. MIFA has called on the federal government in numerous submissions to carry out an audit on state/territory compliance on implementation of reforms to mental health services. An audit process could be tied to an accreditation process, based on service benchmarks or other system tools to measure outcomes based on clear scientifically-based measures. Closer involvement and reporting on the needs of people affected by mental illness is needed. Surveys such as the National Mental Health and Wellbeing Survey need to occur more regularly and can assist in informing regular service audits. There are variable service developments across the country as evidenced by the following comment:

> It really occurred to me for the first time that we may be better off if we shift to Victoria. Mental Health Services for our daughter would be better there. I saw in the report that Victoria has much better services than are available here.
>
> Carer

Continuum and continuity of care

Early intervention

Onset of mental illness most commonly occurs in the second and third decades of life. This is a time when adolescents and young adults are completing education and setting out on a career path. Interruption to the achievement of secondary education and/or vocational qualifications sets up huge barriers for subsequent employment options which, if not regained, result in dependence on welfare, a cycle of poverty, and lowered self-esteem. Unless young people who are affected by mental illness can be diagnosed and treated early, their ability to reconnect is jeopardised from where mental illness interrupts their life transition. Those reconnections should be aided by targeting education and employment programs for this group.

Proper diagnosis and appropriate treatment is the first phase and incorporates education to both the individual and the family network and includes measures to optimise a return to a normal life transition as soon as possible. Diagnosis and treatment is the province of clinical services. Such services however only form part of the requirements for people affected by mental illness. There is evidence that targeted employment and education programs will do much to reduce relapse and facilitate reconnection in the community.

Community care focusing on rehabilitation and recovery

Not all people affected by mental illness require hospitalisation. Mental health services have successfully trialled Hospital at Home (H@H) for some clients during an acute episode of mental health care. Use of H@H services for an acute episode of mental

[1] New Zealand Mental Health Commission: Report on Progress 2002-2003: towards implementing the Blueprint for Mental Health Services in New Zealand.. *Key Findings*.

illness should be encouraged, based on clinical assessment of suitability. H@H has become widely accepted and available across other health sectors. In most instances cost savings are made and consumers prefer the option. There are a number of examples of successful H@H programs for people with a mental illness such as the step-up/step-down program in Victoria. The expansion of such options as an alternative to hospitalisation should be encouraged.

Implementation of community services for people with a psychiatric disability have failed to meet the need and failed to optimise better health outcomes for individuals with a mental illness. Community services encompass far more than the primary care provided by GPs.

Many studies point to better outcomes for people with a mental illness where there is a good interface between mental health service providers and other jurisdictions dealing with issues of people with a mental illness. Such interface between service sectors needs to be formalised, properly resourced and not left to the decision of individual departments or practitioners. The service interface needs to occur at multiple levels – at federal and state/territory department level; at service administration level; at regional manager level and at service practitioner level. Mental Illness, unlike many other illnesses, crosses and draws upon multiple sectors. These sectors include social welfare, disability, education, vocation, drug and alcohol, justice as well as the health system. Unfortunately, as in the Cornelia Rau case, involving immigration, mental health literacy among allied services is poor and mental illness is generally treated as a single illness entity.

A balance between acute and psycho-social support services

There has been a trend in Europe to reinstitute more long-stay hospital beds for people with a mental illness. Australia should avoid this approach. Hospital services should focus on acute service delivery. Rehabilitation and psycho-social support services needs to focus on providing support and appropriate interventions for community tenure.

A return to the institutional model of care for people with a mental illness is at times promoted by medical practitioners. Psychiatrist and other professionals can at times have what is called a 'clinician's illusion'. A clinician's illusion is the illusion that the particular service locale they operate within is assumed to provide the complete picture of the illness. Planning of service realignment needs to encompass and incorporate the people most affected, that is, the carers and consumers as well as service professionals.

Service interface

The federal government should lead by example by ensuring a formalised and functional interface between the multiple service sectors that people with a mental illness draw upon. These services include, inter alia:

- Health
- Housing
- Drug and alcohol
- Criminal justice systems
- Welfare support agencies
- Employment agencies
- Education

Personnel from agencies, such as those listed, that have a great deal to do in service provision need to be part of the service planning as well as service delivery. Indeed improved interface between the multiple sectors involved in assisting people with a mental illness could do much to improve outcomes.

Carers

Education, support and information to carers has been a neglected area in both the federal evaluation reports and availability of funded and dedicated education and support services is lacking in many State/Territory responses. People with psychotic disorders represent 3% of the population and studies indicate that close to 50% of people with a psychotic disorder live at home. The burden borne by families is considerable and is frequently carried out with insufficient support from services. Some health professionals refuse to meet or speak with carers. Carers play a critical role in the sustainment of many people with a mental illness. National standards that make explicit the methods that can be used to involve carers would be a value in addressing outmoded paradigms of family involvement that many clinicians still have.

The involvement by consumers and carers in service planning has been a central tenet to the mental health reforms of the last decade – indeed mental health has led the way in this for many health services. Nevertheless all too often, although carers are both willing and able – they are still excluded from participation in the care planning by clinicians. The provision of carer education and supports has relied heavily on the NGO sector. The NGO sector however has had insufficient funds to meet the demand.

MIFA has trialled a well-researched program for carers called 'Well Ways' which was developed by the Mental Illness Fellowship of Victoria – see attached evaluation report as Appendix 1. The capacity to roll the course out more widely is hampered by lack of funds and lack of funding in some states and territories. The outcome is that some states will benefit from better prepared and supported carers than others. This inequitable situation in a democratic country like Australia should not continue.

Despite international recognition of the place family education has in reducing relapse and increasing medication compliance among people with a mental illness – there has been a failure to implement national education and support programs for carers. A review of the Family Intervention model by the Cochrane Collaboration stated "family intervention, as part of a multi-dimensional approach to care, decreases the frequency of relapse and hospitalisation over periods of seven months to two years". International research shows that with support and education more families can have a positive effect on the person with a mental illness and many family breakdowns have the potential to be avoided.

The simple message is:

Carers who are educated, trained, and informed and have supports, cope better

Carers who cope better are able in turn to provide better support

Carers who provide better support can contribute to the well-being, and rehabilitation of their loved one

Apart from a prolonged period of hospitalisation, my son has lived at home with us since he first developed schizophrenia in his first year at university. He is in the second decade of the illness since his diagnosis. He is sometimes classified 'treatment resistant' and despite trying all available medications he remains quite disabled by his illness. There is no suitable accommodation available locally that provides the level of help he requires. Following five years in hospital he was trialled in a boarding house on one occasion, but became unwell within a fortnight and was readmitted to hospital. The boarding house was poorly run and he was placed in a share room with a 50 year old, at a time when he was in his early 20s. I cannot bear the thought of him returning to that and so he lives at home.

