

SUBMISSION TO MENTAL HEALTH INQUIRY

Sent: Friday, 20 May 2005 11:15 AM

To: Committee, Mental Health (SEN)

Subject: SUBMISSION TO MENTAL HEALTH INQUIRY 2005.doc

Herewith, my Submission. I would respectfully ask to be included in a Public Forum, if and when it is held.

SUBMISSION TO MENTAL HEALTH INQUIRY - 2005

I am sure that the Committee is fully aware of the stresses placed on families and carers of the severely mentally ill. However, I would like to make mention, that both my husband and I could have added to suicide and heart attack statistics, as a result of a very frightening and frustrating period after our daughter had been discharged from a long hospital admission, even although she was not, in our opinion, well enough to be discharged. Trying to get my daughter re-admitted, phone call after phone call to the Registrar at the hospital, reporting her bizarre behaviour, ambulance pick-ups, repeated admission denials, my daughter all the while sinking deeper and deeper into psychosis and bizarre delusional behaviour, was soon to be just too much for us to bare, resulting in attempted suicide by myself, and emergency by-pass surgery for my husband!

After sitting in Emergency for a minimum of 7 hours, trying to manage and control my daughter (she was suicidal, angry, highly agitated and wanting to run away), only to be seen to by the Triage nurse, nothing further was being done to help contain her and nobody even offered to help me keep my daughter quiet. I eventually reluctantly took her home with me. She then ran away, with no money, no warm clothes, and no shoes and in the pouring rain. My husband and I spent hours trying to locate her, eventually finding her in Newtown, breasts bared, screaming and shouting and refusing to get into our car! This was an experience that we both never ever want to go through again! We felt sure that the hospital would again find some reason not to admit her! Through a "friend" in the system, we were able to finally have her admitted, but she was placed in the general section of the psychiatric hospital and ran away the next day! I had reached the very limits of endurance and took an overdose. I was found in time, and rushed off to hospital. My husband, 10 days later, was rushed in for quadruple by-pass surgery, and that we were not added to the list of statistics is a miracle! Maybe, "someone up there" had more work for me to do! From that time I have "fought" for every bit of help for my daughter, who then spent many months in Psychiatric hospital when she was finally found. She had become so severely psychotic and delusional - and in my mind, this was the end of the loving, gentle daughter we had always known, before the onset of mental illness.

My daughter spent many months in hospital after she had been finally admitted, and the doctor told me that had this incident happened 20 years ago, she would've been locked up in an Asylum and the keys thrown away! As terrible as may sound, in my mind, at least she would've been safe! What an indictment to feel this way about a loved-one!

It is an absolute disgrace what happens to people, so disadvantaged by mental illness who are continually denied their basic human rights; TO BE ADMITTED AND GIVEN THEIR BASIC DUTY OF CARE IN HOSPITAL, AND ONLY DISCHARGED WHEN THEY ARE FULLY WELL ENOUGH TO COPE WITH THE OUTSIDE WORLD. This wonderful country is rich enough to generously aid other countries in distress, and while I am in

full support of such actions, CHARITY BEGINS AT HOME! If our country has such a huge sum of money to donate to other countries in need, then it can find the money to first improve our hospitals, pay better wages for doctors and nurses, and care for our socially, financially disadvantaged mentally ill citizens.

In 2002, again after months of trying to get my daughter admitted, neighbours calling to report her behaviour and the police picking her up on numerous occasions, it seems the problems of getting her admitted was once again on our plate. What basis is used to decide whether a person needs to be admitted or not? On 29 January 2002, I got a call at work telling me that my daughter was causing terrible problems at her public housing unit, throwing out electrical appliances and furniture, screaming, banging constantly, and causing a major disturbance. I was powerless, and once again, overwhelmed by fear of what to do. I once again called the hospital (who never responded to my calls), the Crisis Team, and then the head of South East Sydney Mental Health Services, and at the same time, I called Bob Carr's office (Bob Carr is the Member for the area that my daughter lived in), and the Minister of Health as I was so frantic to get help. I had absolutely no idea of what else to do. When I got home from work, I drove out to her home and what I found was beyond belief. At my wits end, I drove to the Maroubra Police Station to make a statement, as I knew something was going to happen. The Policeman on duty was reluctant to allow me to do this, as there was no reason, in his opinion, for me to do so. I pleaded with him, as I felt it was imperative to place the situation I had just witnessed, on record. Unbeknown to me, the disaster that I had always predicted, was happening, for when I got home, I got a call to say that my daughter's unit was on fire. It was only then, that the hospital found a bed for her!! In the days before the fire my daughter had been taken to hospital many times either being picked up by the police or by ambulance, and each time she was denied admission. The night before the fire, I had pleaded with the hospital to admit my daughter, after a very harrowing weekend, and the Registrar on duty was not prepared to listen to my story. The next day she was picked up by the police and charged for supposed bad behaviour, taken to hospital, the Police recommending that she be admitted, otherwise her behaviour will continue, but she was turned away. It took a major life threatening incident to finally have her admitted. In the ensuing weeks, the Ambulance accounts were forwarded to me and totaled over a dozen!

