mental illness
fellowship victoria

Submission to the Senate Select Committee on Mental Health

Mental Illness Fellowship Victoria
April 2005

This submission is made as part of Mental Illness Fellowship Victoria's (MI Fellowship) role as an advocate for a better mental health system. . It is Victoria's largest membership-based mental health organisation and has 170 staff, 500 volunteers, 1500-plus members and over 40,000 supporters. For more information: www.mifellowship.org

In 2004 MI Fellowship had contact with over 1,100 people with a mental illness through program delivery, 12,000 through telephone contact and counselling, 8,800 through carer support groups and family education and 2,000 through community and business education.

MI Fellowship is part of the Psychiatric Disability Rehabilitation Services sector and runs 35 programs across Victoria including rehabilitation, education, respite and vocational programs. It has an annual budget of $8 million

This submission addresses the issues raised in the terms of reference but only as they impact Victoria, which is where we have a mandate.

The typical stories detailed have been told in countless different ways by hundreds of people over the years and in telling them we have maintained confidentiality.

Re Terms of Reference 1 a)

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

The first National Mental Health Plan addressed the structural issues of mental health services structural issues in Victoria, including consumer rights, mainstreaming, and service mix, carers and non government organisations and standards. The Commonwealth provided leadership within this process, and committed substantial funding to underpin these developments. Much was achieved. However, consumer and carer participation and service responsiveness remained major issues.

The second plan took up these issues and extended the plan into promotion, prevention and early intervention, but this strategy was not effectively resourced, the leadership from the Commonwealth was reduced and fundamental issues remained.

The theme of prevention continues into the Third plan but has derailed the process and disenfranchised the very people with the greatest need. The third plan states that it wants to take a 'lifespan approach' and promote 'wellness', yet specifically states that it will not specify projects that it will fund, instead it identifies priority areas. It does not give voice to funding to its cross-sectoral intentions, of addressing lifespan. 76% of people with a psychiatric disability do not have work, 48% of people with chronic mental illness surveyed in a low prevalence study had not completed their secondary education. There have been neither leadership nor resources from the Commonwealth given to these areas. Hundreds of people in Victoria on a nightly basis are living in marginal housing, and service responsiveness remains only a dream for many. The constant concern of people with mental illnesses and their families who seek advocacy and support from this organisation is around services listening to them about deteriorating health, and about the inability of services to provide a timely response.

The Third plan is extremely disappointing in focussing attention, addressing barriers or providing leadership within the mental health sector, let alone in cross-sectoral government departments. Barriers within the mental health sector occur between the acute treatment sector and community rehabilitation and support. Some models are developing that begin to bridge these gaps. Partnerships that this organisation has developed (and is developing) with Goulburn Valley Health and Alfred Health are examples of this. These local initiatives aim to show best practice and, through funding and evaluation, want to work to full replication. As part of working towards replication, evaluations need to be done to determine transferability and national significance. The results needs to be shared both across sectors and with the community (it is not only services that are unintegrated, but knowledge also).

Some facts

- The national mental health budget accounts for 7% of the total health budget, but 20% of health demand
- The agreed model of mental health treatment includes biological, psychological and social rehabilitation components but 91% of the funding is allocated to clinical (or medical) services. We know that the average person with a mental illness is in contact with clinical services for only 18 months but spends the vast majority of their lives in the community, which attracts only 9% of mental health treatment funding.

Priority issues

- Strong leadership from the Commonwealth is needed in mental health issues
- Increase mental health budget to 15% of total health budget across all states within five years
- Increase psycho-social rehabilitation and community-based treatment funding to 15% of the total mental health budget

A typical story

“We were able to access medical treatment for our son, but as soon as he was discharged back to our local GP we had to search for support services. We were told there were day programs, but there were none in our area. We were told there were residential rehabilitation services but the waiting lists were over a year long. Medications had stabilised him, but had not made him well. Instead of getting the support he needed to become well again, he remained semi-unwell all the time. It was only when he relapsed that we could get services again. It seems to be a revolving door through psych wards.”

Re Terms of Reference 1 b)

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

The lack of provision of after-hours support and treatment services is extremely problematic. The Crisis Assessment and Treatment Teams (CAT teams) will categorically not attend any incidents for people with mental illness outside of business hours, leaving the only option for people to be transported to Emergency Departments willingly, or police intervention. Despite the best intentions of police, limited training and life experience most often hinders their effectiveness in these situations and limits the public’s confidence in calling them to assist. In the worst cases, misreading and mishandling of crisis situations by police has led to preventable deaths by shooting.