He was told by his mental health service provider last month [April 2005], that he was to be discharged as his needs are too great for services to be able to meet them!

That afternoon he threw himself in front of a car.

What other area of health services say 'we do not have anything available to meet your high level needs?'.

Do palliative care services say 'don't die this week we haven't got enough services in place to meet your needs in the terminal phase of illness?'

Carer

Mental Health workforce – education, training and retention

The knowledge, competencies and attitudes of staff working with people affected by mental illness is vital to the achievement of the best possible outcomes. There is a critical shortage of professionals and support staff to meet the current and future increase in demand for their services. The federal government needs to enhance plans to meet those needs. In some instances incentives may need to be offered to ensure service provision demand is met. Such incentives could include improvement of the psychiatric nurse role through extending nurse education to 4 years, encompassing the psychiatric component. The Tolkein report of the early 1990s envisaged an expansion of the psychiatric nurse role

The mental health literacy in some agencies providing services to people with a mental illness is quite low and action is needed to improve knowledge levels and improve skills in dealing with people with a mental illness. For example, people working within many Job Network agencies have little knowledge about mental illness and there are no imperatives to assist that group in finding work. This can have the potential effect of leaving the choice of who to assist in those programs to those who can be readily placed. Practice standards and core competencies would assist in overcoming this situation and such a program should encompass attitudes as well and knowledge and skills.

Enhancement of the level of knowledge about non-pharmacological service options and promulgating the new evidence about psycho-social rehabilitation and outcomes such as employment as achievable goals, should form part of on-going education for all practitioners. Support workers need improved education about mental illness and work within a structured team with ready access to the case manager level direction and supervision.

Employment options for people with a mental illness

Work is important to the mental health and well-being of all individuals. For people with a mental illness, work is an opportunity to regain lost self esteem, to move away from welfare dependence and re-integrate into the community. Since mental illness often begins in adolescence or early adulthood; there is a resultant interruption in achieving educational goals and establishing a career. There is evidence now that assistance and support to return to education and employment can be very effective in reducing symptoms of mental illness. Suitable employment enables social and economic participation in society. The Disability Support Pension needs to be readily available as a fall-back income support at times when a person with a mental illness is unable to continue employment or in the event of a recurrence of episodic illness symptoms.

MIFA was fortunate to host Professor Gary Bond from the U.S as key-note speaker in Schizophrenia Awareness Week. His research provides evidence of much better employment outcomes for people with severe mental illness through a change in the organisation and delivery of services. Australian studies show that 80% of people with a psychotic illness do not work. Apart from the welfare burden on Australian society, and the impact of unemployment on the individual; research shows that up to 50% of these people could work with the right program and on-going support.

The evidence of much improved employment options is of great interest to MIFA currently. A background research paper written by research scientists from the Queensland Centre for Mental Health has been prepared for MIFA. MIFA will be preparing a Public Policy Statement on the Employment of People with a Mental Illness. The research evidence points to a number of key ingredients or principles which are essential elements in successful employment programs for people with a psychiatric disability. Those principles are as follows:

1. Eligibility based on consumer choice.
2. Integration of employment service with mental health treatment.
3. A competitive employment goal.
4. Rapid commencement of job searching.
5. Services based on consumer preferences.
6. Ongoing support to retain employment.
7. Benefits counselling.
8. Intensive on-site support.
9. Multidisciplinary team approach.
10. Emphasis on rehabilitation alliance.
11. Stigma and disclosure strategies.[2]

The Senate Select Committee had an opportunity to hear evidence from both Professor Gary Bond and Geoffrey Waghorn about the research evidence and Australia's poor performance in this area. MIFA is very keen to see improvements in employment options for people with a mental illness and believes that demonstration projects need to be funded to trial the 'supported employment[3]' model described by Professor Bond. It is

[2] Waghorn Geoff. Lloyd C. (2005) The Employment of People with a Mental Illness: a discussion document prepared for the Mental Illness Fellowship of Australia.

[3] The term 'supported employment' is applied differently in the U.S.A. and the closest Australian equivalent is open employment.

imperative that the Federal Government enhance the services and improve the current employment outcomes. MIFA is interested in participating in reforms in employment services including research of programs which have proved successful overseas.

MENTAL ILLNESS FELLOWSHIP of Australia Inc

Well Ways – a traveller's guide to wellbeing for families of people with mental illness

A multi-family peer psycho-educational program

Evaluation report on the transferability from the creators, Mental Illness Fellowship Victoria to other Mental Illness Fellowship Australia members

August 2004

Report authors Sue Farnan, Liz Crowther and Margaret Springgay

The Mental Illness Fellowship of Australia gratefully acknowledges the support of Eli Lilly Australia in making this project possible.

Sponsored by an unrestricted educational grant from:

Lilly Answers That Matter.

Overview

The paucity of programs for carers of people with a mental illness within Australia has been highlighted in many reports.[4][5] Demand in a number of jurisdictions within this project testifies to that. The efficacy of such courses in improving outcomes both for the carer/s and the person with a mental illness is well documented. The value of such courses being provided within a family to family model of teaching is also the subject of research and has been validated as the most effective mechanism for support and education. Despite the evidence, funding for specific programs in most jurisdictions within Australia is poor or at worst non-existent. The non-government sector of mental health is struggling to survive in many locations throughout Australia. This fact has been borne out during the current project with a number of MIFA members unable to proceed with implementing Well Ways within their state or territory. Further, some that did have constraints in supporting the development of an on-going support group, which is a fundamental outcome anticipated with the Well Ways program.

This report identifies success of transferring a multi-family peer psycho-educational program for families of people with mental illness from Victoria to other states demonstrating effectiveness in reducing anxiety, depression and worrying.

Recommendations

Some of the recommendations contained in the draft report have already come to fruition. These include the fact that Janssen Cilag have funded the production of state based Well Ways manuals and fact sheets and that Eli Lily are committed to funding a shorter course that meets the needs of rural areas and people with limited time.

Recommendation 1: That in order to participate in this program it is necessary for organisations to be able to make commitments to resourcing the process.

