April 27th 2005

To: Senate Select Committee on Mental Health

Dear Senators,

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

One of my older sisters has had schizophrenia for over ten years and has had the added misfortune of being ‘treated’ in a mental health care system that is totally under-funded and inadequate.

It is clear to me that lack of treatment and support my sister has received over these years has been as devastating to her and her family as her condition.

My sister has chronic schizophrenia with no insight into her condition. She has never taken anti psychotic medication without being legally required to.

Initially, our family tried to support her belief that medication was not the only answer and we hoped there were community resources for alternative therapies such as cognitive behavioural or other therapy for people with a mental health condition. We learnt that there were and still are, no resources available, apart from anti-psychotic medication – with the cheapest (and not necessarily the most appropriate) drug always being the first prescribed.

For 10 years, staff from community mental health care units and emergency teams, and doctors and nurses from two separate hospitals, have pointed to the lack of funding as being the cause of the negligent care my sister has received.

What has been so devastating for me (let alone my sister) is that I have been forced to support a system that I have no confidence in, as the lesser of two evils. In order for my sister to comply with any intervention, her family have had to encourage her to accept the treatment given by the mental health services.

My sister has tried to live without medication on a number of occasions but she has never been able to cope for more than a few months without it, as the visual and auditory hallucinations she experiences become completely overpowering. The last time she stopped taking medication, which was due to an administrative error[1], she talked about voices telling her to jump in front of cars to save babies. She becomes a danger to herself.

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[1] Her Community Treatment Order, which had been renewed routinely every six months, was accidentally allowed to lapse.

On the other hand, I have seen the rationale behind some of the decision-making processes of health care providers, namely financial ones, which has meant my sister has had her rights as a human being abused. But because no intervention is worse than inadequate intervention, I have had to cooperate with this abuse.

If I could name the main problem with the care she has received, it would be, the lack of continuity – in terms of treatment and staff. Her family have had to tell and retell a revolving army of health care professionals, who are too overworked and/or inexperienced to read her bulging file, her story. We tell the same saga, over and over again. And if we don't make the effort and track down the latest health professionals involved and call and leave messages and ask questions, people make the wrong decisions, she is taken off medication or put on a medication that has already been tried and failed, and ends up, a few months down the track, terrified and in hospital against her will – again.

For a system that is apparently so chronically under-funded – the cost of having my sister regularly put back into hospital, for weeks at a time, must far outweigh the cost of providing the proper care and support to prevent her from ending up there in the first place.

Her deterioration is not merely due to her condition. It is due to the treatment she has received. I was informed by a number of health professionals at the end of last year, that whenever my sister suffers from a psychotic episode – this causes permanent scarring of the brain. Which means, each time her medication has been allowed to lapse, through professional misjudgement or administrative error, the subsequent psychosis that inevitably occurs further damages her brain and exacerbates her condition. I have seen my sister change from a once health-conscious person into an obese chain smoker who finds it tiring to do any physical activity, as a side-effect of inappropriate medication and of the stress of endless court hearings and forced hospitalizations.

The rhetoric of involving families in the process of treatment for people with a mental illness is, in my experience, ridiculous. It has very often been my experience that staff who know her case do not return my phone calls, nor are acting staff available, her file cannot be found and promised calls back or home visits are not made.

What follows is the most recent example of mistreatment by the mental health services that my sister (and therefore her whole family) has experienced:

In late 2003 my sister was receiving fortnightly medication injections[2] 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 and it had seemed to be an end to the cycle of medication non-compliance, acute psychotic episode and forced hospitalisation. It had been a long and arduous process to help set this up. My sister invited me (and my mother when she was in Sydney) to sit in on a number of the renewal hearings, and while she didn't believe she needed medication she seemed to accept my and my mother's views at these hearings, that she did.

In December 2003 my mother (who lives in Alice Springs) 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 told her, as was her right, that the CTO had lapsed. As soon as she knew this she walked out of the clinic, overjoyed.

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 us that they were all recommending that this order be granted and that it would enable her to maintain her treatment.

My mother 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, the panel did not grant the other new order the MHC staff sought. Despite my sister's huge file detailing a 9 year history of 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 most agonising thing of all was that the family was told that the only way a new CTO could be obtained was once my sister's condition deteriorated to such a serious state that she would have to be scheduled with police in attendance and put into hospital. Again.

