PUBLIC SUBMISSION
TO THE AUSTRALIAN GOVERNMENT'S
SENATE SELECT COMMITTEE ON MENTAL HEALTH

Dear Senators,

Prologue

My mother and myself are the primary supporters for a family member who suffers from severe and chronic schizophrenia. This person is my older brother and her son, and as we prepare to put some words on paper for your consideration, we are struck by how little has changed in the course of his illness and our family's close association with schizophrenia and its distressing consequences for all in its sphere. My mother kept a copy of a similar submission she made in 1983 in response to the then VSF's survey of how families coped with the mental illness of a family member and their experiences with "the system". Sad to say, most of her words are still as apt today as they were then.

My brother is now 57 years old and his illness *(as is often the case with schizophrenia)* began to appear when he was in his late teens/early 20's. His particular illness is deep seated and its manifestations are with him constantly *(unlike some sufferers, he does not have periods of remission).* Long ago, he lost his friends, and any real hope of a recovery which could lead to a 'normal' life. For more than 35 years, his family has stood by him, offering the emotional, physical, financial and practical support that at least lets him live with some sense of self esteem and dignity – but it has taken a toll on those around him and becomes increasingly hard to sustain as we grow older, his psychiatric condition degenerates and the physical effects of ageing and years of 'treatment' *(from the appalling ECT to strong, continuous medication)* become more apparent in him.

Now, as then, the allocation of funding to provide a reasonable level of community based services and resources to help support people like my brother appears to be woefully short of what is needed. Higher priority in funding to Mental Health may not be "sexy", but in a society that strives to be reasonably equitable, we believe it is sorely and urgently needed.

Access to and Quality of Treatment

Moving to our current concerns in the medical management of my brother's illness, I am pleased to say that in the past couple of years, the contact between Mental Health professionals (Doctors and Case Managers) and ourselves has become more collaborative. There does seem a willingness to involve the family in discussions of the sufferer's 'treatment regime' *(though for my brother this is now on-going medication).* However, the Public Mental Health Service in metropolitan Melbourne to which he is aligned seems to continuously rotate its staff. This means that just when a useful rapport has been built up between my brother, ourselves and the Doctor/Case Manager, they seem to leave or be moved on! Change like this is particularly difficult for those with mental illnesses to cope with and we seem to be continually going over old ground for the benefit of a new set of medical staff. In addition, we seem to be given significantly varying versions of how the Service intends to provide patient management (eg: "the Government's aim is to make GP's the key point of contact for chronic sufferers" from the Case Manager before last, but from the current case Manager, we have received a very basic brochure about a general Community Health Service which they would like to pass my brother on to, as they regard acute cases as a higher priority and would prefer not to support him at all!).

We believe that my brother deserves and needs to have continuing access to community based Mental Health professionals. Therefore, perhaps the issues surrounding the staffing of Mental Health services *(eg: salary levels, workloads, training, resourcing and retention strategies)* need to be addressed or at least reviewed, so that these professionals don't get 'burnt out' and leave on such a regular basis and also have a consistent message about their service delivery.

Accommodation and Community Care

The major concern we have for my brother is his future ability to cope with daily living as the burden of supporting him becomes too much for my elderly mother and me. Being a prudent and careful financial manager, my mother was able to purchase a flat years ago for my brother to live in and she continues to pay most of his utility bills. Under the current tax regime, she is not able to make any deductions for this financial burden *(it would be helpful if some concessions could apply in such cases),* but at least knows that he has somewhere to feel secure.

In earlier times, my brother used to be able to interact reasonably well in the general community and at least do his own shopping and some cooking. He is now very withdrawn, wary and much less confident. Therefore, he is dependent on us every week to support him by:

- Shopping and delivering household items and 'reserve' food *(tins, frozen meals etc)*
- Providing and delivering home prepared meals *(more nutritious than the fast-food he would normally buy)*
- Copious amounts of personal laundry
- Cleaning and maintenance of his flat
- Advice and supervision of his personal finances
- Advice and support in dealing with his medical professionals and any other external contacts *(eg Banks, Government Agencies, Medicare / Medibank etc)*

Also, it is not unusual to receive up to six telephone calls per day and as he refuses/is unable to come out to our home *(a 15 minute taxi ride which would be paid by for by us),* all the above has to be taken to him. Over the past 12 months we have been able to persuade him to accept some council services *(limited cleaning and 3 meals/week)* though we are paying for these as he now lacks the ability to manage his finances responsibly.

Our question is where do we go for the next step in his accommodation? The time will inevitably come when we must look for supported accommodation for my brother that is capable of meeting most of the above needs that we currently provide. None seems to exist!

Such accommodation we believe should be available to people before the accepted aged care age of 65 years, it needs to be of a standard that meets overall community expectations of care, cleanliness, quality and 'livability' and it needs to be 'purpose-run' by staff who fully understand and cater for those with chronic mental health problems. To see such community accommodation being backed by the Government as a priority, would be timely and a great step forward in 'normalising' perceptions of mental illness in the community and in raising the quality of life for those who have to live with its unrelenting burden.

Thank you for considering this Submission

27 April 2005