Submission No. 504
(Inq into better support for carers)
A.o.c. 7/7/08

22 June 2008

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

The Committee is seeking a better understanding of the situation for Carers in Australia. Use any or all of the following starting points to help you write your letter:

I feel that my role is given that we have two daughters with serious mental illness - one with schizophrenia and one with bi-polar disorder - to support them both to the best of my ability. We therefore have managed to provide them each with independent accommodation. Very few carers, however, have the financial resources to do this.

I contribute to Australian society by trying to ensure that our family members' mental health is monitored so that they do not become an undue burden on society and they are able to live satisfying lives. My aim is to assist them to become well enough to maintain themselves in the workforce.

I also contribute to Australian Society by chairing a mental health support group for the families of people with Mental Illness: Inner South Parents and Friends. We have about 120 members, a committee of seven people and all of our work is voluntary. We are represented on a number of committees in the Alfred/Bayside Region giving us a voice on Carer issues. (brochure attached) Website: http://www.vicnet.net.au/~waiora/

I face the following problems

Very great uncertainty as to what the future holds for our girls. Government policy seems to be changing vis a vis mental health. Mental Health services are very fragmented between Clinical and PDRS services and all services are focused on 'throughput' and 'moving people on'. There are many mentally ill people who are not able to simply 'move on'. They suffer from high levels of anxiety and when subject to pressure have a high rate of relapse. Each time a relapse occurs it becomes more difficult to rehabilitate them (medication is less effective and their self-esteem is further bruised). It is invariably difficult to get help prior to them relapsing completely and requiring hospitalization. Case Management is short term and once transferred back to the community for management - generally to a GP - families have considerable difficulty in maintaining input into their welfare as communication with the treating doctor is very often regarded as inappropriate or confidential.

I work part time in alumni administration for my old College at the University of Melbourne but would like more paid work but have a lot of commitments related to ISP&F and need time to assist our two daughters who, although now in their 30s each still relapse periodically although their health has improved considerably allowing them both to study and one to work part time as well.

I worry about the future faced by a great many of the Carers I am in contact with because they are not given sufficient assistance to understand the mental illness and how best they can help their family members. They are seldom included in the treatment 'team' - if indeed one exists. In many cases mental illnesses do not simply 'clear up' - a framework for managing people suffering mental illness needs to be provided long term, not just for 1 - 2 years because invariably when all supports are removed and relapse occurs it is an immense struggle to get an individual back into the system by which time they are very seriously unwell and a huge cost to mental health services.

The things that stress me the most about being a Carer are: the fact that we can never go away for more than a couple of days without making complicated arrangements to support our daughters if they begin to relapse. For example, for ten years my husband and I had not been overseas although we had both reached an age when normally one would have been free of family commitments. Most of family live in the UK as does my step-mother to whom I am close. We made arrangements to spend August 2006 in Europe but the local mental health clinic which had provided Case Management for our daughter with schizophrenia decided to discharge her at the end of June despite our pleading to maintain some oversight for just two more months until the end of August. We were told that it wasn't possible so having made all our bookings we couldn't cancel and had to rely on friends to monitor things in our absence. We were away one month in which time our bi-polar daughter became manic and eventually spent six weeks in the Alfred and the effect of her being ill on our schizophrenic daughter was to trigger a relapse early in 2007 which sent her into a private clinic for 6 weeks.

We also worry about the future for the girls because, currently we have an administration order which enables our family solicitor to manage what money is left from my mother's bequest to them both (which they inherited when they each turned 25). When unwell they have each spent extremely freely and it is difficult to persuade VCAT that it is in the girls' best interests that their money be held in trust. They have each had cannabis habits in the past and the fact that they had some money of their own made them 'honey pots' for local drug dealers. Currently they seem to have conquered their drug and alcohol problems but neither really accept that they have mental illness and would both like to give up their medication (a common scenario). We are very fortunate to enjoy very good relationships with them both (as does our eldest daughter who is well) but mental illness is episodic and our experience tells us that we can't necessarily look forward to them remaining stable and it is difficult to gain the ear of the guardianship board unless they relapse sufficiently to require Community Treatment Orders of involuntary admission to hospital which would be extremely counter-productive given that with each relapse they are less likely to regain their current relative competence. I'm not sure whether it is really understood that families/carers walk a tightrope which is not good for their own health!!

