23rd April, 2005

The Committee
Mental Health Inquiry

Dear Sir

I would like to place my submission before the Mental Health Committee for two specific reasons. Firstly so that committee members can be given a first hand account of how the inadequacy of mental health facilities in rural areas is destroying rural families. The need for mental health facilities is increasing but services are not. This is particularly true in rural areas where services are stretched well beyond their capabilities. We live in a reasonably large rural centre and yet to receive even slightly adequate care we are forced to constantly place our daughter in a Sydney hospital. Any person who is unwell is better off in their own environment. People with mental illnesses are even more dependent on the maintenance of routines and continuity of relationships. Being constantly forced to leave a supportive family environment in order to access even basic help increases the severity and frequency of periods of psychosis. This issue needs to be addressed immediately.

Secondly I would like to make the Committee aware that the existing facilities, based unfairly in major cities, do not in any way address the varying needs of individuals and this results in individuals with psychological illnesses being treated with total lack of respect or dignity. Not all people with mental illnesses have intellectual disabilities or drug of alcohol problems but are all are lumped together with total disregard for individual differences and individual needs. Being exposed to issues of drug and alcohol abuse adds immeasurably to the paranoid tendencies of schizophrenics.

To understand my concerns I would like to explain my family circumstances so that my grave concerns can be seen in context. I am a 51year old teacher. My husband is a bus driver. I have two daughters. My youngest is a 21 year old student who lives away from home. She works part time and receives AusStudy allowance. My eldest daughter is an intelligent, 25 year old woman who suffers from paranoid schizophrenia. I have reached a point in my life where I can see nothing but pain and distress ahead. The future frightens me and the present is day by day turmoil and anxiety. I would like to put to the enquiry the chain of events that has led to this point of desperate concern in my life, and the lives of all my family and I am sure is a fact of life for many other rural families.

My family and I live in a small rural town in New South Wales of approximately 2,000 people. My husband and I were both raised in the New England area. Our daughters have both been raised here. Our nearest large town is Armidale, which is approximately 20 kilometers away and has a population of about 20,000 people. Our daughters were both educated at local schools. During Year 9, our eldest daughter began to suffer symptoms of withdrawal, difficulty in personal relationships, and moved from being a high level-achieving student to a student who could not complete assignments. After consulting our local GP she was prescribed tranquillisers and life continued with no further support. Our daughter continued to have difficulties and in Year 12 we again sought help. Because of our concern, I arranged an appointment for her with the only psychiatrist in Armidale. The diagnosis was stress caused by the exams. No other advice or symptoms to look out for was discussed with us. No further treatment was recommended. No time was taken to address our concerns or to discuss our daughter's medical history. The consultation was not particularly successful as the level of communication between our daughter and the Doctor was not good. She was prescribed tranquillisers. This was ineffective and had the consequence of making her very lethargic. There was a change of medication, which did not improve the position in any way. Our daughter went on to complete her Higher School Certificate, and performed far below expectation. Again the degree of her problems was not diagnosed.

The following year our daughter enrolled in TAFE in Eco-Tourism and Outdoor Guiding. She continued to have difficulty completing assignments and became very anxious about any excursions that took her away from home overnight. She eventually completed this course and gained her Certificate.

During this period her only paid work was as a nanny. She cared for a four-year-old child in his own home, at our home and in her grandparent's home.

As no other employment opportunities had arisen, in 2000 our daughter obtained a casual position for the winter months in the snowfields as a lift attendant. This was the first time she had been away from home, and she boarded with some extended family members. Her mental state continued to deteriorate even though she fought hard to fulfil her obligations at work.

In about July or August of 2000, she called me and started to talk about hearing voices and seeing things that she knew were not there. We discussed the situation and she said she would see a doctor. She saw a GP and was hospitalised and diagnosed as a schizophrenic suffering a temporary psychotic episode and she returned home. We consulted our local GP and obtained a referral to a specialist in Tamworth. Tamworth is about 90 kilometers from our home. At the consultation the Psychiatrist said that our daughter was mildly psychotic, that it was probably a one-off incident and in all likelihood she would be better within six months. We also received from this specialist the best and most practical advice, which could have been given, which was to sign her up for private medical cover.

