Inquiry by the Senate Select Committee on Mental Health

Submission presented by

Judith Player
Executive Director

On behalf of the Board of Governance

ARAFEMI Victoria Inc.
Suite 1, 10-91 Toorak Road
Camberwell Vic 3124
Ph (03) 9889 3733
Fax (03) 9889 2878
admin@arafemi.org.au
www.arafemi.org.au
Reg No A0000883B
ABN 21 094 487 229

About ARAFEMI
ARAFEMI Victoria is a community managed, not for profit incorporated association, registered as a community support service under the Victorian Mental Health Act 1986. Its mission is "to promote the well being of people affected by mental illness". It is committed to deliver services that are of high quality, professional and innovative, to both those who experience mental illness and those who care for them.

Membership
Members of ARAFEMI Victoria are carers of people with a mental illness, people who identify as experiencing mental illness, mental health service professionals and interested others. There are over 400 financial members in 2004-2005.

Services
Family support services include a range of groups and courses catering for particular needs. There are open family support groups, including a long-running group in regional Bendigo, facilitated by volunteer convenors. Bridging the Gaps groups in Melbourne's East and South provide an educational forum for parents and other carers to explore options for services for young people (16 years+) experiencing mental illness and for their families. The Offspring Group is a professionally facilitated closed group for young people who have grown up with a parent/s with mental illness. ARAFEMI co-facilitates with other agencies a support group for families and carers of peoople with a borderline personality disorder.

Office based services include telephone support, information, referral, short-term individual counselling, a library and a quarterly newsletter for members.

The work with carers remains at the core of ARAFEMI's identity. Activity indicators for 2003-04 included 405 members, 2700 telephone and counselling contacts, 310 individuals attending support groups, 2200 quarterly newsletters and 2800 monthly newsletters distributed. This work is accomplished with funding equivalent to 1.5 full time staff supplemented by internally generated funds.

The Camberwell Bipolar Support Group, established in 1984 for a group of carers who wanted their relative with bipolar disorder to learn with them, is now directed to people who identify as experiencing bipolar disorder.

ARAFEMI volunteers have championed the Community Development Program based on "The Kit", a product of the National Mental Health Strategy. Assisted by philanthropic funding and Commonwealth Carer Resource Centres carer funding, ARAFEMI members have been delivering training in advocacy to carers. Five courses will be delivered in the year 2004-2005.

The bulk of ARAFEMI's service provision is to people who have experienced mental health problems. ARAFEMI provides home-based outreach support to more than sixty people living with a psychiatric disability in parts of the eastern and northern suburbs of Melbourne. Psychosocial rehabilitation workers visit people living in their own or ARAFEMI sponsored accommodation and provide assistance to enable people to live in the community. The support is determined through a consultation process between the client and the worker, resulting in an individual program plan which is updated at least once every six months.

The Intensive Outreach Support program in Melbourne's north is directed to people with mental health problems who are homeless or at risk of homelessness and who have complex needs.

In November 2004 ARAFEMI joined with Eastern Health to open the Linwood House prevention and recovery care service. Linwood offers a supportive environment to people who are at risk of relapse or who are recovering from an episode of mental illness. There is residential accommodation for eight people and an additional two places for clients to join the day program. It is staffed 24 hours, seven days a week and clients can stay for a maximum of four weeks.

ARAFEMI endeavours to support an holistic approach to mental illness, where the active symptoms of illness are only one part of the difficulties encountered by people experiencing mental health problems. Understanding and support from family and friends, community awareness, lessening of stigma, access to secure affordable housing, access to general health and community services, preparation for entry or re-entry to education and employment, supportive assistance at a time of exacerbation of symptoms all contribute to the well-being of people who experience mental illness and those who care for them.

Response to Terms of Reference

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.*

As stated in the National Mental Health Plan 2003-2008,[1] the aims of the National Mental Health Strategy remain an appropriate guide to change. However the resources committed to mental health remain inequitable. Mental illness accounts for almost 30 per cent of non-fatal disease burden in Australia.[2] Growth in spending on mental health has mirrored overall health expenditure trends since the commencement of the National Mental Health Strategy, however the proportion of the health dollar allocated to mental health has not altered.[3]

In Victoria all public mental health inpatient services are delivered in mainstream hospitals, with the exception of the specialist inpatient unit for forensic patients. At the commencement of the National Mental Health Strategy the per capita spending in Victoria was at a higher base than other states and has now been overtaken by WA and SA. There has been some new spending by the State government but there have been financial demands from an industrial agreement with nurses which, from our viewpoint, have not translated into better services for patients.

