## SENATE SELECT COMMITTEE ON MENTAL HEALTH

My submission to this committee is based on my experiences as a parent of a young man with schizophrenia. The following account addresses some of the Terms of Reference but not in any particular order. The account is a personal one, although I have also attached a document provided by an ex-worker of the local mental health service.

My submission addresses (sometimes only in part) the following Terms of Reference: (b); (c); (e); (g); (h); (i); (l); and (m).

In support of this submission, there are a number of documents which should provide a sense of my frustrations with either lack of, or diminishing, resources; inadequate services; inept management; and lack of political will to support an appropriate service. These attachments are listed here:

- **A & B**: Letters to the General Manager of the local hospital dated 6 October 2001 and 19 December 2001

- **C & D**: Letters from the General Manager of the local hospital dated 11 October 2001 and 30 January 2002

[**missing**: Letter dated 1 November 2001]

- **E & F**: Letters to the Manager Community Health dated 1 May 2003 and 2 July 2003

- **G & H**: Letters from the Manager Community Health dated 15 July 2002 and 9 May 2003

- **I**: Letter from the Acting Chief Executive Officer of the local Area Health Service dated 28 July 2003

- **J**: Letter to the Acting Chief Executive Officer of the local Area Health Service dated 20 August 2003

- **K**: Submission by an ex-worker to the then local MP re inadequacies of the local Mental Health Service 1998

- **L**: Letter to the local Director of the Department of Human Services dated 16 July 2003

- **M**: Speech (pers.) supporting continuation of funding for a young people's worker of the local Day Program Service dated 26 April 2004

## BACKGROUND

Our son used marihuana, a drug we naively believed was simply recreational with few ill effects apart from affecting motivation. We had a lot of beliefs back then in 2001 when, aged 21, he suffered his first psychosis. Many of these beliefs have since been challenged. Like many in the community, we were casual about mental illness and the ramifications. That is, until it affected us.

Our son has subsequently been diagnosed as first, drug-induced psychosis and now probably, schizophrenia. He has now had 3 major psychotic episodes requiring long stays in hospital (up to 8 weeks) and all of them are traumatic for us (and him of course) and needless to say we live a part of our life on a knife-edge waiting for the next.

**Terms of Reference (l) and (e)**

Our son's illness has taxed his relationships with his siblings and extended family and this is a great sadness to me. For older people (grandparents for example) there can be a lack of knowledge about mental illness that feeds mystery and fear and can compromise their ability to relate easily.

For our son's siblings, their relationship with him is further compromised by his now being a born-again Christian and his narrow spiritual beliefs are difficult to reconcile with our family values of tolerance and equity. Many people with a mental illness seek spirituality for a variety of reasons but it can be an added difficulty.

Families are significantly affected when someone they love has a mental illness. Workers can sometimes forget this. It is special when someone does understand one's needs and proffers a shoulder to cry on.

More information and support for all stakeholders would be useful for both the person with the mental illness and the people in their caring network.

**Terms of Reference (b) and (e) and (g) and (m)**

**- Acute Care**

Our experience of acute care has been through the local hospital. In two instances, the police have been the referring agent and have done a very good job.

Our son has been admitted through Accident and Emergency to the local hospital's inpatient acute psychiatric facility. In one instance, he was sent home rather than being admitted as he was deemed as not being sufficiently unwell. On this occasion, he ran foul of the law and so it was the intervention of the police that led to his being admitted; he was most certainly unwell and required a 6-week hospitalisation.

Our son's hospitalisations can only be described as "detention cells". It is too long to go into here but there are many aspects of acute care that are inappropriate. In the very acute stages, our son needs to be confined for his own safety. It is not a pleasant experience for us to see our son like this and neither is it pleasant for him.

However, we accept this is necessary. But the high dependency facility can only accommodate a very small number of people. It sometimes happens that other people in this unit are so unwell and their behaviours so inappropriate (as well as bizarre and frightening) that they it is not always possible for other patients to share the unit with them. These difficulties place enormous burdens on staff and clients.