On another occasion, despite recommendation to have my daughter Scheduled by the Acute Care Team, and a GP, my daughter being so unwell and under-nourished, the hospital still chose not to admit her. As a parent, and to be placed in such a position of seeing your own flesh and blood being treated worse than an animal, is what still gives me recurring nightmares!

I have spared the Committee, all the details of what my daughter's home looked like, which would've indicated how unwell she was. Nothing ever prepared my husband and me for the treacherous ride that our mentally ill daughter was taking us down - no education, no advice, no information, no coping skills and techniques to manage the downward spiral of mental illness when it is not treated- NOTHING. All we had was a head of a department at the hospital, giving us no support, and telling us there was nothing wrong with her, that we must practice tough love; "if she had no money, let her find a way, if she has no shoes, let her go bare feet, if she throws away the keys to her apartment, let her sleep in the streets"!! Here too, I stress that our input and opinions were never ever taken notice of. Who better knows a daughter than her parents?!

Because of the recent publicity given to Cornelia Rau, I would also like to mention that my daughter could well have ended up in a situation just like Cornelia Rau, for she too disappeared so many times from the so-called safety of a psychiatric hospital and on one occasion, was found several days later, only because luck was on her side. She was recognized in Canberra by a nurse who had worked in the same hospital during one of her admissions. She had apparently

presented to a hospital in Canberra, whether by the police, or not, I can't say for sure, but was turned away, penniless and into the streets. Because there is no missing person's data base, the hospital was not able, I presume, to check that she had absconded from a hospital in NSW. Not to have a missing persons register available inter-state, or hospital data base, in this day and age, is also beyond belief. How much time, money, effort and stress could this save! She ran away from admissions on so many occasions, and this should never be allowed to happen.

Without my husband's and my unfailing love and care, there is absolutely no way that our daughter would ever have survived up until this point. Community Treatment Orders are not always worth the paper they are written on, unless the person is well enough to understand the ramifications of the order. There were many times when an order was made, and it was only because of our involvement, that our daughter was able to keep appointments and do all that was expected of her. My daughter is under a Community Treatment Order at present, but she is relatively well, and is being seen by the psychiatrist at the hospital every two weeks, and of course as parents, we are able to help with the maintenance of her unit in public housing, shop for her, make sure she has food and clean clothing, and takes her medication.

The strain and stress has, and continues to have a major impact on our lives, and it is for this reason that I make a submission, in the hope that this large voiceless sector of the community, is not ignored, and better resources are available to help this come about. To my knowledge, no other sector of the community is treated like the mentally-ill, and yet almost 25% of the population is affected. While I appreciate that no system is ever perfect or will ever be perfect, what is happening now, is not acceptable, and I will never ever give up my fight for justice, no matter what it takes.

TERMS OF REFERENCE -

b. the adequacy of various modes of care for people with a mental illness, in particular, prevention, early intervention, acute care, community care, after hours crisis services and respite care.

