8 November 2005

Committee Secretary
Senate Select Committee on Mental Health
Department of the Senate
Parliament House
Canberra 2600
ACT

Dear Secretary

I write in 2 roles:

- Carer of 2, now adult, family with mental illness, one well and working, other on Disability Benefit via psychiatrist, managing some voluntary work, both living independently, so not severely ill now, relapse possible, but unlikely,
- Semi retired urologist (medico), who has tried to find out and help.

In this latter role I am a volunteer for Mental Illness Fellowship Victoria (MIFV) for 5 years, liaised with Melbourne Division of General Practice and less with other Divisions about problems for GPs over about 18 months, and Melbourne Health MHREC (Mental Health Research and Ethics Committee) for 15 months ongoing. I do not speak for any of these.

1. *Resources*

Information indicates that 30% of GP visits have a mental illness component, that overseas 17 –20 % of health demand is for mental illness, and that is similar in Australia, yet here we spend only 7% of health budgets on mental illness.

2. *Housing,* Clearly at State level we need to do more spending, especially as when Mental Hospitals and Institutions were closed, real estate became available with ability to raise money, yet at present there are *not facilities to adequately house in varying degrees of supported accommodation for the more disabled with mental illness,* who previously may have been incarcerated. *As well due to fear and ignorance in the general community about Mental Illness*, there is often opposition to provision of new facilities, and ensuing greatly increased effort and use of time by those trying to arrange a new housing or community facility. *Adequately trained staff to give appropriate support at various levels are needed.* (see next para)

3. *Community Care is similarly inadequate* and *not evenly spread in geographic areas*, but *also mostly uneven in what type is available*, in the sense that there may be Day Programmes, but not Housing in an area, inadequate Support Workers in an area, depending where the particular sufferers are and how informed their Carers, how able is Advocacy for better service, in different State Mental Health boundary areas. Those with mental illness are a diverse group, some start quite unable to manage their life, need basic care and help, retraining in hygiene, management of house and clothing, understanding nutrition, financial management, reintroduction to socialisation, time management, location and travel skills etc., where others have lesser needs. Exacerbation or improvement change needed facilities for the individual. *Country areas are even worse off than those in metropolitan areas, although some regions are better and more enlightened, and should be emulated elsewhere.* Often this depends on individual skills and aptitude.

4. *Police and CAT (Crisis Assessment Teams), are at present overstressed and inadequately supplied in numbers and liaison capabilities, resulting in unnecessary deaths from suicide at times and other times lack of adequate support for police from*

> *CAT teams results in police shooting like young, inexperienced soldiers. Police training also leaves something to be improved, but with incidents below they seem unlikely to win unless they are better supported by CAT teams.*

I am privy to some information about this, and from my own experience can report inadequate CAT support when my daughter disappeared for 3 days when clearly psychotic. CAT attitude was that it was clearly not an emergency to attend quickly to assess my daughter when she reappeared, but was not able to respond to family efforts to seek treatment for her and there was no capability to enable compulsory assessment, other than by CAT team. CAT offered an "urgent"appointment in 2 weeks time, which my daughter declined. Clearly CAT felt they had more urgent problems, but our daughter did not agree to treatment for a further 2 years, which is adverse to prognosis. My daughter was at least 3 times seen by police "hanging around" and sitting on kerbs for some hours, she reported later to me. Police were very kind, she reported, but able only to talk to her for their assessment, which did not help. CAT did register her with the police, so early intervention could be enabled in crisis.

Other less personal information concerns death from suicide from lack of a bed in an acute hospital and CAT misjudgement, and death from police action, this latter when CAT did not attend, did not pass on to Police information known to CAT that the person had expressed death wishes recently. That person confronted police and ultimately died, apparently from police intervention. It seemed clear to inquiry that CAT team acted from self preservation and lack of experience or thought in a potentially dangerous situation, leaving the ill person and police at disadvantage. CAT teams need better guidelines and negotiating skills it seems, including compulsory attendance to help police.

Police are forced to arrest and incarcerate for want of better options such as Acute Hospital Beds, since deinstitutionalisation in Victoria and insufficient compensatory beds for acute mental crisis problems. Lengths of general hospital stay are short and result in revolving door problems for those ill and carers very often, which "step up and stepdown care beds" could greatly help, as could more beds and longer stays in Acute Care.

5. *Privacy Laws, their misinterpretation, misguided "Ethical Principles"* <u>on many occasions disadvantage those Mentally Ill and their Carers.</u>

When those mentally ill are well treated and respond adequately to treatment, they are often, or even mostly, indistinguishable from those who are well.

On the other hand, when they are ill or becoming ill, those with mental illness may lose what most of us feel is normal perspective, in which situation a Carer may need to act on their behalf to ensure their safety and appropriate treatment. To do that adequately a Carer will need to know what the problem is and has been, the treatment and the appropriate therapist or facility to contact. To do this early may avoid problems becoming so severe that the mentally ill person needs full hospitalisation, with the added inconvenience and expense that may entail for both the person, the carer and the community including Governments. At present misguided interpretation about privacy prevents optimum action, including use of "step up and step down "facilities in an optimal way, including provision of sufficient such beds. Less stigma about admission to a less severe illness facility could be beneficial. Respite is not so bad as hospitalisation.

