

Committee Secretary,
Senate Select Committee on Mental Health,
Department of the Senate,
Parliament House,
Canberra ACT 2600

19 April, 2005

Dear Sir/Madam,

I have a son aged 31 who was diagnosed with schizophrenia at 20 years old, a brother diagnosed with schizophrenia when he was about 40, after being ill for many years, and a sister diagnosed with schizophrenia when she was about 25. Medication has stabilized each of them, but in my son's case it took six years of trauma and a suicide attempt before the 'right medication' was found.

I wish to make some points concerning the Mental Health System based on my experiences with three different Area Mental Health Services.

(son)

Initially it was impossible to access help from our G.P. despite our desperate pleas, resulting in a crisis presentation at the local hospital Emergency Department, with our son, a highly achieving math student, in a state of catatonic psychosis. The following months of trauma were greatly relieved by the high calibre of the members of the Crisis Assessment and Treatment Team (Cat team) who treated him at home, sometimes with twice-daily, and highly-needed, visits.

Once the initial crisis was seen to be over, our son became a client of the local Community Mental Health Centre, where ever-changing doctors tried to stabilize him. He was even taken off medication on the advice of a well-meaning but ignorant case-worker, resulting in a suicide attempt.

This incident emphasizes the need to liaise with carers. Stabilization took six years and only occurred with my and my husband's intervention. The psychiatrist at the Centre was at a loose end to find the right medication, saying "I don't have a magic wand". After advice from a friend we went to a professor at a city hospital. He took our son off all medication and then introduced medications one at a time to judge the effect. He was able to find the right combination to stabilize him.

- **He did have a magic wand.** However our son eventually needed to be monitored back at our local Community Health Centre once he was on Clozapine.

Once stability with medication is seen to be achieved, the system is prone to abandon the patient to remain at that stage of rehabilitation for the rest of his life, although spasmodic efforts are made at random to be seen as attempting to carry through a programme of rehabilitation.

These efforts are generally only made at the instigation/insistence of a committed carer.

Our son is now being discharged from the Area Mental Health service to the care of a private psychiatrist, without case management, which means his social rehabilitation needs are unlikely to be met.

He needs, now, at thirty-one to live independently in order to make his own life but without access to subsidized accommodation there is little chance of affording a suitable rental property on the disability pension. We have contacted an agency for low-income rental who told us the case-manager must do the referral. However even the case-manager was then told that the books are closed at present.

The agreed model of mental health treatment includes biological, psychological and social rehabilitation.

Currently there is no full time psychologist employed at our Community Mental Health Centre, only one part time visiting psychologist.

Side-effects are not dealt with in an appropriately serious manner by most health professionals. Since starting Clozapine our son has saliva-soaked bedding daily. His weight-gain is a constant reminder that his medication impacts on his appearance and he has to fight drowsiness constantly. These side-effects are never stressed as being the immense drawbacks to normal living as they are in reality. People are put on Clozapine without fully understanding the implications. So not only does he have an illness to contend with, but side-effects as well, all affecting his ability to form relationships, socialize and work. These issues need to be addressed seriously, before a person begins Clozapine, and certainly as part of ongoing treatment once a patient is on Clozapine.

(brother)

On a community treatment order, my brother is stabilized but stagnating. His life is spent in a lonely flat waiting for his regular visits to his sisters. He literally paces the room or sits throughout the major part of each day doing nothing apart from a short walk to buy his 'take-away' meal. He has little idea of normal etiquette and hygiene or house-keeping, having been ill for so long without treatment. He has no insight into his illness and no attempt is being made to educate him as to why he is on a CTO. His treatment should encompass training in living skills, and intensive therapy to motivate him to engage in normal activities. As he has no insight into his condition, his physical health is part of his problem- he refuses to see a G.P. even when it is obvious to everyone else that he has a medical condition which needs attention. **It should be part of his rehabilitation programme that he is seen by a G.P.** Once again the **psychological and social rehabilitation** of my brother has not been attempted.

(sister)

The lack of cohesiveness and follow through in my sister's treatment over many years has been shameful. She is at present being treated at her local Community Mental Health Centre-an appallingly busy, under funded clinic. She is afforded a few minutes once a month with a G.P. approved to monitor Clozapine patients. Many requests have been made for a Case Manager, with her Doctors agreement, but to no avail. After she begged for help for a long-standing, deep-seated anxiety phobia, **virtually making her a prisoner in her own flat, there was no attempt to address this in a rehabilitation plan.** Instead sporadic efforts are instigated by different people. This results in a waste of precious funding as workers are sent to her without any idea of what she really needs.

SUMMARY

- I cannot emphasize too strongly the importance of the Crisis Assessment and Treatment Teams. These invaluable teams require increased funding to be able to function well 24/7. **They are understaffed and underfunded.**
- The agreed model of mental health treatment **including biological, psychological and social rehabilitation, must** be followed. Funding must be found to provide for expert mental health professionals to address the agreed model.
- Once the patient is stabilized on medication, **a constructive rehabilitation plan must be made and implemented.** The plan should draw from all areas of expertise, in consultation with carers, with regular review and advancement as goals are achieved - to achieve the best possible outcome.
- The carer's advice, experience and knowledge of the patient and his/her symptoms must be deeply respected and taken into account.

- Too often workers are not pro-active, nor adequate to deal with the needs of patients. Case-managers may not have the necessary expertise to assess needs properly and may simply be acting in role of coordinators. This results in a waste of precious funding as time is spent in ineffectual meetings, or no meetings at all as it is assumed by means of a phone-call that the patient is “doing fine”.
- Carers have to push and badger to get action. Patients without carers are liable to miss out.
- Patients should not be off-loaded until full potential is achieved.
- Patients must be able to access funded supported community housing.