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

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[2] The idea of fortnightly injections was actually suggested by her family, after researching treatment options overseas. Up until that time my sister, who is completely non-compliant with medication, was at first required to SELF MEDICATE and then later was required to go into the local mental health service EVERY DAY for oral medication. The first arrangement meant that she took no medication at all, became increasingly psychotic, and was hospitalised. Amazingly, this method – self medication i.e. no medication – crisis – hospitalization, was employed on a number of occasions. The second arrangement i.e. making sure she took the medication to avoid later hospitalisation, was better, but meant that my sister felt her dignity and independence was being compromised, as she had to spend so much time at the mental health service. This increased her unwillingness to comply with medication.

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. I know the early warning signs of a psychotic episode for my sister – I would say I'm fairly experienced in that area. I made repeated calls to let MHC staff know about the changing behaviour of my sister and her withdrawal from the family. I was told again and again that this behaviour did not constitute a danger to herself, that she had a right not to want to respond to family contact, and that until she became a danger, they could do nothing.

I was studying at university full time and worked to support myself. I tried to keep tabs on my sister as much as I could over the next few months. My sister occasionally called my mother in Alice Springs. When she did, I knew that she was alive. I had given up on the MHC staff and was waiting for a phone call from the police saying that she'd been picked up.

My sister contacted my mother and brother in June as she was being threatened with eviction. She was so paranoid and delusional that she was too scared to leave the house to go to the real estate agent to pay the rent. When I contacted the real estate agent, they said that my sister was weeks behind in rent and had recently become verbally abusive towards them. My family paid the arrears. In late June I finally saw my sister. I was delivering a package to her from our mother, so my sister finally opened the door to me. The flat was dark and cold, graffiti, rubbish and rotting food was everywhere, the windows had been painted to keep the light out. My sister had huge rings under her eyes, cold sores and greasy hair. She muttered like a zombie. She told me she was fine. In a state of total panic I went to the MHC and refused to leave until my sister was taken to hospital.

Finally, that same day, an MHC staff member arranged for two doctors and two police officers to go with us to my sister's flat. My sister was terrified. She refused to leave her flat. She eventually came out when the doctors told her that the police were there. She was taken into the street and restrained by the police officers. She screamed. She threatened the doctors. Her neighbours watched. She begged me to help her. Nobody wanted to be there – my sister, me, the police, the doctors the MHC worker. It should never have got to that point. She was taken into a paddy wagon and driven to the psych ward of the local hospital.

After being put into hospital, my sister was given medication for a few weeks and released, despite the family and the MHC caseworker 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. She was released and then readmitted within a week.

She was put on another medication and stayed in hospital a while longer. Then, again, despite her still having intense psychotic episodes she was let out – despite our huge concern. Off the record hospital staff told me and my mother 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.

It was apparent that hospital staff were so overworked that they often did not communicate with the family or the MHC caseworker to let us know my sister’s whereabouts. There was a total lack of coordination between hospital and MHC staff and even among hospital staff.

I attended 3 separate hearings with my sister at the hospital. Each time there was a new doctor and new panel deciding her fate. Nobody ever knew her history! Nobody ever read her file beforehand! Which meant that I, who was there to comfort and support her, was put in the position, again and again, of correcting people at the hearing by saying that my sister had a 9 year history of mental illness, medication and hospitalisation. Each time I had to speak up in front of my sister about her condition, it was like a betrayal for her. Each hearing was a harrowing and degrading experience for both of us.

My mother, who is on the pension, had to come down from Alice Springs 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 she had worked in the community welfare sector, often as an advocate. Even for my mother, with years of experience behind her, advocating for my sister turned into a surreal nightmare.

There had been little co-ordination or effective support in many areas of my sister’s life. Her totally inappropriate private housing situation was partly due to the total breakdown of the Dept.of Housing’s emergency housing service and its and the MHC’s inability to co-ordinate or communicate. My sister had been on a housing list – lost – for 3 years. The requirements and legislation respecting clients’ privacy often act against the best interests of clients. My mother’s determination and refusal to be palmed off again and again and the embarrassment of the Dept. of Housing resulted in my sister being offered welfare housing within 24 hours!

Similarly, the liaison between the MHC and Centrelink was equally inadequate, resulting in my sister’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 urge the committee to recommend

- As a duty of care issue, when administrative errors are the cause of a lapsed CTO – that appropriate CTOs may be reissued, without having to wait for the person with a mental illness to become critically ill again
- That families are actively encouraged to participate in the process, their experience recognised and their opinion sought about treatment. Duty of care is a higher priority than privacy for the person with a mental illness.
- That medication only be one avenue of treatment for people with a mental illness.

- That medication, when prescribed, is done so appropriately and not solely on the basis of cost.
- More funding across the board – for health services to pool knowledge and communicate effectively.

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

Yours sincerely