April 23rd 2005

To: Senate Select Committee on Mental Health

Dear Senators,

I wish to make a submission to the Senate Select Committee on Mental Health, particularly in regard to services and resources in New South Wales.

One of my adult daughters, who lives in NSW, has suffered from schizophrenia for over ten years. During that time it has become more and more apparent to me and other family members that there are many inadequacies and gaps in the provision of adequate mental health care and community support services for someone with her condition.

I think that the majority of these matters are a direct result of inadequate funds and resources being available to mental health services. This seems to be substantiated by reading and research I have undertaken, in particular when the proportion of funds for mental health in Australia is compared to that in New Zealand. For example a New Zealander friend who has a son with schizophrenia has told me about the services and support available there. These include staged supported accommodation through the Richmond Fellowship and more. However when I endeavoured to obtain similar accommodation for daughter in Sydney, I was told the waiting lists were so long it was not worth putting her name on them.

Over the years I have seen my daughter deteriorate mentally and emotionally, gain a great deal of weight as a result of medication and become a very heavy smoker. She has no insight into her condition and feels treatment is an abuse of her rights. The manner in which mental care is often given has enforced her view.

I support her as best I can and I believe she still trusts and loves me. I have endeavoured, with her agreement, to make contact with the health professionals responsible for her treatment. There have been times when her condition has been of huge concern as her behaviour or experiences have terrified her and hugely concerned all her family. It has very often been our experience that staff who know her case do not return our phone calls seeking professional assistance, nor are acting staff available, her file cannot be found and promised calls back or home visits are not made. The rhetoric of involving families and the importance of family support is an empty and broken promise.

To give a specific example of my daughter’s experience:
Towards the end of 2003 my daughter was receiving fortnightly medication injections at her local Mental Health Centre (MHC) under a Community Treatment Order (CTO), reviewed every six months. This had been routinely renewed over several years. When I was in Sydney at these times, my daughter invited me to sit in on the renewal hearing.

I was telephoned by staff at the MHC to say they were sorry they had not applied for a renewal hearing within the correct time frame, due to an administrative error.   They had offered my daughter an opportunity to receive a new and possibly better (and costly) medication that was available to a limited number of patients, before telling her, as was her right, that the CTO had lapsed. As soon as she knew this she walked out of the clinic.

They prepared a new submission to the review panel (or board) who usually deal with CTOs to try and put in place an alternate order which would enable them to have her maintain her medication. Apparently they could not seek any extension of time to apply for the renewal of the CTO. They assured me they were all recommending this order should be granted and it would enable her to maintain her treatment.

I checked the website were the legislation around CTOs is shown and was surprised to discover that nothing in the document covered any contingency in which an administrative error by mental health professionals needed to be addressed. The document was very firm about the requirement for mental health clients to comply.

Despite the assurances of the MHC staff, in fact the panel did not grant the other new order the MHC staff sought. Despite my daughter's huge file detailing her illness and non compliance with taking medication unless an order was in place, the panel decided to let her do what she wanted. As she now had no order in place she took no medication.

The MHC staff were shocked and the family were extremely anxious at this result. By this time the family fully understood a new CTO could only be obtained once my daughter's condition deteriorated to such a serious state that she would have to be scheduled with police in attendance and put into hospital. So over the following months from Christmas 2003 until mid 2004 we had to watch as her coping and independent living skills deteriorated bit by bit. Despite assurances from the MHC that they would still keep in contact with her and monitor her condition – in fact (partly due to her not wanting them involved) they did not do anything for her.

In June her younger sister was so concerned about her mentally ill sister, she rang the MHC to be told that as her ill sister was no longer their client they could do nothing. On visiting her ill sister again, and seeing she was very psychotic, her younger sister (at great stress to herself) went to the MHC and refused to leave until she got help for her ill sister.