Remember that it will help the Committee to understand your point if you can support it with examples from your own experience.

The Committee would also like to hear of any ideas, solutions or strategies that will support you in providing care. Use any or all of the following suggestions for getting started:

I need help with negotiating arrangements with the girls that will best provide for a relatively secure future for them. I think that a mechanism for dealing obtaining support from VCAT or would be the best solution for me. Our youngest daughter, who has schizophrenia, is due to have her Administration Order reviewed at the end of August and I am concerned that it will be revoked, because she is relatively well at the moment. Her administrator agrees with us that she has little knowledge or self-control in handling her money but whether he will be able to persuade VCAT to keep the order in place for a further period remains to be seen. And, in any case, what happens after the next three years? We are speaking of someone who has been hospitalized 8 times for periods generally of 6 - 8 weeks and has not much sense of reality.

Many of the carers referred to our support group have been struggling to make sense of the mental health system for more than ten years and have never been referred by mental health service providers to the support organizations such as SANE, Mental Illness Fellowship or ARAFEMI. It would be very helpful if clinicians, both public and private were expected to connect families with education and support. I know from my own experience what a huge difference it makes to have the support of others who've faced similar problems. It also makes a great difference to have access to books, journals and other materials so as to develop an understanding of mental illness.

I think the Government can better help Carers by setting up structures which require clinicians, GPs and PDRS services to treat families more inclusively. After all, in general we take on day to day responsibility for our mentally ill loved ones and research world-wide indicates that treatment outcomes are better where families are involved and the general community is well educated. When things have been particularly bleak (we have had to rescue our bi-polar daughter from Japan on two occasions - once when she was so manic that she became psychotic and on another occasion so depressed that she couldn't leave her bed) I have found the support of the psychologist at CarersVic invaluable. Family friendly drug and alcohol services have been extremely helpful too but there is appallingly little co-ordination between mental health and D&A services - despite the rhetoric. In fact that's the biggest problem with the entire system. There is very poor integration between services, support is discontinued far too soon (everything is geared towards 'throughput' so that the numbers look good. Staff turnover is very rapid in an 'industry' where building personal rapport is all important.

Housing is a huge issue for most families. It is simply not possible to treat people with mental illness and drug and alcohol problems if they don't have safe supported housing. The situation in this regards has deteriorated badly in the past 20 years. In 2004 our daughter with schizophrenia discharged herself from the Alfred High Dependency ward (after a Psych nurse had accompanied to the hospital teller machine and assisted her to clean out her account to the tune of $600) She went off with a heroin addict whom she'd met on the In-patient unit to his rooming house in St Kilda where they shared his room. When her money ran out her 'friend' vacated his room so that a young aboriginal prostitute could use it and he charged her $100 per hour to feed his drug habit. We went to the rooming house to retrieve our daughter and found about 20 residents living in indescribably filth. The poor young mentally ill heroin addict committed suicide a few months later. We insisted that the hospital take our daughter back since she had not been properly discharged which they did very reluctantly for another week. The admitting doctor claimed she was subject to the law of 'diminishing returns' - it simply wasn't worth treating her. In fact, because we insisted on an orderly discharge she returned home and in fact has not been involuntarily admitted since. She has completed her Visual Arts degree at RMIT, has finally quit cannabis and drinks very little alcohol. Perhaps it was a salutary lesson but I think that most families would find it just as daunting as we did to have to navigate as dysfunctional a system.

Staff need to be better trained to listen to families and not to take the view that they are all as dysfunctional as their mentally ill family member - who they only see when they are very unwell. If their communication skills were better they would almost certainly get far more job satisfaction which would reduce staff turnover too.

Remember that it will help the Committee to understand your idea if you can support it with reasons that it will work or examples of things it will help you to achieve.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for Carers in Australia.