Recommendation 2**: That MIFA is funded in 2005 to conduct another Train the Trainer program for Well Ways which will target those sites needing to train additional facilitators.**

Recommendation 3: **That a structured follow up support group model be documented and integrated into the train the trainer program**

[4] First National Mental Health Report 1994 *Department of Human Services and Health (Cwlth),* (Australian Government Publishing Services 1995); 2nd National Mental Health Report 1994 *Department of Human Services and Health (Cwlth),* (Australian Government Publishing Services 1996); 3rd National Mental Health Report 1995 *Department of Human Services and Health (Cwlth),* (Australian Government Publishing Services 1996)

[5] Commonwealth Dept of Health and Ageing 1999 *Education and training partnerships in mental health – learning together (final report)* Deakin Human Services Australia & Mental Health and Special Programs Branch, Publications Production Unit, Commonwealth Department of Health and Ageing Canberra www.health.gov.au/hsdd/mentalhe/resources/reports/pdf/etpmhlt.pdf

Recommendation 4: **Further guidelines be developed for supporting the peer education component of the program which includes how to identify and train facilitators and manage reporting, evaluation and quality control issues of the program.**

Recommendation 5: **That MIFA seek funding to develop a short program for Carers of people with a mental illness. Such a program will complement the existing Well Ways program and be made available to MIFA members in addition to Well Ways.**

Recommendation 6: **That the program is nationally accredited to enable carers gain recognition for their skill.**

Recommendation 7: **That a greater focus be given to the evaluation process in the train the trainer program.**

Background

The Mental Illness Fellowship Victoria (MIFV) researched, designed and validated Well Ways - a multi-family to family peer psycho-educational program designed to be delivered by people with the experience of being a carer of a person with a mental illness. Mental Illness Fellowship Australia (MIFA) identified a national need for evidence based family education and support programs and approached ELI Lilly to fund a roll out of Well Ways to MIFA members. Eli Lilly funded MIFA to develop and a conduct a train the trainer course for MIFA members in Australia. This train the trainer course enabled delivery of Well Ways to carers by Schizophrenia Fellowship NSW (SFNSW), Mental Illness Fellowship Victoria (MIFV - Hume region), Mental Illness Fellowship WA (MIFWA), Mental Illness Fellowship SA (MIFSA) and Schizophrenia Fellowship South Queensland (SFSQ).

Well Ways was developed by the Mental Illness Fellowship Victoria (MIFV) following examination of literature and trial of international programs for Carers and focus group based research cited in Crowther E and Schumacher B (2002)6. What followed was the development, trialing and evaluation of a program suited to the Australian context:

MIFA subcontracted the Mental Illness Fellowship of Victoria to develop the train the trainer project to transfer multi-family psycho education program Well Ways from Victoria to other states of Australia. The success of this transfer was measured by both process and impact evaluation techniques.

Description of Well Ways

Well Ways: – a traveller's guide to wellbeing for families of people with mental illness[7] is a multi-family peer psycho-educational program for families of people with a mental illness. It is designed to increase the capacity of families, carers and friends to care effectively for themselves, other family members and their relative living with mental illness. The program provides a broad and sensitive perspective to the many issues facing families as they manage the impact of mental illness on their lives.

The program consists of formal 8 week structured modules which cover frameworks for the cause, treatment and recovery from mental illness, explores the emotional experience of families, details of the mental health legal, health and carer support systems. It is followed by a support group meeting on a monthly basis which keeps in contact for up to 18 months. The purposes of these meetings are to reinforce the learnings, provide feedback and support for behavioural changes. MIFV has further developed the support group aspect of the program based on the Crowther & Walker Report (2000) report done by the MIFV[8] and the Reay-Young R. (2000)[9] Report and

[6] E Crowther and B Schumacher *Bridging the Gap – Carer Quality Initiative* 2002 (unpublished) Mental Illness Fellowship Victoria and Goulburn Valley Area Mental Health Service

[7] Mental Illness Fellowship Victoria (2003) Program *Summary for MIFA Proposal*

[8] E Crowther & B C Walker *Consultation with SFV and Linked Support Groups* (unpublished) 2003 MIFV

the process reviews of current Well Ways programs. The program now extends to bi-monthly modules on advanced communication, grief and loss, fear of suicide and managing difficult behaviours with social group meetings in the off month. This part of the model is yet to be evaluated.

Well Ways utilises a peer education approach to transfer the program information and model the competence of family members. Facilitators are drawn from participants in the Well Ways program and then undergo training and support to achieve the skills required to lead the program.

The process of transfer of the Well Ways program from Victoria to other states

A two and a half day train the trainer course was conducted by the Mental Illness Fellowship Victoria to prepare facilitators to conduct the Well Ways program in their states. Facilitators who participated in the course came from teaching, community development, health professional and/or experiential background as a carer of someone with a mental illness.

The train the trainer course spanned process, content and skill issues. Topics included the educational theoretical underpinning of the program, theories relating to mental illness and family experience, quality control relating to the model, responsibilities to Mental Illness Fellowship Victoria in maintaining the model and participating in evaluation and training, and an opportunity for everyone to practice and present a module of the program.

Module One:	**Examination of the family to family peer education model**
Module Two	**Challenges and opportunities with family to family education model – quality control**
Module Three	**Adult learning principles and facilitation skills**
Module Four	**The biopsychosocial model of illness**
Module Five	**Feeling the impact of mental illness – the emotional journey**
Module Six	**Walking the talk – Group Presentations**
Module Seven	**Précis remainder of sessions**
Module Eight	**Application to each of the states**

Follow up to the training included staff from Mental Illness Fellowship Victoria acting as mentors for state based facilitators by keeping in contact and assisting them on site.

Facilitators were provided with the material to conduct the program in their location which included manuals, videos involved in the program, fact sheets to be used as handouts, evaluation material, and documented process and instruction sheets.

[9] R Reay-Young (2000) Support Groups for Relatives of People Living with a Serious Mental Illness: An Overview *International Journal of Psychosocial Rehabilitation Vol 5, 56-80*

Evaluation of the transfer of the Well Ways program

Evaluation of the project set out to measure the transferability of this program from MIFV to other participating states. To successfully measure this, process evaluation was used for the Train the Trainer Facilitator's course and the practical delivery of the program in the states, and impact evaluation was used to measure the well being of people to whom the program was delivered. Together these two measures have given us a picture of what mechanisms were successful in the transfer and whether the impact on participants in the programs at state level was successful.

1. The process evaluation of the Train the Trainer Facilitators' course
   This aspect of the course was evaluated utilising a questionnaire format. Participant's opinion of the content, facilitation style, delivery style and the venue was overall very positive. Participants in the course came from a variety of backgrounds despite all having the experience of being a family member of someone with a mental illness. Some were in a professional role as a health educator employed by the state based organisation, and others were family members acting in a volunteer health educator roles for the organisation. This meant that the course had to meet two different needs which required balancing and fine tuning.

2. The process evaluation of the experience of MIFA organisations the practical delivery of the course and participation in evaluation systems at state level
   Each state had a different experience of ease of delivery of the program. This was influenced by a range of factors such as organisational resources, the lack of dedicated funds for education, referrals from Mental Health Services, and previous experience in evaluation.