This resulted in two MHC staff and two police officers going with the younger sister to her ill sister's flat where she witnessed her ill sister being manhandled into a paddy wagon and taken to the psyc. ward at the local hospital. I understand this is the current legislation – I find it appalling and inhuman and not remotely conducive to any sort of healing.
After being put into hospital, my daughter with schizophrenia was given medication for a few weeks and released, despite the family all pleading with the hospital to keep her a bit longer as it was quite clear to us this medication was not reducing her psychosis. In fact she had to be taken back to the hospital within a week. She was put on another

medication and stayed in hospital a while. Then, again, despite still having intense psychotic episodes she was let out – despite our huge concern. Off the record hospital staff told me the reason she was let out was due to a shortage of beds!
She had to be re-admitted for the third time around August.

I went and spent some time in Sydney having completely lost any faith in the ability of the Mental Health care system to function in a rational, responsible and effective way.

Prior to retirement I had worked in the community welfare sector, often as an advocate. So I decided there were now two serious and quite separate problems: one my daughter's illness and two: the mental health and support services systems.

I spent a great deal of time on Sydney addressing the latter. I discovered that there had been little co-ordination or effective support in many areas of my daughter's life. I found that her private housing situation (rats and blocked drains etc) was partly the result of a total breakdown of the Dept.of Housing's emergency housing service and its and the MHC's inability to co-ordinate or communicate. In fact requirements and legislation respecting clients' privacy often act against the best interests of clients. My determination and the embarrassment of the Dept. of Housing resulted in her being offered welfare housing within 24 hours. So that she now, thankfully, has a safe home after three years 'lost' in some system!

Similarly, I discovered liaison between the MHC and Centrelink was equally inadequate, resulting in my daughter's rent allowance being allowed to lapse. As people with schizophrenia deteriorate it is harder and harder for them to deal with bureaucratic requirements of big government departments. This results in a snowball effect, as one unanswered letter or missed appointment triggers off more and more punitive results. This is an area that needs professional co-ordination and case-workers with enough time to ensure such muddles are resolved quickly.

I do not wish to name particular professionals. I feel that in the main most of the problems that my daughter has suffered within the health and other support services are due to totally inadequate staffing and lack resourcing of those staff. In many instances the gaps in service, or lack of support have often individually been very small matters, but incrementally and collectively have often resulted in huge suffering for my daughter.

This lack of staffing and resources is not only within the community services, such as MHC etc. but also in the psyc. ward at the hospital. I have witnessed huge staff turn-overs, and staff recruited from over-seas trying coming to terms with the Australian system and appalled at the inadequacy of the mental health services here.

There seems to be a very inadequate rehabilitation service and little or no diversionary therapy. When I have asked for information about such services for my daughter, overworked staff have occasionally given me a phone number but do not know if these services are currently available, appropriate, affordable or accessible.

My daughter is a member of a large and caring family, we speak English as a first language and are educated to tertiary level and have a fair general knowledge of mental health issues. I worry very much about many of the other clients I have seen in the psyc. ward who do not speak English as a first language, and whose families may have neither the knowledge or skills to advocate for them.

Additionally I think that the current focus on medication as the primary solution to mental illness is very inadequate. Although many policy documents espouse a more holistic approach to effective mental health care and treatment, my experience has been that mental health professionals have neither the specialist knowledge nor the mind set or time to offer other approaches. I have shown mental health professionals letters sent to my daughter, and also policy documents published by their own department of health, offering a range of support for clients and their families. The health professionals laughed despairingly and told me this does not happen. Such holistic approaches are available in some northern European countries and to some extent in New Zealand, I understand.

Apart from the suffering of the person with mental illness, and the burden carried by their families and the community, it makes no economic sense to inadequately resource the Mental Health services. In my daughter's case – if the cost of her three stays in hospital during the past year or so was estimated it would hugely outweigh what it would have cost to adequately support her and ensure her medication was maintained while living in the community.

The side effects of mental illness and its treatment such as weight gain and heavy smoking also have huge health implications, which I do not see being researched and treated in any effective way. Whenever I have tried to raise these matters with my daughter's health professionals they have virtually brushed them aside, looking overwhelmed or in denial.

I am growing old and feel huge concern about my daughter's future health care. As I age and will have less ability to advocate for her.

I am willing to attend a meeting (in NSW or NT) and talk more on these matters, if required.

Please can you do something to address these matters for all the people who suffer mental illness in Australia.

Yours sincerely