Our daughter was now highly medicated and unable to work. She slept continually and had no motivation to participate in any family life. Neither she nor our family were offered any support. She had to fight to obtain a disability allowance and we had to constantly drive her to Tamworth for doctor's appointments, a round trip of 180km.This meant I had to take time off work or we had to travel outside working hours.

The only psychiatric facility available in our local area was psychiatric beds in the Public Hospital. Totally unsuitable for a young girl who had had no exposure to violence.

I think it important that it is understood that our daughter had had no involvement in any type of substance abuse. She did not "do" drugs, she did not drink to excess, and she didn't even smoke. Our daughter has a psychiatric illness, which has robbed her years of young adulthood of any pleasure and dignity, and there was no support system at all other than our immediate family to cope with the consequences of this. Isolation from adequate services I feel has had a very damaging affect on the course of our daughter's illness. I can see how this hopeless situation is contributing to youth suicide.

While continuing with her treatment our daughter had to see the specialist in Tamworth approximately once every six weeks. Appointments were not easy to get as the Doctor had to cover an enormous area of central NSW as she was the regional consultant. We had some very frank discussions with our daughter's specialist at this time. As a very experienced practitioner, who communicated effectively with our daughter we respected the opinions and advice given. Some of this advice related to what we should do in extreme situations, and we were advised never to allow our daughter to be admitted into a number of local Public Hospitals due to the standards of service and care received by psychiatric patients in those places. Mental health workers admit that facilities are inadequate and can compound patients problems rather than help rectify them.

During this period our daughter first exhibited suicidal tendencies, and we were able to provide nearly fulltime care only because my husband was home during the middle of each day between his bus runs. Our daughter could not be left alone for anything more than a short period. This was not only because of her deteriorating mental condition, but also the need to administer her medication for her. Our daughter has always been compliant in taking her medication, in fact in taking any treatment option offered which may ease her suffering, however she has been so heavily medicated since her condition was diagnosed that she has always needed assistance with her medication.

During 2001 it was clear that our daughter's condition was deteriorating. Her specialist referred her to another specialist at a private hospital in Sydney. This hospital is 500 kilometers from our home. There was no facility closer to our home that could offer the treatment that our daughter was likely to need. This was a private hospital. As soon as we were able to arrange an appointment. My husband and I travelled down to the hospital with her. At this time our younger daughter was in Year 12, and studying for her Higher School Certificate. The constant strain of caring for our elder daughter and trying to find help for her had a negative affect on her exam preparation and affected her health.

Following the consultation with the specialist in Sydney, our daughter was immediately admitted to the hospital, and she stayed there for about three weeks. Her condition continued to deteriorate.

For the next three years our daughter underwent various treatments including electric shock therapy. She was in and out of the hospital for varying periods of time. When in hospital we would visit every fortnight and had regular consultations with her Doctor. She was dependent upon these visits to maintain any degree of connection with home and reality. Either alone or with my husband, I drove to Sydney approximately 20 times a year over this period. The constant stress and exhaustion of this constant travelling has made it extremely difficult to remain in employment and to maintain family relationships. On each occasion when we have travelled to Sydney we have had to stay for at least one or more nights in local motels, hotels or when available at the hospital itself. This has placed severe financial hardship on our family.

When at home during this time our daughter still had to be supervised constantly. The suicidal tendencies had worsened and she was still heavily medicated. I was fortunate enough to obtain fulltime employment, with a very understanding organization, as I frequently had to take days off to rush her back to hospital when she suffered an episode and required hospitalisation. Again I must reiterate that there was no local support or assistance. I had to find full-time employment so that our family could continue to function and to enable our daughter to access a reasonable level of treatment.