   New South Wales experienced considerable success implementing Well Ways. The timing of the course followed the implementation of the SFNSW Carer Support Unit (CSU) in 2002. Well Ways is now being delivered in metropolitan Sydney and in the Hunter Valley, Greater Murray, Illawarra and Northern Sydney areas. Another training program is scheduled for September 2004 to broaden the delivery base of the program even further.

   South Australia delivered the course to 10 participants despite little support from mental health services and few organisational resources. While the concept of continuing the existing group as a support group was greeted enthusiastically by the participants, the organisation had insufficient resources to support and provide training in running small groups, skills in presentation and confidence building of potential facilitators.

   South Queensland delivered a successful Well Ways program, as did Western Australia. The advantage for Western Australia was that two people were allocated to work on the program - a person who co-facilitated was a carer and she was supported by a staff member who organised the administrative components of recruitment, scheduling, communications

and materials for the programs. Three courses are being planned for next year combined with a concerted effort to develop carer potiential and group support mechanisms.

Victoria took the opportunity to train a carer from a rural region, which enabled further extension of the Well Ways program into rural Victoria.

Northern Territory was unable to proceed with the course due to lack of referrals and resource difficulties. North Queensland also had resource difficulties but has recently delivered a program so the impact evaluation results are not yet ready for inclusion in this report.

3. **The Impact evaluation of the Well Ways program for carers**
   This part of the evaluation was designed to establish whether the product retained its potency once transferred. This study used the Involvement Evaluation Questionnaire (IEQ) which was developed by Schene and van Wijnaarden, Department of Psychiatry, Academic Medical Center, Amsterdam, The Netherlands. It measures 7 domains; sociodemography, caregiving consequences, financial impacts, general health, professional help, consequences for children and an open question section. General Health Questionnaire 12 (GHQ) was used as a brief measure of carer anxiety and depression.

Impact evaluation method

The questionnaire is planned to be administered across 4 time spans at;

- commencement of the structured component of the program
- conclusion of the 8 week structured component
- 12 weeks after conclusion of the formal input
- 20 weeks after conclusion of the formal input

The evaluations were given to family members to self report in a questionnaire format. These were administrated by trained family workers in each state, coded and supplied by Victoria. On completion the questionnaires were returned to Victoria by the family support workers.

While this process was satisfactory for the first and second administrations, the return rate for the 3rd time was affected by this diverse distribution method, therefore the collection method has changed and times 2, 3 and 4 are now managed by Mental Illness Fellowship Victoria.

Results in this presentation represent data from times 1, 2 and 3 collections. This report is unable to report on the results from time four evaluation due to a number of factors. Not enough time has elapsed for sufficient numbers to examine results of Time 4.

Some questions have skip out provisions for those not having sufficient contact with the person with a mental illness and consequently N varies for this component of the evaluation, and has reduced the number of overall valid completed questionnaires.

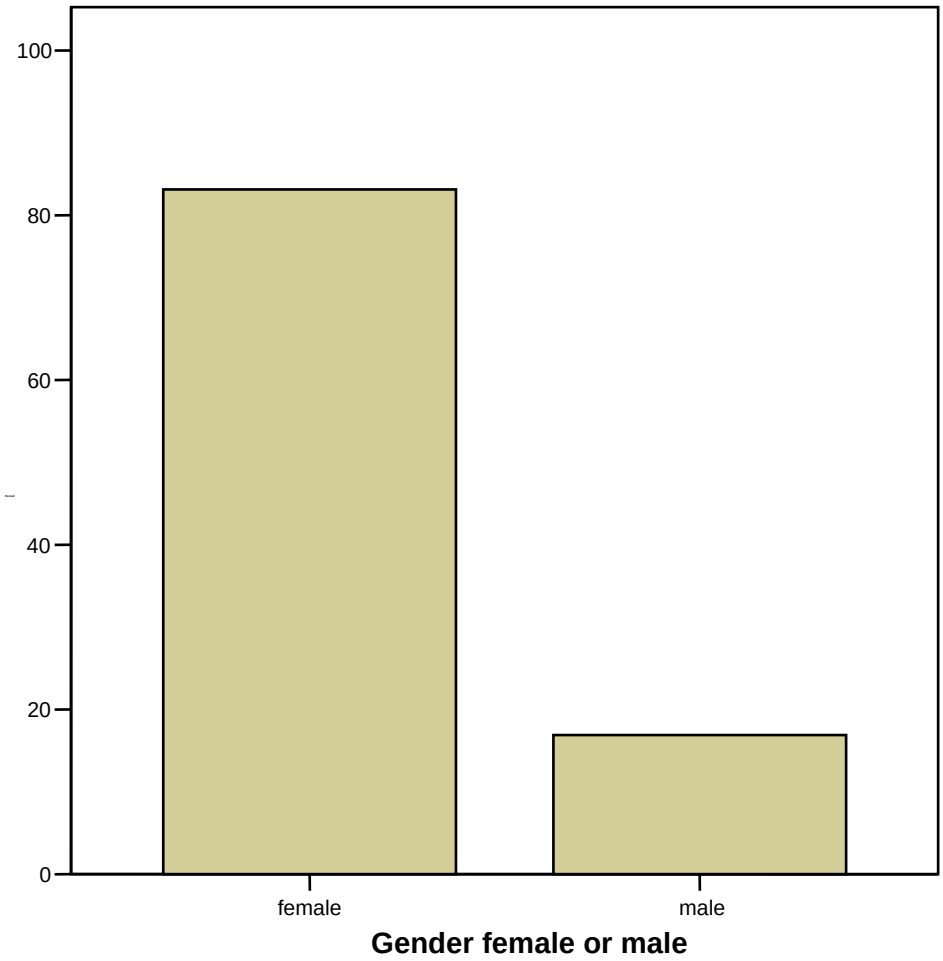
Results

Nationally 75 people have participated in this evaluation of the Well Ways program. 42 of these 75 people have returned times 1, 2 & 3 questionnaires and findings are based on these 42 cases. These people are from New South Wales 19, South Queensland 8, South Australia 5, Western Australia 5, and Victoria 5.