Originally envisaged that CAT teams would be available to make assessments in the community and to be available at crisis times, CAT teams have become increasingly difficult to access. Families in contact with our services constantly report refusal by CAT Teams to attend people’s homes to make assessments. The CAT teams themselves have developed procedures that make clear that they will not attend anyone’s home between the hours of 11.00pm and 7.00am. The stated reason is that they are under-resourced and only one team member is rostered overnight. The safety of the CAT team members themselves has become the first (and perhaps the only) criteria for deciding whether to attend at people's homes. Police still rightly have an expectation that CAT teams will attend at their request, but even this is not guaranteed. CAT teams state a preference to do assessments at a police cell or at a hospital emergency department. The consequences of CATT not attending in crisis situations are all too often fatal. CAT teams themselves seem to have become institutionalised. Their not being part of emergency services has developed into them not being a crisis service either.

The consequences of the breakdown of the CATT support are far-reaching: Families are often left to deal with situations for which they are ill-equipped. On a very practical level, the difficulty for a family of getting a young person in an acute psychotic state into a car to present at an emergency department cannot be overstated. Emergency departments have seen an increase in presentations of people with acute symptoms of mental illness for which they too are ill-equipped. Police increasingly need to negotiate situations with people with mental illness without the support of CAT teams, for which they are ill-equipped. People with mental illness often end up in police cells waiting for assessment, adding to the already traumatic experience of acute symptoms and adding to the trauma of the whole family. It is difficult enough for family members to call CAT teams to come to their homes and assess a loved one without the real and added fear that their family member may end up in a police cell. The net result is that people, by virtue of being ill, are subjected to trauma that both exacerbates their symptoms and discourages them form cooperating with treatment. It is difficult to imagine how this could be handled worse.

Some facts

- CAT teams have developed a culture of considering their own safety needs rather than the treatment need of a person and the safety of that person and the safety of the family
- CAT teams as a matter of protocol will not attend at anyone's home between at least the hours of 11.00pm and 7.00am (when family stories would indicate that night time is the most likely time for a crisis to unfold)
- CAT teams have only one staff member rostered overnight
- One-third of police work involves negotiating situations involving people with a mental illness, but police in Victoria receive only 220 minutes of training in mental illness in their initial 20 week training program

Priority issues

- Police education and training to give police the necessary knowledge and skills to manage effectively incidents involving a person with a mental illness
- A review of the crisis role of CAT Teams in the mental health system
- A review of the standard protocols between police and CATT
- An increase of resourcing to ensure 24-hour home-based crisis service

A typical story

"We have rung the CAT team on several occasions when our son was acutely unwell. We were terrified that he was going to kill himself. When we mentioned this to The CAT team, they said we should ring the police because the CAT team had no way of managing potential violence. They said that later the police would probably ring them to do an assessment. Our son had paranoid symptoms and the last thing we wanted was police turning up. He hadn't done anything wrong"

Re Terms of Reference 1 c)

Opportunities for improving co-ordination and delivery of funding and services at all levels of government to ensure appropriate and comprehensive care is provided throughout the episode of care

Little progress has been made in coordinating delivery of inter-sectoral programs. Although mental illness effects a person's whole life, the main strategy has been symptom management or 'episode of care'. The reality for many with chronic illness is once the 'acute phase' has become manageable the person is left with residual life deficits. This acute model approach is of itself problematic as an individual requires inputs from welfare, education, employment as well as health interventions that are coordinated. Timely education, assertive treatment and support are uncoordinated and too often the family is left to advocate for these services.

There are no clear recovery pathways for people with mental illness. The lack of coordinated rehabilitation following treatment in an acute phase equates to giving someone a heart bypass operation and then offering no follow-up rehabilitation. The consequence is that people relapse more often and the demand for hospital beds increases. The cost of hospital beds is prohibitive and funding that contributes to aiding recovery and minimising risk of relapse is a considerably better use of limited resources.

Some models of integrated service-delivery have been trialled. One such model is PARC, a partnership between Mental Illness Fellowship Victoria and Goulburn Valley Area Mental Health. The model can be described as follows:

> ***Prevention and Recovery Care***
>
> Prevention and Recovery Care (PARC on Maude) is unique - it provides both clinical and psychosocial rehabilitation services to prevent relapse and expedite recovery, all within an established mental health system. Goulburn Valley Area Mental Health (GVAMH) provides intensive assessment, treatment planning and specialist mental health care, and MI Fellowship provides general supervision, psychosocial rehabilitation and therapeutic group activities.
>
> PARC is the first of three pilot programs intended to avoid hospitalisation and promote recovery following an in-patient admission. The Crisis Assessment and Treatment Team coordinate entry to PARC and provide clinical needs assessment. Where possible, PARC staff are involved at every stage to ascertain the use of a PARC placement for the client.
>
> ‘Step up’ occurs when a person is becoming unwell. The client will enter PARC and receive early intervention treatment, to avoid a hospital stay. ‘Step down’ provides short-term transitional support after discharge from an acute admission, providing supported discharge, to minimise the problems associated with premature discharge. PARC bridges the gap between clinical treatment and the all-important psychosocial rehabilitation.
>
> PARC was officially opened by Bronwyn Pike, the Victorian Minister for Health, in March 2004.
>
> . Contact Lisa Pearson, PARC on Maude Program Manager, on 03 58 21 8850 or visit http://www.mifellowship.org/ProgramInfo/ResiRehabSRRP.htm

This model is being replicated now in a partnership between MI Fellowship and Alfred health. It addresses many of the issues of coordinated care, especially early intervention, appropriate discharge planning and continuity of clinical care and rehabilitation.

Some facts

- There are no clear recovery pathways following acute treatment for people with a mental illness
- Recent amendments to the Mental Health Act (Vic) 1986 have legislated standard requirements for treatment plans, there is still no standard for discharge of patients nor for rehabilitation and support following acute treatment
- The availability of community-based rehabilitation services varies considerably among areas, so having access to them remains a matter of historical accident (or luck) rather than planning

Priority issues

- A seamless transition from clinical services to rehabilitation and community-based services so that 'episodes of care' do not finish with clinical services
- Clear recovery pathways through acute and post-acute phases of illness that lead people to recovery
- Priority funding to be given to replicating successful partnership models of care such as the PARC service in Hume, Victoria, a partnership between Goulburn Valley Area Mental Heath Service and the Mental Illness Fellowship Victoria
- Funding that reflects learnings from best-practice models and that replicate best-practice models

A typical story

"It took us over four years to get our daughter into treatment. Finally, she became so unwell that she had to be hospitalised involuntarily. But after just four days in hospital, she was discharged, even though she was still floridly psychotic. We weren't even informed. She went missing for months. She has been in and out of hospital for ten years now. No one ever told us about follow up support services"

Re Terms of Reference 1 d)

The appropriate role of the private and non-government sectors

The creation of the Psychiatric Disability Rehabilitation Services sector in Victoria has made important inroads and the Victorian government have the best-developed system in the country. However there are problems with coordination between sectors, with quality of services, with critical mass of agencies and with capacity to develop the infrastructure to support quality, best practice and replication.

The separation of community support in this sector and clinical approaches has brought considerable benefit, and support and interventions where people are living are one benefit. However the role of these services is not well understood, and accessibility for those people who are reluctant to attend is problematic.

The role of the private sector is especially problematic. When people are seeing a private psychiatrist, they are ineligible to receive other support services, such as case management. The private sector is principally funded on an inpatient basis. Their only post-acute services are hospital or office-based, not based where people are living. People are required to attend day clinic in a hospital or office-based setting. If a person does not attend, they simply fall out of the system. There is no evidence base for the effectiveness of these services and there is plenty of evidence to show that they are ineffective, but current funding models pushes these inappropriate and ineffective interventions. It is not too overstated to say that the private sector is unaware even of the existence of the non-government sector.

Some facts

- The private sector is funded on an inpatient base
- People accessing a private psychiatrist are not eligible for other support services in the public sector
- Post-acute interventions in the private sector have no evidence base and are ineffective
- Current funding models encourage inappropriate and ineffective interventions

Priority issue:

- More appropriate funding and development of community interventions in both the private and non-government sectors
- More coordination between the private and public sectors and between the private and non-government sectors
- Funding priority to be directed to post-hospital rehabilitation and support interventions that are effective and that are evidence-based

A typical story

"At MI Fellowship, we were working with a 19 year old woman who presented for counselling. She displayed symptoms both of psychosis and counselling. When we tried to refer her to her local area mental heath service, they said that, although she met all the criteria, they simply did not have room in their service for her. She could not afford a private psychiatrist and we could not locate a bulk-billing psychiatrist who would take her. We were left supporting client who needed clinical treatment but simply could not access it at all"

Re Terms of Reference 1 e)

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

Housing and Accommodation

Safe, affordable and appropriate housing remain outside the life experience of thousands of people with a mental illness. There is no clear way of capturing the scope of this problem. Hundreds of families report that a family member remains in the family home beyond an age-appropriate or development-appropriate time as there are not other options. Families who are primary caregivers and who are housing their unwell relative express huge concern about where that person might live once the parents are not able to care for them anymore. Upon discharge from hospital many people with mental illness are without housing, which should be a major plank in their integration back into the community and their rehabilitation from illness and its effects. Boarding houses and the like are inappropriate accommodation most often, particularly for younger people with mental illness who have a whole life ahead of them. The effect of this housing and independence crisis is felt not only by the person with a mental illness but also by their families who feel and express the strain of having to take such a 'hands on' approach to caring for their relative in the long term.