Our youngest daughter continued to suffer during this period. When her sister was at home our focus had to be upon her welfare. When she was in hospital we had to visit every second weekend to offer our love and support, and consult with her doctor.

After finishing Year 12, our younger daughter worked close to home for 12months and then, finding home life impossible to cope with, she moved to Queensland to start a TAFE course.

Our elder daughter was eventually diagnosed as suffering treatment resistant paranoid schizophrenia. Although the private hospital she was being treated at is not a residential unit, she reached the point where she could only be at home for about a week before having to return to the hospital because she was suffering from another acute episode. Our routine became one where when her condition deteriorated I would ring the hospital and have her there for admission within 24 to 36 hours. There was no other option. This is an unbearable way to live. Sitting with a suicidal child through the night to keep them alive until you can get them an adequate level of help is indescribable and is a direct result of the terrible lack of facilities for people like our daughter in rural areas.

At this stage our daughter’s specialist began consulting with another specialist at a well-known and respected public hospital in Sydney and her treatment regime was changed. Part of her treatment was now administered fortnightly by injection in conjunction with other drugs. This injection is difficult to administer, as it is a slow release, oil based injection. The correct dose to last a fortnight is only delivered if the injection is correctly administered. The specialist from the hospital told me that he would arrange for the Mental Health Team in Armidale to organise someone to administer the injection. Although both the Doctor and our daughter tried to contact the Mental Health Team, no one came to give the treatment and she had to be readmitted to hospital in Sydney. Following another period of hospitalisation, with great difficulty (two weeks of constantly trying to contact or have someone return phone calls) the specialist treating our daughter organised for someone from the Mental Health Team in Armidale to visit our home to administer the injection. This was the only circumstance under which she was to be allowed to return home. This health worker was to monitor her condition and to provide support and back up in an attempt to keep her out of hospital for an extended period of time. There was no supervision after the administration of the injection, and no support or casework involvement was offered.

The local Mental Health Team has only part time workers who cover 100's of patients and there is no full time service available. As this was unacceptable for our daughter's treatment we had to go the local GP to administer the treatment. The treatment was incorrectly administered and therefore she did not receive the correct dosage. In spite of these problems as we had no other alternative she continued to receive her treatment when at home from the GP. Before long she again had to be admitted to hospital in Sydney.

With no local caseworker, support or service, when at home after a short period our daughter becomes unable to cope, her symptoms worsen and she has to be readmitted to hospital in Sydney. This became and still is, a continuous cycle.

On one occasion our daughter attended a session conducted by the Mental Health Team in Armidale. She had to be taken to and from this facility by her father, as there is no suitable public transport. She found this session distressing. The participants had histories of drug and alcohol abuse and she had nothing in common with the other participants.

No emphasis is placed on personal differences between patients. All labelled with psychological problems are lumped together and treated as one. This can expose sufferers to terrible mental distress and exacerbate feelings of humiliation and lack of self-confidence and self esteem. Again this can lead to suicide.

To my knowledge, the local situation over the past years has only deteriorated. There is no longer a full time psychiatrist in Armidale, rather two specialists visit one day a week. This, when coupled with the part-time Mental Health Team, means that when a person suffers an acute episode there is no one to turn to for support. This can have tragic consequences for sufferers and their families.

By the end of 2004, our daughter could not sustain life at home any longer, and was hospitalised for five months. She would occasionally be home for a week, before her condition would deteriorate and I would rush her back to Sydney.

This situation was untenable. However it seemed that there was no alternative. In late 2004, because she was not responding to any treatment and was experiencing distressing and life threatening side affects, it was suggested that she be moved to a rehabilitation facility. She had an interview with the team at a public hospital in Sydney and was accepted into their program, which placed patients into cottages with 24 hour support, and programs to rehabilitate them so that hopefully they would be able to live at home. She was admitted to this hospital in December 2004.