Sociodemographic analysis

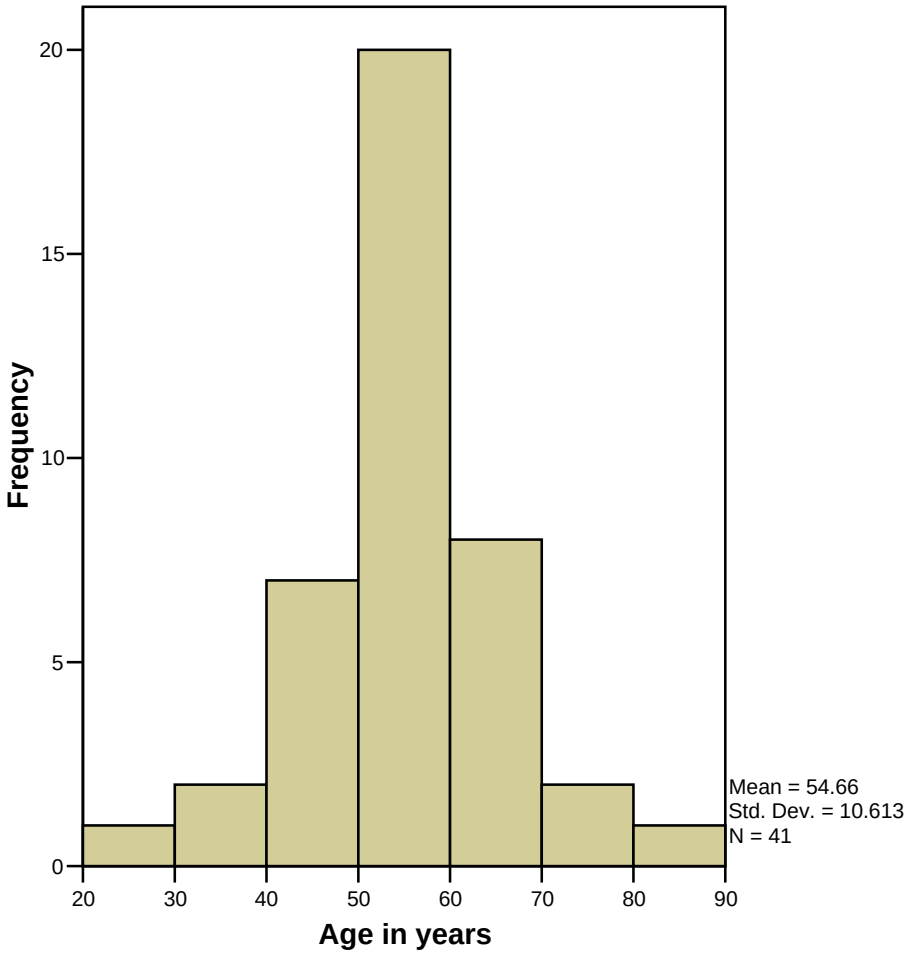
Gender

83% of participants were female and 17% were male



Age

Participants spanned a wide age range, 41 of the 42 respondents identified their ages; the youngest was 21 and the oldest, 83 years.



20 of the respondents were in their 50s, with a mean 54.66 years.

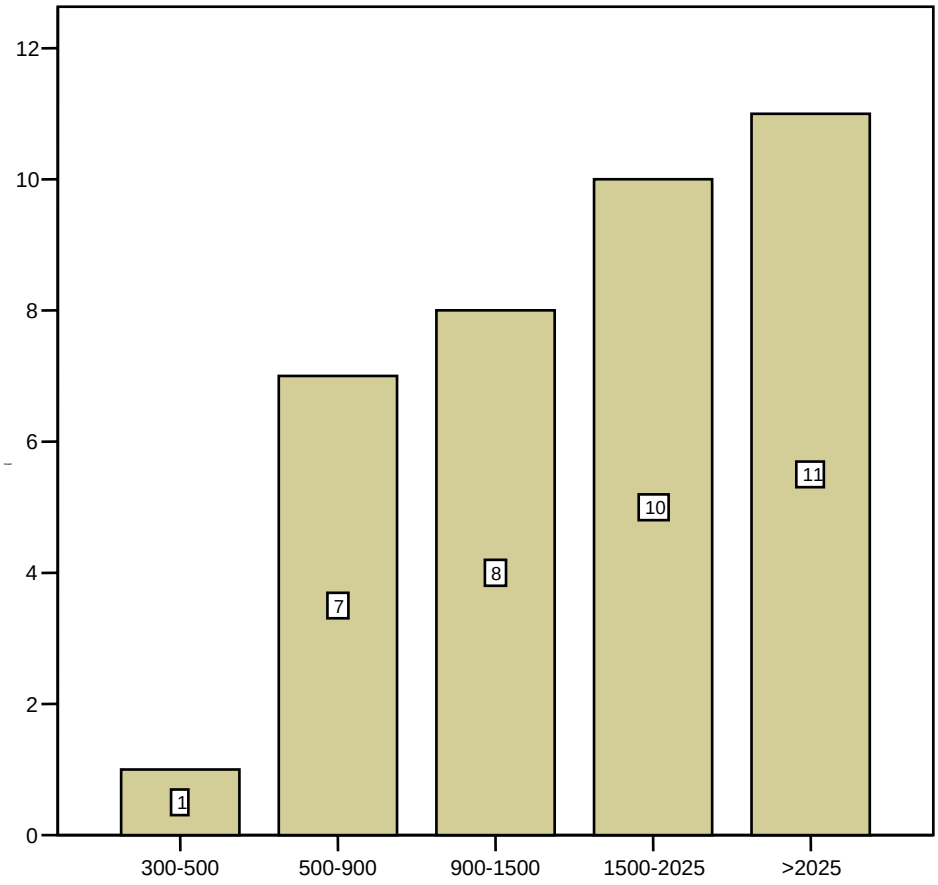
Financial status

37 of the 42 respondents reported their monthly income after tax, and insurance as:

- Over $2,025 per month — 11 respondents
- Between $2,025 and $1,500 per month — 10 respondents
- Between $1,500 and $900 per month — 8 respondents