Of those who are placed in supported accommodation, availability and not suitability is the basis. The type of support people need ought to be determined by their needs and their level of disability. Emergency and refuge accommodation services now typically give conservative estimates that more than 75% of their clients have mental health issues and many have florid mental illness symptoms.

The instability that comes with the lack of secure and affordable housing makes a direct contribution to relapse and hinders recovery.

Some facts

- 24% of people living with a psychotic illness in Australia live in marginal housing (i.e. homeless, crisis shelter, rooming house, hostel, rented hotel room) *National Survey of Mental Health and Wellbeing Bulletin 5, National Mental Health Strategy 2002*
- Only 4.9% live in purpose-run supported accommodation *National Survey of Mental Health and Wellbeing Bulletin 5, National Mental Health Strategy 2002.*

A typical story

"We have been looking after our son at home for thirty years. We're now in our seventies and he in his fifties. We are worried sick about what's going to happen to him when we die. It's already become too difficult and we're not getting any younger"

Priority issues

- Being sick should not lead to poor housing. A variety of housing options: safe, secure, affordable and supported. Differing levels of support are required for people with different levels of disability
- Greater availability of support where people live to help people develop tenure in the community

Employment and education
MI Fellowship have, for many years, run innovative programs to train and support people with psychiatric disability to enter or return to employment. Pre-vocational training, including entry-level work placements, has meant that people believe they can work, and they have developed work skills to support employment. The key issue that we experience preventing people from entering or returning to open employment relates to the lack of suitable employment opportunities combined with the provision of on-going support

Employment opportunities are limited for many reasons. Stigma is a key issue preventing some employers from employing people with a mental illness. Employers are also fearful that the fluctuating and episodic nature of mental illness may limit the productivity of the employee. For some people with a mental illness, educational attainment may also have been compromised, of they became unwell during late teens and early adulthood.

Clinical mental health services and private psychiatrists are rarely able to provide the support necessary to enable employment for clients with a persistent mental illness. Agencies such as Commonwealth Rehabilitation services and Job Network providers offer time limited support, usually not on-site, to some clients with a mental illness. Business Services have provided some employment opportunities for people with a mental illness however these are limited in that people do not work for award wages and the setting is not integrated. In Victoria, rehabilitation services are provided by Psychiatric Disability Rehabilitation Support Services some of which include pre-vocational aspects in their programs. MI Fellowship is one of the few organisations to run rehabilitation services targeting employment as a goal and adopt novel approaches to work preparation, such as time-limited work placements to facilitate skill development, and ongoing support.

MI Fellowship has also gained Registered Training Organisation status and offered, for the first time in 2004, a Certificate of General Education for Adults, from which 15 students graduated. There are 20 students enrolled again in 2005. All of the students have a mental illness and all have attempted further studies in mainstream education institutions, but those institutions have not been able to respond to their particular needs.

In both employment and educational settings, accommodations have been legislated that allow people with physical disabilities to access them. However, the lack of such accommodations for people with psychiatric disability equates to a hidden discrimination that excludes people with psychiatric disability from gaining both employment and educational opportunities.

Some facts

- 47% do not complete secondary education *National Survey of Mental Health Bulletin 5, National Mental Health Strategy 2002*
- *8*0% of people with a mental illness in Australia are unemployed *National Survey of Mental Health and Wellbeing Bulletin 5, National Mental Health Strategy 2002*

Priority issues

- We would like rehabilitation services to be funded to provide employment services that have the capacity to place clients with persistent mental illness in work, and provide on-site coaching and support in a time unlimited way. This approach responds to the ongoing and fluctuating needs of people with persistent mental illness and is informed by research evidence that suggests this approach is superior to traditional prevocational approaches (Crowther, Marshall, Bond & Huxley, 2004). Commonwealth funding support does not currently provide an incentive for services to adopt this model and the split between state funded health services and commonwealth funded employment services also presents a barrier to providing an integrated approach.
- We would like to see a greater range of employment options available for people with a mental illness. A key initiative taken by MI Fellowship has been the establishment of Australia's first social firm for people with a mental illness. Social firms are small businesses that employ a mix of disabled and non-disabled workers. All employees work for award rates and eligible for the range of positions available at the workplace. The working environment enables flexibility, provides for

unpaid time off (without risking the job), is not time pressured, provides a mix of unskilled and skilled positions and is supportive of disclosure. Ongoing and responsive support/education, and intensive training for employees with a mental illness is provided for all employees through MI Fellowship's project team. MI Fellowship aims to develop a "blueprint" for replication throughout Australia. The development of innovative programs, such as this, requires secure funding support.