The proportion of spending in community services has increased, however the resourcing of the non-government psychiatric disability rehabilitation support service sector has not kept pace with increasing costs. For the financial years ending 30 June 2001- 2003 ARAFEMI Victoria had an operating deficit. This organisation is frugal in its expenditure, has an unpaid Board of Governance, makes extensive use of

volunteers, minimises administrative and overhead expenditure and generates some income. We had operated with a slight surplus for the previous 21 years. Hence our concern at funding non-clinical community based services to people affected by mental illness.

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;

Because people are spending significantly less time as inpatients, families and community services are supporting people who may be acutely unwell. Ten years ago people would be admitted to hospital for a medication change. They would be monitored by medically trained staff for changes in their mental health status and for unwanted side effects. When people were experiencing a relapse in their mental health status they would be admitted to hospital. Now they may be monitored by an outreach service of the community mental health service. Family members may be carrying responsibility for overseeing medication and monitoring their relative's symptoms.

We are in total agreement with the placement of mental health services within the community, however the outreach services of crisis assessment and treatment teams may be inadequate to relieve the burden of care being placed on families and on community support services.

Early intervention

Family members report frustration when they are picking up cues of possible relapse but the area mental health service is unable to respond. The triage system for placement on the crisis assessment and treatment team alert or to receive a visit from a CAT team focuses on symptoms of acute illness, rather than early intervention to prevent further relapse.

For example, in late 2004 the 70-year-old mother of a 42-year-old woman was becoming concerned about her daughter's level of wellness. She was observing a range of indications that her daughter was relapsing. Mother contacted the area community mental health service. Mother received complaints from the daughter's landlord about inappropriate behaviour, neighbourhood complaints and her level of hygiene. Mother again contacted the area community mental health service and stated that the neighbours had called the police to the premises. Over a period of at least twelve weeks, the crisis assessment team telephoned the daughter on two occasions. When the mother inquired as to whether any action was being considered, she was informed that her daughter sounded "fine" and did not want the team to visit. Eventually police and the CAT team removed the daughter from her home; she was admitted to hospital. The daughter lost her housing. Her mother was requested to pack her belongings and place them in storage, clean the rental property, and commence the process of finding new housing when her daughter was ready for discharge from the acute unit.

Acute care

Are there enough inpatient beds available? Beds have decreased by around 87% over the last 30 years. Some areas appear to have an appropriate number of beds to meet

demand. In other areas people spend periods of time in emergency departments which are ill equipped to meet the needs of an individual who is in an acute phase of mental illness. Family members may be asked to take their relative to an out of area hospital because there is not a bed in the local unit.

Hospital inpatient units can be hostile environments for many patients. As well as symptoms of mental illness, some patients can be withdrawing from an array of substances. There may be inappropriate behaviour which can be physically or sexually intimidating. It is not surprising that many people are very reluctant to accept admission to hospital. We are hopeful that the new prevention and recovery care programs being trialled in Victoria will be able to meet the needs of people who do not require admission or who are ready for discharge from acute care units but need additional support before they can resume independent living.

c. opportunities for improving coordination and delivery of funding and services at all levels of government to ensure appropriate and comprehensive care is provided throughout the episode of care;

Most clients of our home-based outreach service are in receipt of the Disability Support Pension. Many live in public housing. Their medication is subsidised through the Pharmaceutical Benefits Scheme. They are able to access a range of community activities, some of which have been subsidised through a local government and charitable foundation grant. Some clients access Job Network programs. Coordination to ensure that clients access all services to which they are entitled is a major task of the ARAFEMI outreach staff. We know from the telephone calls of family members that many other people miss out on services because they do not have a case manager or because they are unaware of what is available.

d. the appropriate role of the private and non-government sectors;

Some of the clients of our home-based outreach support service are now receiving their medical care through local general practitioners. This can be entirely appropriate. Other clients participate in shared care, where they see a private psychiatrist but receive case management services from the area community mental health service. Some families continue to pay private hospital insurance to ensure that their relative can access private hospitals; however there can be difficulties since one of the largest private health insurance funds in Victoria no longer has a contract with one of the largest private psychiatric hospitals.

Very few psychiatrists offer bulk billing to their patients and there is a dearth of private practice psychiatrists outside the metropolitan area.