A person retrogressing due to illness may well become difficult, even paranoid, lacking insight, yet not realise that themself, so it is imperative to try to educate and perhaps legislatively readjust balances. *Privacy in these circumstances becomes a nonsense.*

Such education about Privacy would need first to be to professionals, in the widest sense, involved in mental illness, so that information flows to Carers, but the wider legal profession, as I perceive it, seems unduly conservative in its attitude to Privacy, which possibly means Legislation needs review at Federal and / or State level so those mentally ill are properly served by divulgement of Treatment, how to access appropriate professionals etc. At present legal self preservation, possibly consequent on the litigious, unthinking public, seems far too prevalent. *Possibly Guardianship Legislation with safeguards needs consideration to empower Carers?*

6. *Service Providers of rehabilitation have to tender to provide service and thus may belong to different systems or organizations.* Thanks to their endeavour, mostly they cooperate locally to make smooth arrangements between different service providers on the ground, but necessity for that *co-operation is not always perceived by those at the coal face of provision of service or in charge of that provision,* and also those further removed from "the coal face". At local or central administrative levels obstructions occur at times. For Consumers and Carers this can be extremely frustrating, and for Help Lines the lack of uniformity is frustrating. *My belief is that overall there are far too few providers of rehabilitation and psychiatric and psychological help, and thus often inadequate time to communicate adequately between each other, with clients and carers, gross overwork for those there are, inadequate bureaucratic understanding of extra time required to help someone severely mentally ill or in process of recovery, where even apparent impatience can be a barrier to recovery as the sufferer may think in a different paradigm, which needs to be understood by the provider, therapist or public servant.*

7. *Medical service providers are not always aware that rehabilitation provision and / or psychological services can greatly assist recovery, so may not act adequately as coordinators* ***and need further education about mental illness overall.***

8. ***Lack of cohesion of Service Boundaries for Psychiatric, General Medical, Primary Care Providers etc. causes confusion and frustration at many levels***, worst for Consumers and Carers, who mostly are already overburdened by the illness.

Boundaries should consider Transport Hubs, and facilitate ease of accommodating other needs of those ill and carers. There are already barriers for such people due to illness.

9. *Jobs*, those with mild illness are less badly off, but up to 70 – 80% of those with Mental Illness do not work. Whether to divulge mental illness to an employer is a fraught decision at present, due to community ignorance.

To rejoin the work force may require great support initially, great courage from the ill person, great understanding and patience from the employer and Carers, depending on the severity of the problem. Mentally ill people like those physically ill require that.

Given that support, many can return to work and often become very diligent, loyal, hard working employees literature reports, mostly with greatly increased self esteem and lessened stress, which mostly results in less liability of future breakdown.

Reports about *Social Firms (dedicated to provide a percentage of employment to disadvantaged groups including those mentally ill) and other employers indicate that often co-workers gain a great sense of satisfaction by mentoring others back into work, and often productivity is increased, presumably due to job satisfaction. Such firms aim to make a profit.* Naturally the whole community benefits by return to work, as *less disability benefits* are required.

Mental Illness Fellowship Victoria (MIFV) has started such a *Social Firm*, The Flat Bottle Company, aiming to make a profit and employ 40% recovering from mental illness. They also have begun a *Supervisory Body* to advise future enterprises that employ those disadvantaged by mental illness. Both ventures are at arms length from MIFV, and the business gives standard wages and conditions.

Work and its consequent socialisation away from family or therapists provides more community input and supervision, and that is likely to lessen feelings of unworthiness and stigmatisation, which are big factors that inhibit full recovery. It also informs the community that those mentally ill are humans like all of us.

10. *Stigma, statistics suggest that about 50% of those mentally ill do not accept treatment due to fear of Stigma, and also that early treatment leads to better outcomes.*

My personal experience agrees with that, as my son took about 3 years to agree to assessment and treatment, despite support from university football colleagues and administrators including a doctor associated, and other friends. His fear was about future relationships, jobs etc., which was realistic. Alas lack of family unity due to ignorance did not help, and has taken some years to overcome, as we all learned how best to cope.

My daughter, younger, had similar misgivings and to an extent still has, although improving, which to me seems to have contributed to increased illness severity, more severe and prolonged paranoia, and resulted in a nice person who was a competent, very well trained and reasonably experienced rehabilitation nurse being not only lost to her profession, but also debarred from practice for what I see as good reasons, (although my daughter would not agree the latter point). The family stress in that matter was and is enormous, and my daughter cannot at present accept that the Nursing Board has a rehabilitative aim.

11. *Education to destigmatise Mental Illness.*

My long career has led me through many disability experiences, a moderate number of different countries and their people, admittedly for only months re the latter two. People with Brain disability from Multiple Sclerosis, Brain injury from birth or trauma, people rendered spastic etc., were encountered over many years.

An attitude of respect and equality served me well, so in very few instances was I unable to communicate adequately and achieve a good outcome, and no doubt if I had more knowledge and skill at particular times even better outcomes for others and me would have been possible.

Many Sufferers and Carers have taught me much!

Enormous effort, Publicity, Education of Educators, Education of Press and Media, Outreach into the Community will in my view hugely repay us all, limit adverse outcomes, limit Dual Diagnosis, (psychological and drugs issues as some try to self medicate with drugs & / or alcohol), which latter may well be due to fear of stigma in some cases, just as is fear of treatment for mental illness. Early in the Education process, schools, both primary and secondary and tertiary educators need also to be involved, so our community does not perpetuate our mistakes, often made due to ignorance and lack of thought, which applies to Press and Media, who also are critical to engage in the process of community education.

It is of course difficult to submit, but I have tried to ensure there is a thread to each representation that is based on observation and experience.

Yours faithfully