- Supported education opportunities need to be provided for people with a mental illness to commence or complete education. For some people with a mental illness, TAFE and university communities need to provide a higher level of ongoing support than currently available. Flexible study options, including part-time study, are also important. Entry requirements and cost also operate are also barriers for some people with a mental illness and so mechanisms to support entry need to be developed.
  (See Crowther, R, Bond G, Huxley P. Vocational rehabilitation of people with severe mental illness (Cochrane Review). In: *The Cochrane Library*, Issue 2, 2004. Chichester, UK: John Wiley & Sons, Ltd.

A typical story

"My son was being treated in an area mental health service and was being case managed. He was discharged from case management and I was told this is as well as he could get. He was one of the 80% of people in Australia with mental illness who were unemployed. He wanted to work. At my own expense, I opened a house painting business to create work for him (I'm a school teacher by profession). I found the work and then supervised him. His health has improved and so have his skills. He now works more independently, but I have had to work part time now for the past four years to achieve this."

Re Terms of Reference 1 f)

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

Drug and Alcohol

Despite high rates of drug use among people with mental illness, mental health services and alcohol & other drug services use different treatment models. Many people fall between the cracks, being excluded from both services on the grounds that a person needs to deal with the 'other issue' first.
In some cases, people are denied even emergency psychiatric treatment on the grounds of being drug-affected. Dual diagnosis (when a person has both a mental illness and a problematic drug use issue) needs to be seen as the norm in the newly diagnosed group. Services need to look to treating whole persons, not particular groups of illnesses. In Victoria, dual diagnosis services have been established to begin working with both mental health services and alcohol and other drug services to increase integrated interventions, but they are secondary consultant services and do not even begin to address the scope of this problem.

Some facts

- A conservative estimate is that 60% of people with a mental illness also have a drug use issue
- Drug use is seen as normative in Australia, especially among younger populations, mitigating against effective treatment outcomes

Priority issues

- Better integration between mental health services and alcohol and other drug services
- Better integration of intervention types
- Focussed community support

A typical story

"My son presented at an area mental health service and was told while he was using marijuana there was nothing they could do for him. When he went to drug & alcohol services, he was told to go and deal with his psychosis first and then they would put him through drug rehab. As a result he was getting no treatment at all and continued to get worse."

Social and geographical isolation:

A study in 2001 found that the overall death rate of people with a mental illness is 2.5 times higher than in the general population. Also, people with a mental illness experience 16% more deaths from heart disease than general population and have higher death rate from major diseases than the general population. Despite a cancer rate the same as the general population, people with a mental illness have a 30% higher death rate once the disease is diagnosed. *(Duty to Care: Physical illness in people with mental illness, R Coghlan et al, Department of Public Health and Department of Psychiatry and Behavioural Science, The University of Western Australia 2001).*

For people with a mental illness living in rural and remote areas, stigma remains a significant issue. This discourages people from seeking treatment exacerbating the problem. Further, in rural and remote areas availability of treatment is also an issue. There is often no option to seek treatment in the private system, which may reduce the stigma in smaller communities. But access even to public mental health services can be difficult.

Some facts

- 62% of people with psychiatric disorders do not utilise mental heath services. Reasons given include poor distribution and costs of specialist services, inappropriate public services, stigma and fear of medical treatments *Out of Hospital, Out of Mind, Mental Health Council of Australia 2002*
- Increased funding to provide access to treatment in 100% of cases

Priority issues

- Equality in health services for people with a mental illness and effective community supports
- Community educations to reduce the stigma surrounding mental illness
- Greater incentives for private practice in rural and remote areas

A typical story

"My partner was a gym instructor when he was diagnosed with bipolar disorder. He received treatment for bipolar but when he presented for any other illness he was considered a psychiatric patient. His physical health and fitness deteriorated very quickly because the mental health system had labeled him".

Re Terms of Reference 1 g)

The role and adequacy of training and support for primary carers in the treatment, recovery and support of people with a mental illness

Training and support for carers of people with a mental illness remains extremely problematic. Availability of carer training and support is ad hoc. Some Area Mental Health Services and some PDRS (Psychiatric Disability Rehabilitation Services) provide this but many do not.