Sometimes it is necessary to discharge patients from this unit even while they are still at risk of absconding. On discharge from this unit, the patient is accommodated in an

open ward where they can “escape” as there are often insufficient staff to monitor them.

Our son has “escaped” once and this could have had significant ramifications for his recovery but for a few things “that went his way”. Of course his self-discharge caused much consternation and necessitated invoking other services such as police and hospital services in the capital city to which he absconded, the cost of which in time and money might have equated to the cost of providing adequate staffing at the hospital facility in the first place.

Appropriate staffing levels and appropriate decision-making in regards to our son’s needs would have been helpful in minimising the stress for everyone involved as well as constituting better care for him.

My letters to the local hospital provide further detail regarding what happened in our son’s case. I felt my concerns were not dealt with adequately and I believed I asked some pertinent questions that the hospital failed to address. See **Attachments A & B**. Regarding the final letter from the then General Manager of the hospital dated 30 January 2002, I declined his invitation to meet with him and the 2 other staff he nominated to be present as I felt this arrangement was intimidatory and not conducive to an empathetic discussion. I did however arrange to meet with the General Manager without additional staff involved but he could not meet with me and in his absence I met with the then Acting General Manager. I did not receive any satisfactory outcome from this interview.

These responses from the hospital should give insight into my frustrations in dealing with a system that I felt didn’t care and indeed probably in law failed its duty of care to my son (and his family). It is bungles such as this that could well result in death and the Committee would be well aware of the statistics that support the contention that people are discharged (or abscond) from acute-care facilities and go on to either self-harm (at worst, commit suicide) or to commit a crime (at worst, a homicide). See **Attachments C & D**.

In the less acute stage, the local hospital facility creates rather than resolves problems: e.g., the active encouragement of smoking as a patient “stress management” strategy; the practice of staff cooking cakes (while patients watch) which fills in time I suspect for staff rather than patients and, it could be argued, staff would be better employed providing more useful services (cakes – the eating of them! - also exacerbate the weight problems which often arise as a side-effect of many of the medications used to treat mental illness); I observed staff sometimes give incorrect medication dosages as directions on drug charts are sometimes ambiguous; and some staff simply should not be employed in a psychiatric facility as they are either untrained (or inadequately trained) or do not have the appropriate understanding and empathy for dealing with people with a mental illness (in some cases, it seems staff have become “hardened” to the plight of patients).

Of course, there are some excellent staff; and they are often under-resourced and overworked.

Another issue in regard to the post acute-care situation is that in the case of our son's first psychosis, I had to initiate post-hospital case work. No-one offered me access to services. I had to seek these out and despite my best efforts to have a case worker assigned while our son was still in hospital to facilitate a smooth transition on his discharge, it proved a fruitless exercise. I knew nothing about mental health services and no-one offered me any help or information. It concerned me enormously that if our son had not had an active advocate in me, then he would have been discharged, unwell, and having to fend for himself, with no accommodation and with no knowledge or ability to access social welfare let alone any mental health services (as inadequate as these turned out to be).

**- Community Care**

In our rural town, this is totally inadequate. There is simply no accommodation service and the rehabilitation service comprised only irregular visits by a case worker.

This is why we have had to relocate our son (after his second psychosis) to another town so we could get him admitted to a program which does offer rehabilitation and accommodation services. And despite assurances from our local Community Health and the Area Health Service, our experience was that our son could not get an admission to this other service unless he had an address in this other town. So we had to tear around and find him a flat to live in this other town to facilitate this admission. He lived here for a number of months while still acutely unwell, until he was deemed to be "a local", was assessed and then he had to wait for a place at the accommodation facility to become available.

The staff at the local Community Health Centre (Mental Health Unit) are mostly hopeless or under-resourced or both. Management plays musical chairs taking up secondments in higher positions elsewhere in the service; consequently there is no continuity of service. I found the manager at the time patronising in the least whenever I raised concerns including "no-shows" by the case worker. Our son's case worker was a well-meaning young man but he was often unable to keep appointments because (as I understood) crises kept arising. This suggests under-resourcing and poor supervision.

My experiences, particularly my dealings with management at the local Mental Health service, left me feeling demeaned and traumatised at a time when I (and the rest of the family) was struggling to come to grips with our situation.

