The Chair
Select Committee on Mental Health
Australian Senate
Parliament House, Canberra

To the Chair

I am writing to commend the Senate on the initiative of a Select Committee, for the courage to inquire into and report on the mental health services in Australia.

On behalf of the Mental Health Carers Network Inc. I am forwarding a submission for consideration by the Select Committee. This submission recommends that:

- Funding for mental health services, including funding for services to people with serious mental illnesses (schizophrenia and bipolar disorder) across Australia are increased in line with the levels of funding provided in other developed countries, including significant funding to provide evidence based clinical services in the community and to the non-government sector for support services for consumers and their families and carers.
- The Federal Government review the division and responsibilities of the Federal and State jurisdictions to ensure that comprehensive care is provided in the community, including the range of support provided through the Home and Community Care system which is available to people with other types of disabilities.
- The plight of families and carers in the reform of the Mental Health Services must be recognised and adequate support, including respite for families considered as a high priority recommendation in the committee's final report.

I would be pleased to personally discuss the issues raised in the submission with the committee and/or represent the Mental Health Carers Network on any subcommittee or workshop. I can be contacted at my work on telephone number 02 9762 7639

We look forward to hearing from the committee

Yours sincerely

Janette du Buisson Perrine
On behalf of the Mental Health Carers Network Inc

Submission to the Select Committee on Mental Health

The Mental Health Carers Network Inc is a carer organization that has been established in South Western Sydney since 2001 to advocate for improved mental health services for mental health consumers and their families and carers. We are people who have experienced the reality of a system, which has failed our families and especially the person that we care for.

The family stories of the impact of mental illness are stories of trauma and despair. In a country where adequate health care should be an entitlement and welfare available to those most in need, this is not the case for people with mental illness, particularly those with schizophrenia and bipolar disorder and other serious mental illness. Our stories tell of the depth and gravity of the psychiatric emergency the crisis in health care that our people and our families are facing everyday throughout Australia. It is outrageous that today in 2005, in this country, with the good news from science and medicine, with the potential for real recovery our loved ones' lives are lost. With early intervention, and assertive community outreach, the prognosis for people with serious mental illness is very good. However, these services are not available to our loved ones.

As a community we realise that in mental illness we are being discriminated against by policy design, not by accident, not because someone forgot, design with knowledge. The deliberate underresourcing of the mental health system and the acceptance of the plight of families has lead to treatment failures, treatment denials, devastation to families and individuals who have lost everything.

1. The Funding Shortfall

- **Funding for mental health services, including funding for services to people with serious mental illnesses (schizophrenia and bipolar disorder) across Australia are increased in line with the levels of funding provided in other developed countries, including significant funding to provide evidence based clinical services in the community and to the non-government sector for support services for consumers and their families and carers.**

The funding allocated for mental health services across Australia is significantly lower than in comparable developed nations across the world. The outcome of this is that there are many people who are unable to access the services they need, particularly in outer metropolitan, rural and remote areas. This situation is leading to tragedies in many families, avoidable suicides, human rights abuses and neglect.

In particular, we would like to highlight the need for services in the community, both clinical and support services. A well resourced community mental health system ensures that the number of admissions to hospital beds are minimized, relapses are prevented and that people are able to lead productive lives.

Research in the United States has identified a range of community-based clinical services that have been proven to be effective for people with schizophrenia and bipolar disorder. Australia should be adopting these evidence-based practices, to complement the inpatient system of mental health care. Information about these programs is available at www.dartmouth.edu/~westinst All of these approaches require partnerships with consumers and families and carers in their implementation.

The range of evidence-based clinical services that should be funded include:

- Medication management approaches – using medications in a systematic and effective manner. This would include consideration of a wider range of medications, including injectable versions of atypical antipsychotics to be available through the pharmaceutical benefits scheme.
- Supported employment - - an approach which helps people with psychiatric disabilities to obtain and keep competitive employment, through providing ongoing support and training tailored to the needs of the individual consumer.
- Family psychoeducation – providing the information that families and carers need in order to be able to care effectively
- Integrated treatment for people with coexisting mental health and substance use disorders – the problem of coexisting disorders is so prevalent within mental health clientele now, that providing integrated treatment for both disorders should be considered the core business of all mental health services
- Illness management and recover – giving consumers the skills they need to learn to live successfully with their illness.

Unfortunately, none of these evidence based approaches are being implemented routinely across Australia, and the last 4 approaches are very rarely available.

In addition, the range of support services available through the non-government sector should be assisting people to make choices about their lives and assisting them in areas where their psychiatric disability impacts on their functioning and quality of life. Accommodation support assists people to maintain stable housing, which is essential for good mental health. Currently, these types of services are not available in many places.

2. Roles and Responsibilities of State and Federal Jurisdictions

- ➢ **The Federal Government review the division and responsibilities of the Federal and State jurisdictions to ensure that comprehensive care is provided in the community, including the range of support provided through the Home and Community Care system which is available to people with other types of disabilities.**

The complex two tiered health care system in Australia across Federal and State jurisdictions has compounded the problems experienced by mental health consumers and their families and carers. This system has meant that many people are falling between the legislated or perceived responsibilities. The experience in NSW is that the state government appears to recognize their responsibility primarily in the area of acute hospital beds and inpatient services. This has been a disaster for community based treatment and support services, as well as support for families and carers.

We would call on the Committee to urgently review the roles and responsibilities of Federal and State governments in the area of mental health care and support, including inter- and acoss- governmental approaches. Strategies need to be developed to ensure that access to early community based approaches to treatment and support are widely available.