Despite the fact that much of the caring role falls to the families of people with mental illness, they are still typically excluded from the system. Issues of patient confidentiality often override the need families have for basic information even as simple as a diagnosis. Despite s120A of the Mental Health Act (Vic) 1986, which allows for mental health professionals to provide primary carers with information necessary to the caring role, many carers are given no information at all. Many treating psychiatrist are unaware of s120A of the act. In many instances, treating psychiatrists refuse even to speak with family members, so vital information that families may have regarding a person's symptoms is not accessed by treating doctors. Given the nature of many mental illnesses, this is disingenuous and in many cases can lead to misdiagnosis or unnecessary delay in accurate diagnosis. Many clinicians seem unaware of the trauma that families experience when a loved one has a mental illness and even when they do choose to communicate, it often exacerbates the confusion, isolation, guilt and unwarranted self-blame that families experience.

Even in services where early intervention and prevention strategies have currency, carer education is often seen neither as a necessary part of intervention strategies nor of health promotion. This is despite overwhelming evidence that family interventions make a significant contribution to better outcomes for people with a mental illness (For a full account, see

Much of the funding carer support and education has been allocated to generic carer services such as Carers Victoria and Commonwealth Carer Respite Centres, and while these generic services provide important services, they are unable to address the specific needs of those caring for people with mental illness in grounded ways. The limited funding ends in making very important processes compete for the most deserving.

Education and training given by area mental heath services for carers is in most cases non-existent, and even those services that attempt to involve carers use interventions that have no evidence base and are nor evaluated for their effectiveness. Among the rehabilitation services, most programs on offer for carers are similarly not evidence-based. There is little or no funding given to the development of such programs.

MI Fellowship has developed a program called 'Well Ways', a multi-family peer-based psychoeducational program which has an eight-week structured sessional component followed by a further twelve months of structured support. The program has been impact evaluated using a General Health Questionnaire and the results are significant in reducing levels of anxiety and depression in those family members who participate. This program is now being piloted throughout Australia through Mental Illness Fellowship of Australia members. The program has received little government funding and has been funded through grants. MI Fellowship has created partnerships with some area mental health services to deliver the program to family members of clients who enter the clinical service. Ideally, further impact evaluation should be done (and is in planning) to assess the impact of the carer education program on the person in the family with a mental illness and on the clinical staff. Similarly, MI Fellowship has developed a dual diagnosis education program for families 'Double Trouble'. It too has been impact evaluated. Both programs are based on accurate up-to-date information and are based on research into effective family interventions.

These group-based interventions need to be complemented with counselling that considers a family's particular situation and aims to develop a management strategy for that family. Once again, this service needs to be provided by agencies that have specific understanding of mental illness and presenting symptoms and particular expertise in the issues of caring for someone with a mental illness.

Some facts

- Most Area Mental Health Services have no carer education and training
- A significant proportion of funding for carer services is being directed to generic carer services who are not equipped to address the specific needs of people caring for someone with a mental illness
- There is overwhelming research evidence now that demonstrates the effectiveness of targeted family interventions in producing better outcomes for people with a mental illness

Priority issues:

- Evidence-based accurate education about mental illnesses and management strategies
- Funding to be directed to evidence-based family interventions
- Funding to be directed to evaluate and assess viability of replicating best-practice partnership models such as those between MI Fellowship and Area Mental Health Services
- Education of mental health professionals to move to family-inclusive practice

- Funding models that encourage family-inclusive practice
- Mental health workers to do placements in community agencies that work with families to better understand the lived experience of families where there is a person with mental illness

A typical story

"When my son was first diagnosed, the doctor came out to me and simply said 'Your son has schizophrenia and I've given him some antipsychotic medications to take. He has another appointment next week' I had no idea what schizophrenia was or what I could do to help. I was just left in the dark as if it didn't make any difference to me that one of my children had schizophrenia. I had no idea who to ask or who to tell, so I kept it hidden from everyone, even my other children."

A typical story

"When our teenager was first diagnosed with schizophrenia, we did not even know what it was, let alone who to speak to. His psychiatrist told us of some websites that had information, but the websites could not answer our questions. It was not until some friends told us about a program called Well Ways run by Mental Illness Fellowship Victoria that we got anywhere. Through it, we learnt to manage better and our son's situation improved as well. If only we had known earlier, we could have avoided a lot of family distress and eventual family breakdown."

Re Terms of Reference 1 h)

The role of primary health care in promotion, prevention, early detection and chronic care management

The primary health care system has a pivotal role in terms of people receiving appropriate health care for mental illness issues. Presently, the sector is limited in its literacy around mental health issues and is unable to play a role of referral and linkage to mental health agencies. We know that 60% of people with mental illness never receive a diagnosis or treatment and the primary health care system could play a large role in reducing this figure.