Insofar as mental illness resulting from drugs e.g. marijuana, without awareness programmes and education, nothing can prevent the resulting mental illness. But, with education and awareness, and authorities recognizing the valuable input of families and carers, episodes can certainly be lessened and more often than not, be prevented, with the help of Community Health Centres, and their teams of trained mental health professionals. I see the first line of defense for education and support - Community Health Centres. To my dismay, Cremorne and Chatswood Mental Health Centres are possibly being closed and relocated to the grounds of the Royal North Shore Hospital. This is a travesty of justice, because these Centres are an asset and are a vital part of the community. Placing them in the grounds of a hospital is totally undesirable. Hospitals and surrounding grounds are not pleasant reminders for those with hospital admissions behind them. From personal experience, I am not sure how we would've coped without the intervention of the skilled and caring teams of Cremorne Mental Health Centre, when my daughter had episodes that we were unsure of how best to deal with. Many an admission was prevented because of their immediate intervention and caring treatment. Centres like this can be utilized for many things, amongst which, would be a place to train and educate those that have fallen into the mental illness cycle. Support programmes and meetings could also facilitate the better understanding of what mental illness is all about. Get-together sessions could be set up for those with, for example schizophrenia, to be given basic skills to get back into the workforce, or perhaps what to do to lessen isolation and boredom. Everything should be done to help break the cycle of loneliness and isolation. Loneliness and isolation, I believe, are 2 of the reasons why so many suicide - they have all reached the limits of enduring long, lonely days and nights.

Acute Wards differ from hospital to hospital. Of the admissions my daughter has had I would say that Royal North Shore and St George were the worst: Cramped and poorly laid out and most have no "friendly" or suitable outdoor areas to walk about in. Most important of all - having males and females together in the same area, particularly at night, is totally unacceptable. My daughter spoke of men coming in to her room and masturbating on her pillow, but who would believe her. Was it psychosis, or real? How would anyone know? A possibility of this happening? Absolutely!

Community After-Care services, from our experience, is available, but unless efforts are made to get clients to attend, they will serve no purpose. For the most part, my daughter is so severely depressed, and to do the most basic chores, e.g. washing, brushing teeth and taking out garbage, is almost impossible, so what would induce her to attend after care facilities? A system should be found to help those like my daughter to attend, and I have no doubt after attending a few chosen groups, everyone would feel much better, and the outcome of higher self-esteem and self-worth would hopefully result.

Bringing medication to consumers while on Community Treatment Orders would fill a dual purpose should the teams be allowed to do more than just drop in medication. Observation of living conditions would indicate the wellness of the consumer, but apparently this is not allowed because of safety for the teams. (I do understand that this might be perceived as an invasion of a person's privacy, and might not always be easily carried out), but this is where early intervention could stop a consumer from getting to a point of having to be re-admitted if they are not able to care for themselves adequately. I mention this because when my daughter was so severely unwell, and her home was like a pigsty, with blood-soaked bed linen and the stench of urine, and black painted graffiti

on her walls, this would have been a clear indication of the need for her to be hospitalized, and in so doing, prevented any possibility of negative outcomes. I took the opportunity of photographing her home should the need arise to prove how unwell she was. I do realize that this is not an easy area to address, but it needs to be looked at.

Respite care, is an essential part of assistance along the recovery road. But just being placed into psychiatric hospital in the general ward for a day or two is not the answer. This time should be used as an opportunity to discover what is going on in the consumer's life, and how they are coping on their own, and perhaps re-enforce ways in which to better deal with their day to day activities and/or problems, but not in a hospital setting.

The Acute care Team is not always available or easy to reach, and are only available until 10.30pm, thereafter it means the impossibly long wait in hospital Emergency. If this is the case, then a better system needs to be found, whereby a database could be accessed, with medication details, condition etc, thereby lessening the wait for a Psychiatrist to be called out for assessment. A better system for mentally ill in Emergencies must be found. There have been instances of waiting more than 12 hours for any outcome to be made.

e. the extent to which unmet need in supported accommodation, employment, family and social support services, is a barrier to better mental health outcomes.

Supported accommodation is a most essential element in assisting those with severe mental health problems who are not capable of living on their own, and carrying out the most basic requirements needed on a day to day basis. Unless my husband and I clean, shop, cook, wash, iron, change bedding, and attend to other daily basics, there is no way that my daughter would be able to cope on her own. Yes, she passed the basic tests needed to enable her to have a public housing unit, but to do the most basic routines daily, her concentration, depression and lack of motivation, prevent her from carrying these out. So she is in a fortunate position to have her parents and public housing, but we are no longer young and not sure how many more years we are able to do what we do, and the scariest is what happens when we are dead. Long stay and supported accommodation are essential set-ups because it is not fair for the family and/or carer to shoulder this burden. After months and months of being in hospital, it is not possible to get back into normal routines, even the most basic, without the help of family/carer. With the ongoing struggle to cope with our daughter, I believe she would be much better off in a long-stay supported environment, with her own self-contained bed-sitter in a hostel-type set-up, with a communal lounge room and a "house mother/ father" to keep an eye on the residents. I feel sure she is far more comfortable amongst those that are like her. Employment another essential, for it not only breaks the cycle of isolation, but gives the consumer a feeling of self-worth. Unfortunately, many have the intelligence and capability, but the illness has taken away their ability to concentrate for long periods. In this instance, I don't believe that my daughter could work more than 2 hours a day, but being able to do just those 2 hours a day 3 or 4 times a week, would certainly help her find a reason to get out of bed, possibly reduce the cycle of depression and improve her self-esteem, and break the cycle of re-admissions. There must be many areas where people could be utilized for such short periods.

