

Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee
on Family, Community Housing and Youth
PO Box 6021
Parliament House
CANBERRA ACT 2600

14th June 2008

Dear Secretary,

As the parents of twin daughters, both of whom developed chronic schizophrenia in late adolescence some eighteen years ago, we have experienced many shortfalls in the mental health system. Our role as conveners of a voluntary carers' support group for the past thirteen years has also provided evidence of a very flawed system.

Many of these inadequacies stem from exceedingly poor communication between mental health clinicians and carers and also between the key-workers in outreach support services and carers. Since the unwell person's mental processing is dramatically affected by an illness such as schizophrenia, it is of the utmost importance that effective channels of communication be established between the mental health professionals and the carers. Unless this occurs, both parties are virtually working in the dark and the unwell family member is struggling in a no-man's land of nightmare and confusion. Nevertheless, the policy of meaningful collaboration between those working in the mental health arena and the family carers of the mentally ill is quite a recent development and is still in its fledgling stage in our Australian mental health services.

Recently, it has alarmed us to hear from two recent members of our carers' group that they are experiencing similar frustrations with the mental health clinic as ours of nearly two decades ago. Their son's mental illness causes him to avoid attending appointments with the doctor and case worker: he refuses help, relies upon his parents financially and is obviously on a downward spiral, and yet the staff at the clinic doesn't follow up his non-attendance or offer any useful support to his highly stressed family.

The vexed issue of confidentiality has traditionally led to a quagmire of misunderstanding and alienation, causing families to feel misjudged and shut out and clinicians to become guarded and defensive. It is no wonder that ignorance and stigma still cloud people's understanding of mental illnesses. Although there is a

“need to know” policy regarding the communication of vital information to carers, it is not always adhered to as conscientiously as one would hope.

Compounding this problem has been the emotional impact of the illness upon the unwell person and his/her family. The family is in crisis and in desperate need of insightful support and practical information. The provision of timely and accurate information about the illness, about the anti-psychotic medications and their side-effects and about appropriate support services has often been sadly inadequate. In the not so distant past, the family’s stress and grief and sense of isolation were increased by an apparent lack of empathy and even a blaming attitude from many mental health professionals. Thankfully, the tide is turning, but it’s a slow process and old attitudes still tend to come to the surface.

On a personal level, we are fortunate in that we have recently been able to provide our daughters with private accommodation, but this was precipitated by problems that we had encountered with their supported accommodation agency. The managers arranged - without proper consultation with her family or her clinical case worker - for one daughter to move into the squalid rental accommodation of her current, very dubious man friend. Her twin sister was then pressured to share with another client under the threat that she would lose her home if she did not comply. This seems to be symptomatic of a drastically under-resourced housing system.

Unfortunately, the support provided by supported accommodation agencies is often distressingly inadequate. The key workers often do their best in terms of assisting the clients with budgeting plans for utilities and taking them to recreational programmes and on outings, but the clients’ house-cleaning and personal hygiene issues typically run out of control. Mental illness can have a drastic impact upon the sufferers’ ability to apply him/herself to cleaning chores and personal hygiene, and constant supervision and re-enforcement of hygiene routines are then called for. When the client is most unwell, a hired cleaner is really required. As carers, we often find ourselves performing these tasks and continually trying to train our family member(s), but we worry about the future when we can no longer offer this support. There is the added complication that, when one’s family member is particularly paranoid and hostile, it is usually impossible to monitor these everyday routines and – if the carer can’t – who will?

In an ideal system, the outreach workers would communicate and collaborate with carers to provide integrated and effective support; carers would be included in regular family meetings and help to plan programmes designed to assist the client to gain and maintain living skills, manage symptoms of the illness and side-effects of medication and fulfil his/her potential as far as possible. A regular review process

should also be established in order to assess the effectiveness of the programme and to set new goals.

We are not ungrateful for support services as far as they go, but they are drastically under-resourced, particularly in terms of out-reach staff. The key-workers should be trained to fully understand the complexities of mental illness and appreciate the importance of networking with other mental health agencies and with carers. Their work-load should take into account the enormous impact of a mental illness, such as chronic schizophrenia, upon clients and, hence, the breadth of support required. A token monthly visit can hardly be deemed “support” in the true sense of the word! Some of the best out-reach workers that we have known have left their jobs not only because of the demanding and confronting world often presented by mental illness, but also because of frustration with the system combined with the meager pay.