Areas which would seem to be the clear responsibility of the Federal Government, including access to appropriate Home and Community Care Services, appropriate and accessible Respite Care, Centrelink Carer Payments and accessible primary health care, are all areas where the system discriminates against mental health consumers and their carers. These services and systems need to be reviewed to ensure that mental health consumers and their carers can access services suited to their needs. The Centrelink system does not adequately take into account the particular circumstances of mental health carers in their assessment and processing systems.

3. Support for Families and Carers

- ➢ **The plight of families and carers in the reform of the Mental Health Services must be recognised and adequate support, including respite for families considered as a high priority recommendation in the committee's final report.**

The impact of mental illness on families and carers has now been well documented. Some of these are summarized below:

Hidden financial costs to families:

- Ongoing expenses of health professionals, medication and health programs.
- Costs of travel whether public transport or personal petrol costs of car & parking fees.
- Replacing everyday items destroyed from loved ones inability to use or care for items (Saucepans; washing machines; vacuum cleaners to personal items of clothing etc.).
- Payment of abnormal expenditure and debts incurred by loved ones.
- Loss of incomes with the need to give 24-hour care to loved ones.
- Loss of housing opportunities, living with aging parents, substandard housing, homeless shelters.
- Loss of careers - carers and family members inability to fully commit to study and /or careers.

Ignored financial costs to the community:

- Lost productivity resulting from carers and other members of family unable to maintain paid employment and / or needing to be on continual alert to the unpredictable nature of mental illness on their loved one.
- Increased number of people with serious health problems -impact to physical health of the continual burden of caring for loved ones with mental illness manifesting in chronic physical illnesses in carers and other key family members.
- Increased demand for public housing.
- Increased demands on the courts
- Increased demands for financial assistance - social security.

Health, Social & Emotional Costs family members (including Children and Siblings)

- Significant health and psychological distress experienced as a result of caring
- Breakdown in relationships due to the burden of caring
- Reduced quality of life – handling the myriad of issues from ongoing crises and / or relapses
- Loss of self worth because of the stigma of mental illness

Sadly, due to the current lack of support for carers, many people feel unable to continue to care and support for their mentally ill family member. This creates a further burden on the community and compromises the quality of life of the consumer. Support services should be available which ensure that families and carers are able to support their family member without feeling overwhelmed in the role. Respite care in particular, is an enormous problem for mental health carers. Flexible respite services need to be developed which are able to give families time off which are suited to their particular needs. Currently, our families tell us that respite is very hard to obtain as a carer of someone with a mental illness. Many families get no respite for years.

Nurturing carers and families and supporting them in their caring role has enormous benefits for the consumer and leads to improved health outcomes for the consumer. There is considerable cultural and organisational change required in mental health system to achieve the family friendly services, which are required to implement the points below. Specific funding should be allocated to develop mental health services that work collaboratively and cooperatively with consumers and their family members.

- Family members are an important resource in the treatment of brain disorders. To be effective, families need support, education and to be involved. Research overwhelmingly shows that when families are informed and take an active part in treatment decisions, consumer outcomes are better. While families do not cause or maintain brain disorders, their knowledge of, and relationship with, the consumer is unique and can be a significant help in determining the best course of treatment.

- Families should be an integral part of the treatment team and should be provided with sufficient education, in all facets of the illness, to allow them to be effective. However, in no case should the presence of a loving and caring family be allowed to be used as a substitute for a delivery system that provides for all of the person's treatment and rehabilitation needs.

- Common courtesy dictates that consumers and family members not only be treated with compassion, dignity and respect, but also be empowered to facilitate mutually agreed upon treatment team goals. The mental health system should support, never supplant families. When treatment is long term, or unsuccessful, it is not the mental health professional, but the consumer and family members who suffer havoc and pain.

- Family advocacy needs to be encouraged. In circumstances where the mental health system is understaffed, under-financed, and services uncoordinated, or other problems impede proper service delivery, the family's involvement and advocacy is essential to ensure the best possible treatment.

- Mental health workers should endeavour to strengthen family relationships and empower all involved members. Sometimes, because of stigma and lack of information regarding brain disorders, the family is not involved. Their absence does not usually occur out of lack of caring concern. When families are respectfully involved, in a way they experience as empowering them, their approach to the patient and the treatment system changes.

- Sometimes the consumer does not want the family involved. In such cases, efforts should be made to help them understand that outcomes are likely to be improved if all interested parties work together. Extensive education and support are required. This includes helping the consumer to understand that neither he nor his or her family is to blame for the illness and how important the family is to the consumer's recovery.

- When the consumer, family and professionals work together, better treatment can be provided and the patient's outcome will be improved.

(Extracted from NAMI Policy Documents in America)

In summary:

- Funding for mental health services, including funding for services to people with serious mental illnesses (schizophrenia and bipolar disorder) across Australia are increased in line with the levels of funding provided in other developed countries, including significant funding to provide evidence based clinical services in the community and to the non-government sector for support services for consumers and their families and carers.
- The Federal Government review the division and responsibilities of the Federal and State jurisdictions to ensure that comprehensive care is provided in the community, including the range of support provided through the Home and Community Care system which is available to people with other types of disabilities.
- The plight of families and carers in the reform of the Mental Health Services be recognised and adequate support, including respite care for families be considered as a high priority recommendation in the committee's final report.

We call on the Select Committee to recommend a comprehensive overhaul of the system of mental health service delivery across Australia to ensure that adequate and equitably accessible services are available in the community to consumers and their families and carers across this country. Mental health care in Australia has emerged to be one of the most disgraceful episodes of the last decades, with our loved ones being taken to hospital in police cars, residing in jails or prison and treated as criminals. Despite the commitment of the National Mental Health Strategy, the evidence on the ground is that not enough is being done. We ask that you would use this opportunity to facilitate reform which will ensure that the hope of recovery is a real one, not just a theoretical possibility.