I had thought that this was a breakthrough, however our daughter's time in this unit has shown other shortcomings of the system. As a 25 year old woman, she has been placed in unit with four young men who are all substance abusers. The daily programs target substance abusers. Our daughter does not fit into this demographic. They offer nothing by way of stimulation or motivation to a young woman of intelligence. This is a major weakness in the Mental Health system.

As a young woman, to be in the company of young men discussing sexual matters constantly is degrading and demoralising. She now combats self-esteem issues not only because of her mental illness but also because of her sex. Again no account is taken of individual differences or sex. This is a disgrace and people who suffer mental illnesses deserve our respect and protection. Two issues that are not being addresses at the present time.

During her periods of institutionalisation, our daughter has also become a cigarette smoker. I can understand this as she has been surrounded by people suffering various forms of addiction for a number of years; this is further impacting on her health and wellbeing.

There has also been a period when the hospital has had no doctor available, and we were asked whether we would like to take hour daughter home for that period. This was indeed recommended as the staff felt that they could not adequately look after all their patients. This was horrifying. This type of resourcing issue causes me deep concern. How can patients with this magnitude of disability be treated this way? On another occasion again when no doctor was available over a weekend our daughter was locked in a secure unit.

Counselling on a one-to-one basis helps these sufferers get through the bad days not incarceration. Can you imagine how soul destroying this would have been for an intelligent woman who only needed someone to talk to? This situation is unbelievable. This type of response only exacerbates the problem. Something has to be done to provide adequate services for those unfortunate enough to be suffering and who need our help.

I am thankful for the commitment and skill of the staff that have provided professional and appropriate care our daughter over the years, however at many times it has been less than ideal. They do not have the man power, basic facilities or access to resources that they need to carry out their responsibilities to the best of their abilities. They need help and immediate assistance.

Our daughter, because of this dreadful inadequacy of resources, is now a young woman who lives a distressing, aimless and hopeless life day by day. Her pension means she will be forever reliant on us financially and has no hope of ever being able to live by herself even if she becomes well enough to do so. She cannot afford to ever look forward to being able to enjoy even the cheapest holiday or own her own car or home or to live independently. Her life seems to her to be worthless and she sees herself as being a constant burden to us. She is not! She is a sensitive human being who, through no fault of her own suffers from a terrifying and debilitating illness. She deserves respect and the opportunity to access services that will help her to achieve the highest possible quality of life. This is being denied her, and the rapidly growing number of people suffering the same illness, at this time.

My husband and I are exhausted after four years of constant travel to Sydney to either consult with doctors, collect our daughter to bring her home or to return her to hospital after an acute episode.

The future holds no foreseeable change. Our local area support is non-existent and our financial position continues to deteriorate. Since our daughter has been admitted into a public hospital she now has to pay $400 per fortnight for her accommodation, plus her private health fund contribution and personal maintenance. Although she receives a disability pension, this does not cover these expenses. My husband and I buy her clothes, toiletries, and pay for dental care and many other incidental expenses. With supporting her and travelling constantly to Sydney all our savings are now gone. My husband cannot look for any alternative work, as he needs to be home when our daughter is home to be with her during the day, and he could not risk any insecurity of employment. As a result we are punished financially yet again. I cannot work less than full time, as we are dependent upon my income to support our daughter and ourselves. We have not had a holiday since 2000 as we cannot leave our daughter unsupported in care and she is too ill to tolerate such a change in surroundings by taking a holiday with us. Any time off from work is spent living in motels, the cheapest we can find, in Sydney and visiting our daughter. This is exhausting, stressful and financially disasterous. What choice do we have? None.