Conversely, once someone has a disability resultant from mental illness the primary health care system has a role in monitoring the 'whole' person's health. However, this is rarely done well as people are seen through the 'eyes' of their disability and not treated for other health issues. Health issues such as dental, routine screening procedures and early intervention for disease are badly accommodated in the primary health care sector.

Re Terms of Reference 1 i)

opportunities for reducing the effects of iatrogenesis (side affects of treatment) and promoting recovery-focussed care through consumer involvement, peer support and education of the mental health workforce, and for services to be consumer-operated

The iatrogenesis of mental illness are primarily social. It is simply unacceptable that, due to illness, this population has an unemployment rate of 80%, that many are homeless or living in marginal housing, that suicide rates are 10% (of people with schizophrenia, and higher with some other diagnoses), that most are childless, that almost half never have the opportunity to complete secondary education, that many have weight problems associated with medications and inactive lifestyles, that very few maintain meaningful relationships, that death rates due to physical conditions are significantly higher because patients are labelled as psychiatric and therefore often do not have rightful physical grievances treated. It is difficult to overestimate the public outcry if these outcomes were replicated among the population of people with cancer or heart disease.

Re Terms of Reference 1 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, the adequacy of legislation and processes in protecting their human rights and the use of diversion programs for such people

The overrepresentation of people with a mental illness in the criminal justice system is a direct result of the lack of adequate treatment services. The research into violence among this population now shows that there is a negligible increase in the risk of a person with schizophrenia, for example, perpetrating violence. That risk increases significantly when symptoms remain untreated. The risk increases again if the person also has a drug use issue.

Custodial settings are the antithesis of the ideal environment in which people will optimize recovery from mental illness symptoms. Reducing stress levels plays a key role in maximizing recovery and custodial settings are particularly stressful environments.

A diagnosis of Borderline Personality Disorder is especially problematic for people. This population is routinely excluded from access to mental health services. Treatment interventions are long term and complex and so this group falls through the cracks. Because of the nature of personality disorders, and the lack of availability of services, this group remains particularly vulnerable to overrepresentation in the prison system. There is only one specialist service serving this group in Victoria.

Some facts

- There is only one specialist service in Victoria that deals specifically with people diagnosed with borderline personality disorder: Spectrum
- People with borderline personality disorder are routinely denied access to mental health services

Priority issues

- More leadership from the commonwealth and more integrated service delivery based on best-practice models would go a long way to easing the overrepresentation of people with a mental illness in the criminal justice system

A typical story

"My daughter was sick for a number of years but would not go to a mental health service. Our family GP believed that she has Borderline Personality Disorder. The only specialist service that we knew of was in the outer eastern suburbs of Melbourne and she was not considered unwell enough to qualify for treatment. The result was that for another 7 years, she got worse until she was considered sick enough to need treatment. Treatment made a huge difference to her."

Re Terms of Reference 1k)

The practice of detention and seclusion 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 minimizing treatment refusal and coercion

The practice of detention and seclusion within mental health facilities ought to be a last resort intervention. Although there are stringent criteria in the Mental Health Act 1986 (Vic) regarding involuntary admission, the lack of services again contribute to higher rates of relapse and greater need for hospitalisation. Families who access our service are consistent in their stories that treatment for their unwell relative could not be obtained until the person was so unwell that he or she needed to be hospitalised. People are routinely denied access to services because they are deemed not ill enough to need them. The result is that the practice of detention and seclusion, which ought to be a seldom-used intervention, has become a routine first intervention for many patients.

The standards of mental health facilities and the standards of care provided in them are both inadequate. Patients who have florid psychotic symptoms are frequently required to share rooms that would be unacceptable in general hospital wards. Too many stories are told to our services of basic human rights being denied. Typical stories include young female patients being placed in seclusion with no clothes and being visible to male nursing staff.

The stories of the many families who access our services are also that the experience of involuntary detention and the inadequacy of humane treatment in these facilities exacerbate lack of adherence to treatment. When a call from the family to a CAT team results in involuntary hospitalisation (and this can come as relief for many families), the experience of the person in these settings can be so traumatic that untold damage is done to family relationships. Family members who made the call to CAT teams are left with the burden of seeing the result of their phone call being that their relative receives inadequate care in substandard conditions.

The inadequacy of care is in part attributable to the inadequate training of psychiatric nurses. Currently programs for nurse training are based on a 3-year cycle. The content of this training is crammed with essential biological knowledge. But graduates from this training lack both the knowledge and life experience to work with psychiatric patients and are unable to provide adequate interventions.