Between $900 and $500 per month — 7 respondents

Between $500 and $300 per month — 1 respondent

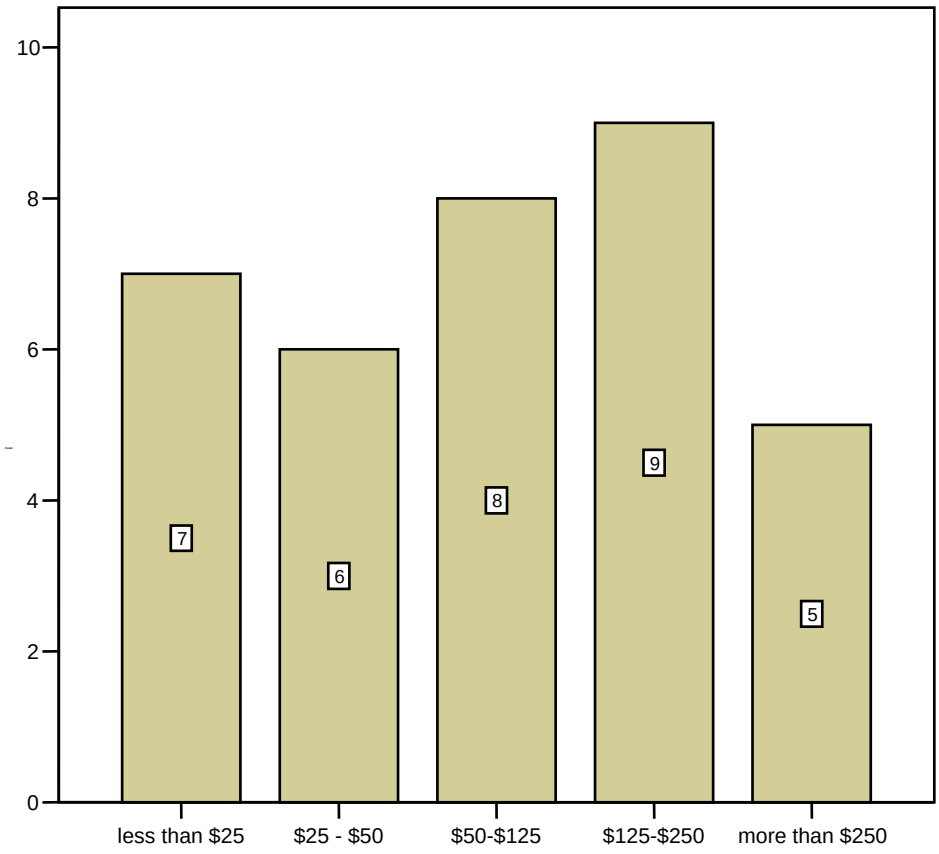


Q14 What is your family's approximate net income after deductions from tax, national insurance etc

Extra expense

35 respondents reported that they had contributed extra financial resources to their family member with a mental illness in the last 4 weeks at the following rates;

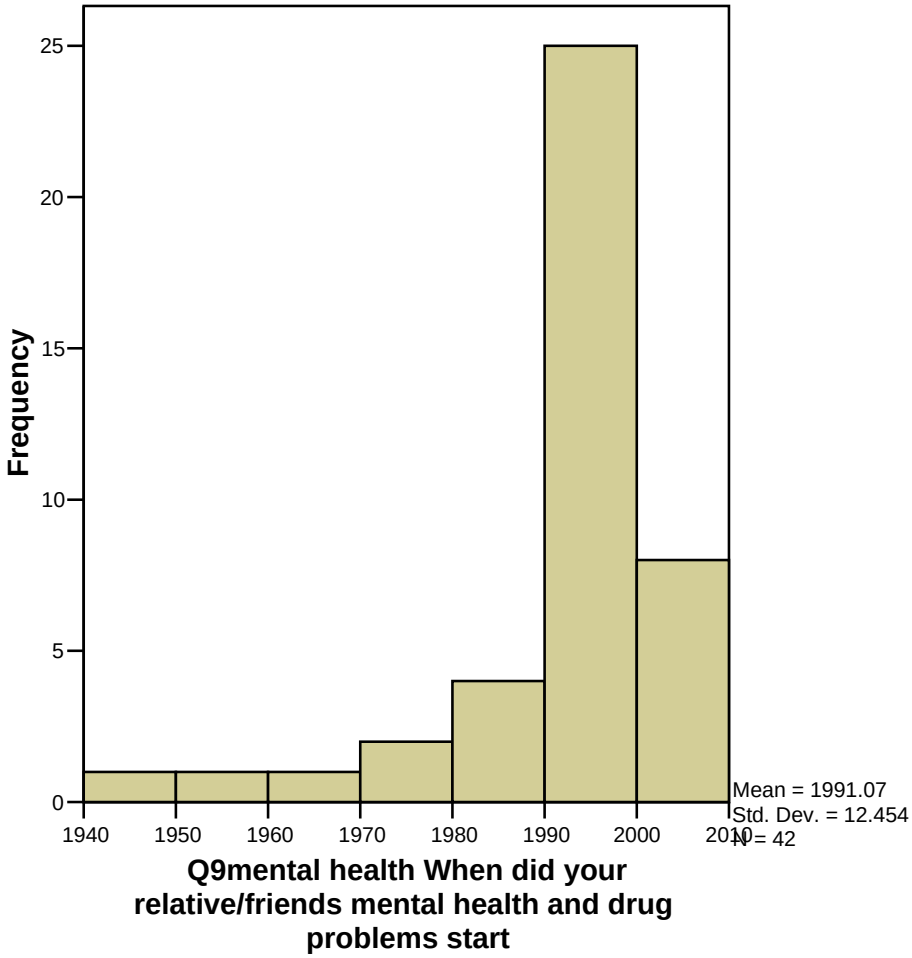
- More than $250 in the past 4 weeks 5 respondents
- More than $125 in the past 4 weeks 9 respondents
- More than $ 50 in the past 4 weeks 6 respondents
- More than $ 25 in the past 4 weeks 7 respondents



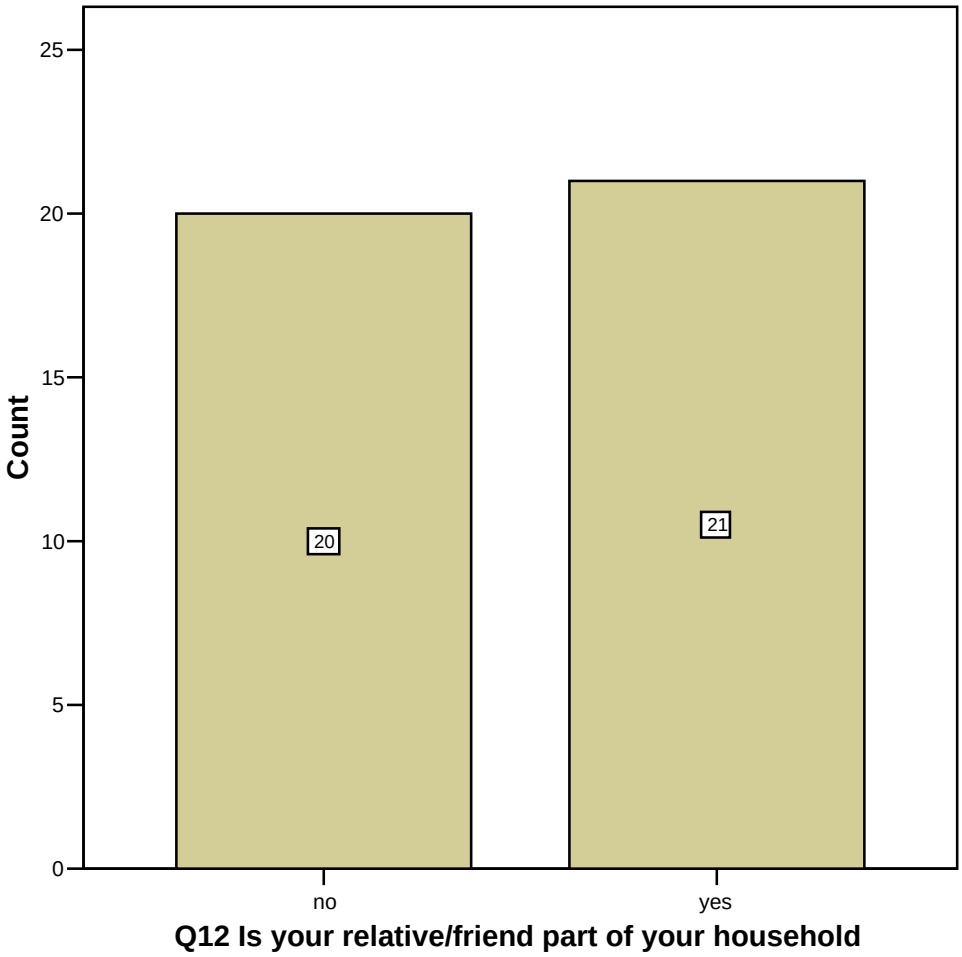
Q54 If you add up all the extra expenses which you have incurred on behalf of your relative/friend during the past four weeks, what is the estimated figure