g. the role and adequacy of training and support for primary carers in the treatment, recovery and support of people with a mental illness.

My husband and I have had no support or training for our role in the care of our daughter. Nothing ever prepared us for the nightmare of caring, supporting and loving our sick daughter. We had to find this all out ourselves but what a

price we have had to pay. Had we been better informed I truly believe we could all have been saved so much stress and anxiety, and suicide not the best option for me, and major heart surgery not an option for my husband. We had no idea where to turn. Nobody ever told us of the need for Case Managers, or what was and who were the Care Team and Acute Care Teams. We had no idea what Scheduling meant, what the Mental Health Tribunal was all about and the meaning of Community Treatment Orders. We had to find this all out, the hard way. I took on a voluntary role to help people with mental illness and did so because I was given a course on dealing with mental illness, thereby giving me a better understanding on what I was personally dealing with.

1. the adequacy of education in de-stigmatizing mental illness and disorders and in providing support service information to people affected by mental illness and their families and carers.

With the availability of a support or information service, marriages very often do not survive. Until my husband accepted and understood our daughter had a mental illness and what it meant, he would get angry and call her a bludger, and yell that she was lazy and a good-for-nothing. The constant bickering and disagreement about her condition, was and is tearing us apart. The atmosphere in our home was and is at times unbearable! Neither of us fully understood mental illness and what we were up against! Insofar as stigma is concerned, the media is more often than not to be blamed in their reporting of incidents, should the person involved have a mental illness. Our children need to be educated from an early age, what mental illness is, and the respect and understanding that people with this illness deserve. Education on mental health should be part of the curriculum from an early age, and with each year at school, discussed more in depth. The positive outcome of this could have far-reaching and positive outcomes, and also possibly enable families to detect what may be the starts of a mental illness.

m. the proficiency and accountability of agencies, such as housing, employment, law enforcement and general health services, in dealing appropriately with people affected by mental illness. Those that are afflicted by mental illness and having to deal with departments, such as housing, employment etc, are always at a disadvantage and for the most part are not respected and listened to. Many times have I had to intervene and speak for my daughter when someone at The Department of Housing, would ignore my daughter's problems and be rude and unhelpful. On once occasion, the first time my daughter had dealing with DOH, was when she was offered a unit and 2 were available. She was not given the opportunity to see both, but was told she could only see 1 and accepts it; otherwise she would lose out altogether on gaining a DOH unit! Because she has a mental illness should not be the reason for those that work in areas of public housing to use their position to bully and disrespect and add to the trauma of coping with basic day to day situations. These public servants should be held fully accountable for their behaviour and possibly need ongoing training and inspections. The culture of bullying is evident in many areas of life, but when so-called professionals are involved, when dealing with the mentally ill; this is a cause for grave concern. I blame my daughter's deteriorating illness on unsupervised Registrars who showed a total lack of respect and understanding of the obvious need for admission and allowed my daughter back into the streets, many times when she had no money, lost the key to her home, very often bare feet, and never making any attempt to notify her parents.

In closing, I respectfully ask the Committee to understand, that while I know that nothing is perfect in life, our most disadvantaged mentally ill citizens deserve better. Our Psychiatric hospitals doctors, nurses and after-care teams, are not only struggling to cope with the ever-increasing demands made by our increasing population, this is compounded by the use of drugs and alcohol in our youth, which also adds to the problems.

Our doctors and nurses are struggling. They are unsung heroes. Without them, we are lost. Please give them the financial support they need to do the job that they are trained for. Please listen to those members of the community who are able to speak for those afflicted by mental illness, who are not able to speak for themselves.