What does the future hold? Our daughter can only access the services of the hospital she is now in for a further 18 months. She cannot live at home as there is no access to appropriate treatment when she suffers an acute episode, and nor is there any support that makes getting out of bed each day a worthwhile activity. She has been offered new treatment but must find her way across Sydney by public transport to access this. This involves changing buses and understanding timetables. A frightening thought for someone who does not see the world as the rest of us do. After discussions some financial aid was offered to send her in taxi, but once this is used she is on her own. Would you like to be finding your way around a large city unsupported, frightened and confused? Especially after receiving treatment that is likely to induce severe headaches. This treatment is our daughter’s only hope for some relief at this time as nothing else that has been tried has alleviated her symptoms. How unfair is it that people suffering to such a degree have to face this type of situation?

Our younger daughter has been deeply and permanently affected by the circumstances of our family. She continues to live away from home on her own, and has difficulty with personal relationships. She worries about her sister and the impact this situation is having on our health.

An intelligent woman with schizophrenia is trapped in a cycle of institutionalisation, chronic episodes and deteriorating self-esteem. Our family suffers exhaustion, deteriorating financial stability and constant stress. Where is the hope? Where is the choice? Where is the quality of life for all of us caught up in this cycle? We are not alone. We are isolated and disadvantaged by living in a rural community. We have been given no assistance or guidance in ways to plan how we can support our daughter in the future. We would like to be able to make financial arrangements for her future care while we are still able to. We do not expect to be given everything for nothing and fully realise that our daughter is our responsibility but as tax payers we also would like to feel that somebody could help us establish a program whereby she and others with similar disabilities can access the care they require for the rest of their lives so that their lives have safety, dignity and meaning. Our daughter worries constantly about what will become of her when we can no longer support her financially. She suffers through no fault of her own. She deserves help and respect, two things that do not seem to be seen as relevant in mental health care at the moment. People in our situation need to be listened to if people suffering this dreadful, debilitating disease are to be kept off the streets and out of gaols. Ours is one family in the New England area, there must be many more. In your deliberations and search for solutions, please consider the predicament of rural people such as us. We need help and a voice so that our concerns can be addressed and that people suffering from mental illnesses can be assisted to achieve a decent quality of life and a productive future not within a major city centre. This is not a suitable environment for country patients and surely if 1% of the population suffers from schizophrenia and associated disorders, suitable supervised and supported housing facilities catering for different sexes, ages and degrees of disability backed up by meaningful and productive programs can be built in smaller regional centres.

Recommendations

- Treat people with mental illnesses with respect – listen to them. They know what needs to be done
- Talk to a range of families and people with mental illnesses from different economic groups. Their needs are not always they same but they need to be listened to be it male/female, country/city, economically disadvantaged/employed
- Appreciate that all people are different and study their differing needs. This is crucial in offering these people an opportunity to feel valued and that different services are available as they age and as symptoms change. These illnesses are not static
- Talk to country people and address their concerns – we are yet again disadvantaged by distance and lack of services. Listen to us, talk to us
- Realise that many of these people suffering mental illnesses are leading very distressing lives with no chance of a cure and no possibility of ever attaining a job

or a reasonable standard of living. Listen to these people and address this issue. Not all people with mental illnesses are drug abusers. Their illnesses are not a result of their actions but a physical handicap. Many do turn to substance abuse to try and cope. These people are often the people on the street and who are filling our gaols. Help them. Listen to them.

- Pension rates do not allow people with mental illnesses to access private health insurance and decent quality services. They can never hope to lead independent and satisfying lives without financial support. Even basic luxuries such as a day trip or short holiday are forever beyond their means
- Listen to health care professionals. They are experts on what facilities are required from the physical surroundings, to research, to back up facilities such as social workers. People with mental illnesses need surroundings that give them hope and safety not the disgraceful archaic facilities they are forced into at present
- Get out and visit secure units and mental health facilities and put yourselves in these people's shoes. It could easily be a member of your family that requires care. Would you like your loved ones to be treated like this?
- We are responsible, caring parents who want to provide for our special, wonderful children. We need help.

Please feel free to contact me at any time to discuss the issues I have raised. I look forward to hearing from you.

Yours sincerely