Average length of illness of the family member

59.5% of participants reported onset of illness in the 1990s. The earliest on set was reported in the 1940s and the latest 2003.



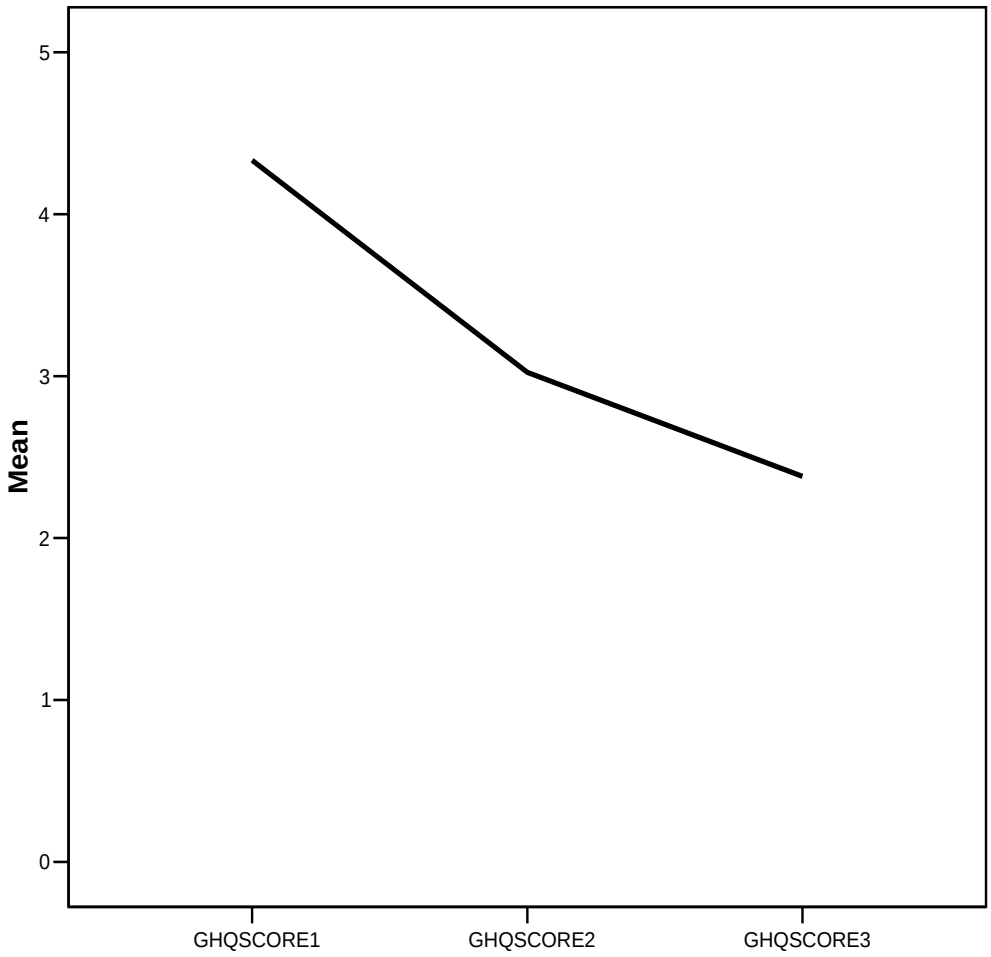
Residency
41 people responded to this question, 21 of whom resided with the respondent and 20 of whom did not.



General Health Questionnaire 12 (GHQ)
The results of the GHQ can be reported as statistically significant. This questionnaire focuses on the measurement of anxiety and depression and shows a significant decrease of reported symptoms between time 1 and time 2 and a continued decrease between time 2 and time 3.

N 42:
Demonstrated significant change between 1 & 2 which was maintained at time 3