We wanted help for our son, support and understanding for ourselves and we felt that our world as we had known it was being torn apart. Our grief was immense and there were times when I felt I was in a terrible black hole.

My dealings with the local Mental Health service only compounded these feelings. I expended a huge amount of effort attempting to get some sort of service and it was basically a waste of time.

We found the appointments not kept by our son's case worker enormously frustrating and our son himself developed enough awareness to describe the case worker as "unprofessional".

I was fortunate enough to receive excellent counselling by a staff member at the local Mental Health service (who has since left). She told me she was leaving as she had become so frustrated professionally by the inadequacies of the service.

My concerns are summed up in the correspondence with the Manager, Community Health and the Acting CEO of the local Area Health Service – see **Attachments E, F, G, H , I & J**.

However, the vital question is worth re-stating: why were rehabilitation services in our town that I am told had been carefully cultivated by a psychiatrist working there a number of years ago had been shut down since he'd left?

An ex-case worker has provided me with questions she was asked by the then local MP – see **Attachment K**. This MP requested that this case worker put forward these concerns and told her there should be a Parliamentary Enquiry into the service. He promised that he'd follow this up and she tells me he never did. That was in 1998.

I am told the case worker situation at the Mental Health unit in the town where our son is now receiving accommodation services is also not of a good standard; no-one in the allied health services can recommend a case worker from this unit to deal appropriately with our son's case apart from the clinical case worker he has now (who may soon have to drop our son from his case load because he is undertaking a special project).

Needless to say, problems in securing appropriate accommodation for a mentally unwell person place great strains on families. It is quite inappropriate for our son to be placed at home for a number of reasons that I won't go into here excepting to say that at one stage I was at risk and it was recommended by his psychiatrist that he not live at home: his recovery is better facilitated away from home where professionals can hopefully manage his illness and his family can continue to support him as family not as crisis workers.

**- After Hours Crisis Service**

We have received some useful advice through the 1300 Mental Health Crisis Line although it can take some time to familiarise the person taking the call with our son's history; this is a problem when there is a critical event occurring!

**Terms of Reference (c) and (g) and (i)**

Opportunities for coordination of services would be greatly facilitated by better communication, sharing of information and breaking down of inter-agency "territorialism". There are significant barriers to the coordination of clinical and so-called non-clinical or rehabilitation services that seem to be borne out of professional jealousy, ignorance or disrespect. This results in gaps in services to clients due to one service provider either not knowing what other services are available and/or a service provider believing (wrongly) that a service is being provided by another agency.

In relation to recovery, the accommodation program and the Young People's Program that my son has access to in the town to which he had to be relocated provide excellent programs to assist young people with a mental illness in their recovery.

However, even this latter program is under threat (the funding is non-recurrent) and still under-resourced. Correspondence re this is attached – **Attachments L & M.**

In addition, through the Regional Health Service from which my son receives services, the support group for carers of people with a mental illness is doing a great job to bring consumers together. I know that it continues to be a challenge for workers in this area to educate clinically oriented workers to understand the usefulness of actively involving carers in the recovery of people with a mental illness; also to have them simple acknowledge carers as stakeholders.

**Term of Reference (h)**

In my view, our local area is woefully short of primary care providers. There are to my knowledge 6 psychiatrists: 1 is private only; and I think of the others only 2 are full-time. One of the part-timers is an overseas trained doctor and has only just started work here; she has been given provisional registration to work only with the Mental Health unit of the town to which my son has relocated; unbelievably, this psychiatrist has been refused reciprocal registration in our town. Really, the state of play in the medical bureaucracies in Australia is just beyond belief!

Waiting lists for private and public patients are long. Also, for chronic care patients, the time between visits can be lengthy (e.g. 2 months). In our son's case, his medication status is still unstable 4 years down the track; he probably should be reviewed more frequently although I am not implying any criticism of his psychiatrist who has been most supportive and will return my calls sometimes at 7 o'clock at night, talk to me for half an hour and then still have 10 patients to see in hospital!

Wednesday, 15 June 2005