Priority issues

- A 4th year of Commonwealth funded specialist training for psychiatric nurses designed to develop specialist psychiatric knowledge and to recruit suitable people to the profession

A typical story

“We had sought treatment for our son for months. When we finally had to call police because things had become so volatile, he was put into a psychiatric ward. When we saw the conditions he was living in, my wife cried for weeks. Our son would not speak to us again and has never forgiven us for putting him though it. But there was nothing else we could do.”

Re Terms of Reference 1l)

The adequacy of education in de-stigmatising mental illness and disorders and in providing support service information to people affected by mental illness and their families and carers

Research undertaken by Mental Illness Fellowship Victoria shows that psychotic illness such as schizophrenia carry a unique stigma, unlike depression and anxiety which are much better understood and accepted. Most research participants said that if someone was being effectively treated for schizophrenia they would not employ them, and would be happy about them going out with their child or baby sit their child. Most indicated that they would feel fearful if someone who had been treated for schizophrenia moved into the house next door. While resources have been allocated to de-stigmatise and gain greater understanding of high prevalence mental disorders such as depression and anxiety, this has contributed little to de-stigmatise low prevalence disorders.

Regarding support service information see our comments under Terms of Reference 1g) above.

Priority issues

- Resources to be directed to where the greatest stigma lies – with psychotic illnesses such as schizophrenia and other low-prevalence disorders

A typical story

“When our 17-yr old daughter was diagnosed with schizophrenia, my own sister did not speak to me for three years. After three years she rang and apologised and said that she wanted to communicate again. She invited my family to Christmas lunch (which we had always had as a family before) but asked that we leave our daughter with schizophrenia at home. Needless to say, we didn’t go.”

Re Terms of Reference 1m)

The proficiency and accountability of agencies, such as housing, employment, law enforcement and general health services, in dealing appropriately with people affected by mental illness

It is clear form other parts of this submission that generic housing, employment, law enforcement and general health services are not equipped to deal with the specific needs of people with a mental illness. It is the absence of clear pathways to recovery that leave non-mental health specific services with an overwhelming burden of dealing with people with a mental illness who are often presenting with untreated symptoms. The particular role of the police warrants further highlighting given the nature and importance of their interventions.

Priority issues

- See priority issues under TOR 1b)

A typical story

"We have needed to call the police a number of times when our 22-yr old son has been so unwell that we did not feel safe. His paranoid delusions meant that he wanted the house constantly locked, windows locked and blinds down and we were not allowed to answer the phone. Most times the police have managed the situation very well, but on one occasion two young officers mishandled things so badly that my husband ended up being hurt by my son. It was avoidable. The officers simply did not know enough about mental illness to handle the situation."

Re Terms of Reference 1n)

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

In this state, the burden of disease between mental health and physical illness is not reflected in funding for research. Given that this unsatisfactory circumstance exists, the majority of funding expended in mental health research is focused on biological treatments. There is little funding in the psychosocial, vocational and educational interventions or into community-based interventions. The capacity to identify what works and what doesn't and to define best practice is therefore not there, so the knowledge about replication and expenditure is underdeveloped. This means that funding is allocated by reasons other than on the basis of what works.

Priority issues

- Funding to investigate best practice and effective interventions in community-based treatment, in partnership models and in family interventions
- Funding to be prioritised to replicate demonstrated best practice models in post-clinical rehabilitation services

Re Terms of Reference 1o)

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

In this state, various data collected in clinical services under RAPID and minimum data sets (Quarterly Data Collection (QDC) for Department of Human Services Victoria) do not relate to each other. While a national project has been developed to standardize this data gathering, we are still confronted with a situation in which different departments are demanding different data collection, which produces both replication, undue administrative cats in a sector already strapped for cash and further undermines any efforts for a cooperative exchange of relevant intervention data across systems, especially in referral processes.

QDC data is also unable to be used by agencies and hence cannot inform management practices in the sector. Management then has to set up alternative mechanisms or not use data at all to inform management practice. One department, when asked about duplication responded that they could not get timely information form the QDC and therefore would not give us direct information.

Priority issues

- Funding to identify best-practice standardized data collection through the spectrum of services involved in mental health service delivery from clinical services through community-based rehabilitation services

Re Terms of Reference 1p)

The potential for new modes of delivery of mental health care, including e-technology

There is considerable potential for e-technology to contribute particularly to ease of referral and information-sharing between various agencies who deliver services to the same client. However, there has been no funding given to facilitate such a development and so referral processes continue to be unnecessarily arduous and duplicitous.

Priority issues

- See above TOR 1o)

I thank you for the opportunity to present this submission and would be pleased to speak to it at your convenience,

Elizabeth Crowther
Chief Executive
Mental Illness Fellowship Victoria