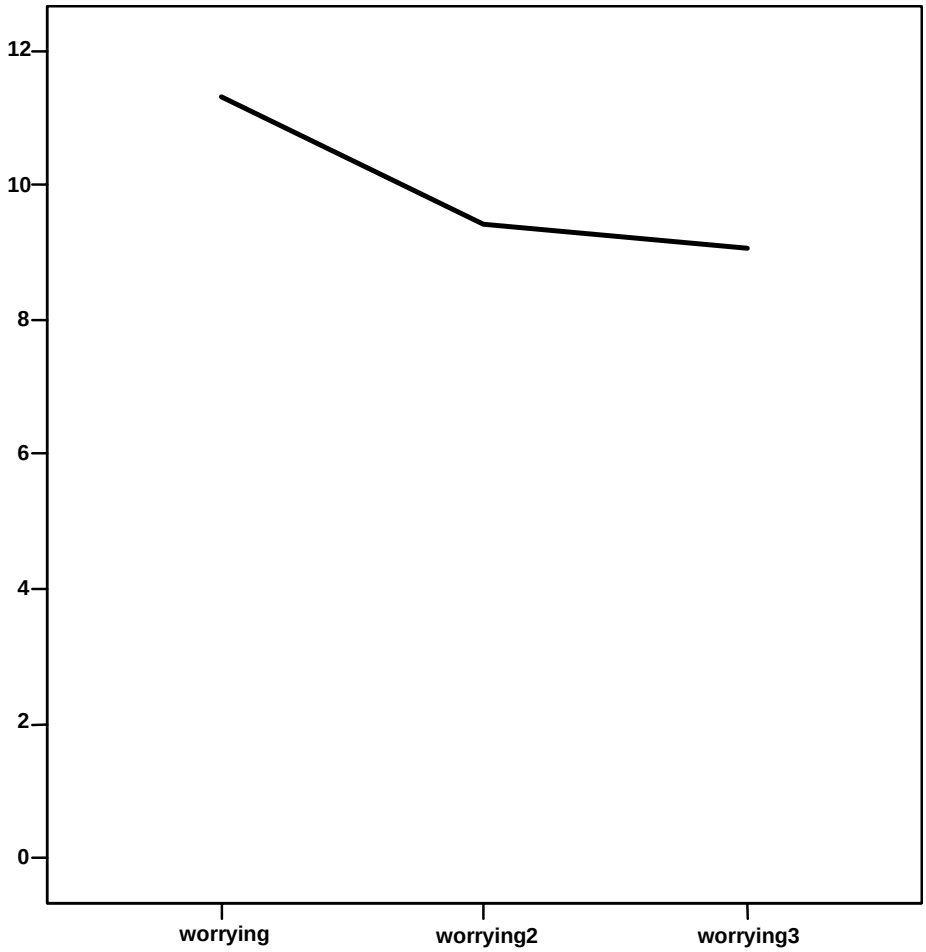
t (41) = 2.65, p<.05



Caregiving consequences
Four subscales exist for the IEQ 12 – supervision, worrying, urging and tension. Carers who spend less that 1 hour per week with the person with a mental illness skipped the supervision, urging and tension subscales. As a result the numbers of respondents in these three categories were insufficient to identify significance. 41 respondents completed the worrying subscale and reduction and anxiety and depression is reported in the next graph.

Worrying
This result can be reported as being statistically significant with a demonstrated reduction in worrying between Time 1 and Time 2 and this remained in Time 3

N 42:
t (40) = 2.44, p<.05



Supervision
Supervision scores remained stable throughout time 1, 2 and 3.

Tension
There was some trend to reduction in this domain.

Urging
There was a trend to reduction in urging.

Discussion

The process evaluation indicated that participants in the train the trainer course were in the main, satisfied with the content and process of its delivery. Further emphasis on content of the program would be of help, as would further consideration about how best to develop the varying skills of the trainee facilitators.

Implementation of the program at state level had various challenges and successes. The need for organisational support and administrative resources was highlighted by the fact that NSW has been able elicit enough interest and was able to resource effectively the running of a primary program and then in collaboration with MIFV conduct another train the trainer program which trained further facilitators. The program has since been conducted at a number of sites across the state. Their ability to participate in the evaluation has also been enhanced by the administrative support and the organisational commitment within the organisation. Similarly, whilst the staff member who was trained remained on staff and the other facilitator was able to participate in the program in WA the success was also high but did not progress to the level of training further facilitators.

Those states that had family members acting in a volunteer capacity attend the train the trainer course were less able to carry out the program (the structured and the support group component) and participate in evaluation mechanisms. Future plans to streamline these processes more with the help of technology and refined plans should go some way to making this easier for agencies with fewer resources.

Error rate in completion of the questionnaire could be reduced in future by including specific training in the train the trainer course in order to better assist participants to complete the evaluation instruments would overcome any potential confusion that might exist.

The impact evaluation indicated that caregivers were less anxious and depressed and reported less worry regarding the person with a mental illness following participation in this program.

This is a very early stage of the evaluation and hence we have limited numbers in this study. We do however have many current groups participating in the evaluation and plan to continue the process into next year. Bigger numbers will allow us to develop a more complex picture which will result in us being able to comment on the subscales of supervision, urging and tension.

At this stage we have conducted the process evaluation and a quantitative impact evaluation. A more robust design will be employed in the future which includes an examination of a combination of carer education and respite programs.

It has become clear as the program has rolled out that the intention of the organisations to resource the ongoing support group meetings for up to 18 months was not explicit. This has led to varying application of this support process and needs further attention in future.

The 'Carers of People with Mental Illness Project' – Final Report (2000)[10] and the Mental Health and Department of Health and Ageing Report[11] identified a need for carers to be recognised for their contribution and skills in providing service to their own family members and to others. Further the impact of mental illness within families results in family carers losing career options and income and formal recognition of the facilitation skills via national accreditation is being suggested as a solution to this. The Registered Training Authority status of MIFV is intended to be a vehicle for this in future.

Future developments in the program will include:

- Attaining more clarity in scoring carer accessed psychiatric support – carers may also be experiencing a mental illness and the current instruments do not allow us to investigate this.
- Investigation of who is benefiting more from the program and for what reasons – men and women, parents/siblings/partners. There appears a trend in this data that suggests mothers benefit more than other participants. It is unclear whether this is a content related issue or a group dynamic issue. It is anticipated that this may become clearer as the number of respondents increase and data on group mix is analysed.

Recommendations

The paucity of programs for carers of people with a mental illness within Australia has been highlighted in many reports. Demand in a number of jurisdictions within this project testifies to that. The efficacy of such courses in improving outcomes both for the carer/s and the person with a mental illness is well documented. The value of such courses being provided within a family to family model of teaching is also the subject of research and has been validated as the most effective mechanism for support and education. Despite the evidence, funding for specific programs in most jurisdictions within Australia is poor or at worst non-existent. The non-government sector of mental health is struggling to survive in many locations throughout Australia. This fact has been borne out during the current project with a number of MIFA members unable to proceed with implementing Well Ways within their state or territory. Further some that did have constraints in supporting the development of an on-going support group, which is a fundamental outcome anticipated with the Well Ways program.

[10] Mental Health Council of Australia, *Carers of People with Mental Illness Project – Final Report*, 2000

[8] Mental Health and Special Programs Branch, Dept of Health and Ageing and Deakin Human Services Australia 1999 Education and training partnerships in mental health – learning together (final report) www.health.gov.au/hsdd/mentalhe/resources/reports/pdf/etpmhlt.pdf

Recommendation 1: That in order to participate in this program it is necessary for organisations to be able to make commitments to resource the process.

Recommendation 2: That MIFA is funded in 2005 to conduct another Train the Trainer program for Well Ways which will target those sites needing to train additional facilitators.

Recommendation 3: That a structured follow up support group model be documented and integrated into the train the trainer program

Recommendation 4: Further guidelines be developed for supporting the peer education component of the program which includes how to identify and train facilitators and manage reporting, evaluation and quality control issues of the program.

Recommendation 5: That MIFA seek funding to develop a short program for Carers of people with a mental illness. Such a program will complement the existing Well Ways program and be made available to MIFA members in addition to Well Ways.

Recommendation 6: That the program is nationally accredited to enable carers to gain recognition for their skill.

Recommendation 7: That a greater focus be given to the evaluation process in train the trainer program.