Another area of immense concern is the apparent lack of police training in mental illness issues. The police have to deal with the mentally ill on a daily basis and yet we still seem to be in the Dark Ages when it comes to providing them with the education that will enable them to respond appropriately to the incidents and crises caused by mental illness. Over the years, our family has received some very helpful assistance from police, but the fact that one quite senior officer recently asked us, “What is schizophrenia?” demonstrates a very serious gap in his training. The symptoms of paranoia and delusions, which often characterize mental illness, cause every social interaction to become problematic. The mentally ill are often the most vulnerable, marginalized and misunderstood members of our society and frequently end up rejected by society, in prison or shot by an ill-prepared police force.

We could go on, but it would probably be more useful to summarize with a list of suggestions for an improved mental health system. Please find our list attached.

Thank you on behalf of all carers for your time and for the opportunity to have a “voice”.

Yours sincerely,

Robert and Patricia

Suggestions for Improving Support for Carers of the Mentally Ill.

- **Meaningful communication with carers by all workers in the mental health system.**

i.e. Informing carers about changes in medication, side-effects etc.

Listening to the carer's perspective and, wherever possible, engaging the carer in support plans and offering appropriate information and guidance. Directing the carer to counselling and support agencies, when appropriate. Ensuring that the carer is consulted and included in any major plans, such as accommodation changes, hospitalization or discharge from hospital.

- **Meaningful and on-going collaboration with carers by key workers in out-reach services.**

i.e. Inviting carers to regular planning and reviewing meetings in order to identify potential crises, tackle everyday-living issues and set and adjust goals.

Always returning carer's phone calls and listening to serious concerns regarding both the client's and the carer's well-being.

- **A well educated police force able and equipped to handle mental illness issues and to contain mental illness crises with a minimum of force.**
- **Crisis Assistance Teams able to respond quickly and effectively when a mentally ill family member needs hospitalization.**
- **Improved psychiatric hospital facilities**

i.e. Much more psychiatric hospital accommodation.

A much greater, well trained staff of doctors and support workers.

A stringent code of ethics for all staff and a careful screening of casual staff to ensure that patient neglect and/or abuse does not occur.

A safe and pleasant environment, conducive to recovery and separate from the general hospital wards.

Insightful and helpful communication with carers by hospital staff and doctors.

Respect for the carer's knowledge of the patient and important support role in the patient's recovery. (Where evidence suggests that the "carer" is misguided or malfunctioning, however, referral to appropriate counselling agencies would be helpful and humane).

Carers to be informed when their family member is being discharged, unless patient has requested otherwise (assuming that he/she is sufficiently stable and capable of making insightful decisions)

- **Respite for carer and client**

- i.e. Where the mentally ill person lives with the carer, assistance in involving the client in recreational programmes in the local community.

- Encouraging client to go on a short respite break.

- Providing short term supported accommodation for client so that the carer can have regular respite breaks.

- **Practical rehabilitation programmes designed to assist the client in gaining a sense of self-worth through meaningful employment.**

- i.e. When the client is well enough, he/she should be assisted by outreach workers in finding some sort of appropriate voluntary or paid employment. Ideally, there would be a mentoring scheme in which the key-worker – along with the client – learns the job skills, assists the client in mastering the skills and is able to take over for brief periods when the client is too ill to work. (e.g. The Mental Illness Fellowship's successful Bromham Place Clubhouse model).

- According to Caroline Crosse, guest speaker at the 2002 Bruce Woodcock Lecture, "work works" for the mentally ill. She has been involved in Social Firm projects, notably in the very needy western suburbs of Melbourne. (In 2001, she was awarded the Churchill Fellowship to investigate psychosocial rehabilitation in Europe and the USA, with a particular focus on those programmes that clearly linked rehabilitation to employment.)

- **A wide spectrum of appropriate housing to meet the varying needs of the mentally ill, together with a much more comprehensive support network to assist with daily living skills such as budgeting, personal hygiene and safety issues.**
- **Improved networking between all agencies involved in supporting the mentally ill, including hospitals, mental health clinics, out-reach support agencies, rehabilitation organizations and police.**
- **Greater public education about mental illnesses, with a view to dispelling the myths and stigma and to promoting greater empathy for sufferers and their families.**
- **Adequate funding for world-class research into mental illnesses, their causes and treatment.**