Organisations such as ARAFEMI are part of the non-government sector. We see a continuing role for the sector to respond with flexible innovative services. We are not as constrained by the geographical boundaries of the public mental health services nor restricted to offering services only to people with a case manager in a public mental health service. We are able to maintain contact with clients through transition periods, whether of re-housing in a new area or moving out of the specialist mental health

service. We can offer a service to carers whose relative is refusing to access any mental health service.

However we are very much dependent on Victorian state government funding and are limited in our capacity to generate external funding to finance such services, without engaging in expensive, time-consuming fund-raising.

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

Lack of access to secure affordable supported housing remains a barrier for people with mental health problems seeking to return to independent community living. ARAFEMI has nomination rights for 40 places, mostly in shared housing. There is very little movement in this housing. As at 31 March 2005 there were 49 people on the waiting list.

Acute care beds can be blocked because of the lack of supported accommodation for people who are ready for discharge. There has been a striking loss of low cost private rooming house accommodation and specialised residential service accommodation in the inner east of Melbourne. Owners have elected not to bring properties up to fire safety standards or statutory room sizes, because of cost.

There are very long waiting lists for access to public housing. Over the last seven years there has been very little new housing available to people with mental health problems. Public housing initiatives in Melbourne for people who are homeless have been directed to the outer suburbs, where property values are lower but there is a significant lack of specialised support services for people with mental health problems.

Commonwealth funds have been directed toward rent assistance, supplementing a pension or benefit to meet private rental payments. Our clients have difficulty accessing private rental; as single people the costs are excessive whilst there may be covert discrimination against renting to people whose only income is a pension or benefit.

There has been an increase in transitional housing and the Victorian Office of Housing has a segmented waiting list, which has allowed some of our clients to access public housing, however we need a much greater range of housing with varying levels of support.

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;

Providing appropriate clinical and community support services for people, especially young people, with co-morbid mental health and substance abuse problems remains a critical need. ARAFEMI Victoria has two support groups for families of young people

(16+ years) and the lack of appropriate services for this group in treating their dual diagnoses is concerning. The families tell similar stories of young people who are excluded from services because of their challenging behaviours, particularly services which are not specifically designed for young people.

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

The Network for Carers of people with a mental illness undertook a project in 2004 looking at the education and training available to primary carers in Victoria. The report can be found at: http://www.carersnetwork.org/publications/network-papers.php

At ARAFEMI Victoria we provide carer training and support services as detailed above. We receive funding under the statewide mutual support self help funding line from the Victorian Department of Human Services. This funding is equivalent to the salary of less than 1.5 EFT workers (anticipated funding for 2004-2005 is less than $90,000). The program cost around $117,000 in 2003-2004 and is subsidised by investment income. We cannot meet the demand for courses and specialised groups which are requested by carers.

A number of carer initiatives have developed in Victoria since 1996, specifically state funded mental health positions in Carer Resource Centres, however these are distributed unevenly across the state with 1.0 EFT in some regions, 0.5 EFT in others and no worker in the remainder. The Carer Support program funded by the Mental Health Branch has provided another avenue of support for carers but is restricted to those whose care recipient is a client of a public mental health service. This means that people caring for a family member with a high prevalence disorder, such as anxiety and depression, or whose relative has been discharged by the public mental health service are excluded from receiving carer support funding.

The Office of the Chief Psychiatrist in Victoria has issued a guideline *Working together with families and carers* [4] which we endorse. The extent to which mental health practitioners are able and willing to implement the guideline is yet to be determined.

The evidence base for the efficacy of work with the families of people with a mental illness, particularly schizophrenia, exists. There is decreased risk of relapse and decreased rate of hospitalisation.[5] The argument has been made that, if there was a medication with the same impact as family intervention work, it would be prescribed.[6] Yet we find that work with families remains an optional extra, which increases the burden on case managers already holding high caseloads. We note that it can be difficult to engage families, especially when inpatient admission periods are so short that any family work becomes the task of the community mental health staff.

h. the role of primary health care in promotion, prevention, early detection and chronic care management;

There is an important role for primary health care in attending to the physical health needs of people with mental health problems. There is an increased incidence of obesity, diabetes, heart disease, infectious diseases and injuries.[7]

i. opportunities for reducing the effects of iatrogenesis and promoting recovery-focussed care through consumer involvement, peer support and education of the mental health workforce, and for services to be consumer-operated;

At ARAFEMI Victoria we facilitate a consumer peer support group and have anecdotal evidence of the effectiveness of such groups. These groups are powerful supports to recovery, allowing people to explore the impact of mental illness in their lives and to make life style adjustments conducive to good mental health through exposure to the example and experiences of their peers.

We encourage consumer representation at board and board sub-committee levels. Clients of our service are active in planning facets of the service, through a service sub-committee.

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;

In NSW 41% of male prisoners and 54% of female prisoners reported some form of treatment for emotional of mental illness during their lifetime.[8] The Victorian Institute of Forensic Mental Health (Forensicare) offers a range of services to people in the criminal justice system, with court assessments, assessment of all prisoners entering the Melbourne Assessment Prison, the specialist Thomas Embling Hospital and a community forensic mental health clinic. Prisoners with co-morbid mental illness and substance abuse problems present particular challenges. The percentage of women prisoners with mental health problems is likely to be similar in Victoria. Our understanding is that the specialist ten-bed women's ward at Thomas Embling Hospital operates at capacity at all times.

At ARAFEMI we find a number of the clients of our home based outreach service have involvement with the criminal justice system, often through petty crime, including failure to travel on public transport with a valid ticket. If the individual overlooks or is unable to pay a fine, the matter escalates. Again, community clients who have access to an outreach worker are much more likely to be present at court when required and the directions of the court are more likely to be heeded. The level of tolerance of unusual behaviour varies enormously and much seems to depend on the capacity of the particular police force member to understand the behaviour when making a decision on whether or not to lay charges against the person with mental health problems.

k. 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 minimising treatment refusal and coercion;

Some carers have expressed concern about the behaviour of some of the patients who are involuntarily detained in mental health facilities, resulting in the facility being locked at all times. We acknowledge the necessity of maintaining locked facilities for some clients, some of the time, but express the wish that staff training emphasises the rights of the patients to humane treatment.

We endorse the recommendations of the *Learning Together: Education and Training Partnerships in Mental Health*[9] report, which recommended that all mental health workers must acknowledge the 'lived experience' of consumers and carers. Attitudinal differences between health professionals, consumers and carers were highlighted in the workshops and in the report *Enhancing Relationships between Health Professionals and Consumers and Carers* [10] but it seems that little has changed in the intervening years.

l. *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;*

There appears to be a higher level of literacy about mental health in the community and newspaper reporting has improved but our experiences in establishing a prevention and recovery centre in a prosperous eastern suburbs neighbourhood of Melbourne in 2004 revealed that there is considerable opposition to community services for people with a mental illness.

m. *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;*

Our members continue to express concern about the level of understanding of mental illness amongst members of Victoria Police. After Project Beacon in the mid 1990s there was an improvement in both knowledge of mental illness and attitudes towards people with mental illness, but this seems to have waned. Police may be frustrated that they are so often called upon when no one else will come.

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

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

p. *the potential for new modes of delivery of mental health care, including e-technology.*

It is frustrating to note the emphasis on technology, when much remains to be done at the level of attitude, as noted under (k) above, and when the evidence base of family work, as pointed under (g) above is ignored.

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[1]Australian Health Ministers. National Mental Health Plan 2003-2008. Canberra: Australian Government, 2003.

[2] Mathers C, Vos T, Stevenson C 1999 The burden of disease and injury in Australia. AIHW cat no PHE 17. Canberra: AIHW

[3] Commonwealth Department of Health and Ageing (2002) National Mental Health Report 2002. Seventh Report. Changes in Australian Mental Health Services under the First Two Years of the Second National Mental Heath Plan 1998-200. Commonwealth of Australia, Canberra.

[4] CPG 05041 http://ww.health.vic.gov.au/mentalhealth/cpg

[5] Pitschel-Walz, G., Leucht, S., Bauml, J., Kissling, W., & Engel, R.R. (2001). The effect of family interventions on relapse and rehospitalization in schizophrenia - A meta-analysis. *Schizophrenia Bulletin*, *27*, 73-92.

[6] Fadden, Grainne, *Training mental health professionals to work with families – learning from the English experience* Keynote address 6th Conference for Carers of people with a mental illness, Melbourne 9 April 2005

[7] Coghlan R, Lawrence D, Holman CJD, Jablensky AV (2001) *Duty to Care; Physical Illness in People with Mental Illness.* Perth. The University of Western Australia

[8] Australian Institute of Health and Welfare 2004. Australia's Health 2004. Canberra: AIHW

[9] Deakin Human Services Australia (1999) Learning Together: Education and Training Partnerships in Mental Health. Commonwealth Department of Health and Aged Care: Canberra.

[10] Mental Health Council of Australia (2000). Enhancing Relationships between Health Professionals and Consumers and Carers. Canberra