

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600
Submitted by email: fchy.reps@aph.gov.au

27 May 2008

Dear Secretary,

Inquiry into better support for carers

Thank you for giving me the opportunity to respond to your enquiry

I am a retired professional engineer. I have a son with an intellectual disability and have, for many years, been involved in the affairs of people with an intellectual disability. Through my wife's bi-polar disorder I am also involved with people with mental illness. I am a member of *ARAFMI Illawarra*, that being a branch of *ARAFMI NSW Inc*, a non-government organisation that supports families and carers of people with mental illness such as myself.

In may 2005, I wrote a submission to the *Senate Select Committee on Mental Health* for its inquiry (submission 185). Having recorded many events in our life at the time these occurred, should these – more than ten years later – be seen as stale and no longer of value? I believe that these histories are a reminder of what happened, and a warning of what might happen again. People change, memories fade, even government resolutions are forgotten.

Therefore, I have revived some of the matters from my 2005 submission in this submission in which I write as the carer for my wife whose bi-polar disorder has spanned more than 50 years. The most recent episode of severe depression started in November 2006 and has persists in spite of electro-convulsive therapy (which has worked in the past as a last resort) and medication, and the continuing support of a good psychiatrist, and our own efforts (we are 84 and 80 years old). We have overcome one attempt at taking her own life by overmedication on her prescribed medication; and taking her own life is again on her mind.

Our home life this week is now typical and – no doubt – an example of the life that many families lead. In bed most of the day. Clinging to me in fear when awake. Living in the past. Still recovering from the memory loss that electro-convulsive therapy has caused. Again talking about taking her life.

We are severely restricted in our movements, in what we do; and certainly I cannot leave home for any length of time. I tend to home and garden and carefully guide her through our daily life.

Should I, when confronted with her crisis immediately seek help? I have our psychiatrist's mobile telephone number as have many of his patients. He is willing to be called at any time; but I will not do so. He too has a family and a life, and his willingness to help may do him damage. That must not happen. We need him.

Should I telephone the mental health service and be told to go to the Emergency Department? That too would be a very last resort and done reluctantly for reasons which will become clear in this submission.

Well meaning friends encourage me to get some help in the house. Not only do I not need this; but a stranger in the home would add to my wife's anxiety to a degree which I know well.

We are isolated. An isolation that is self-imposed; and I will refer to it later, and to the unhelpful attitude of the government bureaucracy.

In any submission from a peak organisation you may get a well ordered submission that satisfies the terms of reference exactly. But terms of reference can be daunting and restrictive. The individual contributor will want more freedom to express himself; and in doing so may give your committee a far deeper background into the fears and feelings and the problems that carers have; and through this your Committee may "obtain an improved understanding of the challenges facing carers and their support needs". This submission is something that members of the Committee may wish to read and then put aside. I have written it to set the scene.

Yours sincerely,

Peter

Submission on the Inquiry into better support for carers

Peter
May 2008

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From the present, 2007-2008:

1. Social Isolation

Breaking down social isolation is one of the tasks for my organisation ARAFMI Illawarra (a branch of ARAFMI NSW Inc.).

We, husband and wife, are in depression. We make little contact with friends. They do not come to us; we do not go to them. Talking with well meaning friends has its moments: often listening to advice and leading to more agitation. Our isolation is self imposed.

But that does not mean that we would reject an invitation to a bus trip which will occupy our eyes, ears and mind. To a park, to the Power House Museum, to a gallery; and to do this with others in similar circumstances who will not use the occasion to open up with their own problems; but will use the occasion for what it is; a social event.

But our local bureaucracy that controls the NSW Non-Government Organisation Grants Program is not of that view and considers such as some personal entertainment that is not a necessity in our disrupted lives, merely a luxury.

Last year, my organisation arranged a bus trip for carers. We learnt that "Eyebrows were raised" at a very high level of the bureaucracy (and this in spite of the fact that carers and fund raising paid for the trip). The narrow view is that what is not stated explicitly in the funding and performance agreement must not be done.

2. Admission to treatment is a hazy concept

The broken leg: the signs are obvious and cannot be disputed. No one will declare that you do not need treatment and then sends you home.

Over the years, we have had many instances, and always to the point when crisis has been reached having coped at home for as long as possible. Enough is enough.

A visit from the crisis team (1994 or thereabouts) who reached the conclusion that hospital admission was needed. It happened; but not directly. The barrier of clinical opinion had to be overcome.

Another time when we – as carer husband and ill wife – presented ourselves to Shellharbour Hospital Emergency Department. The triage sister's stern words to a very confused sick person "Why are you here" were daunting and insensitive leading to demonstrated anger. The psychiatric registrar's conclusion "I'll give you some medication and then you can go home" leading to more demonstration. All that after we had already delayed our decision for several days and perhaps weeks before approaching ED. The registrar relented.

Now, we are fortunate that our psychiatrist is a VMO to the Service and can arrange admission. But even then admission can be delayed for months. Meanwhile we have to cope at home with a broken mind.

No one can blame the mental health service for failures. The broken leg will mend. There can be no guarantee that the broken mind will mend (and well we know it).

Eventually 'treatment in the community' means treatment at home; in our case a joint effort between husband, wife and psychiatrist.

3. A Mental Health Unit

I have tactfully omitted locations.

A mental health unit – more than any other – exhibits a great variety of patients and their particular needs and sensitivities; sensitivities to their environment; sensitivities to each other.

Hospitals remain a necessity. But the few hospitals that I know are not designed for peace of mind. The new mental health unit at ----- (it has been designed for architectural splendour) – is noisy. The unit is ever busy. Staff and patients walking hither and thither. It is not restful. It is upsetting and entirely contrary to a restful environment to heal the mind. It is open plan; no opportunity to withdraw from the turmoil of people walking back and forth, talking, sometimes shouting, but always busy. No quiet room that is sound insulated. The staff know it and regret it, the Director knows it. So how did this happen that no thought is given to the particular needs of people with mental illness?

This is not aimed at staff, but at the ambience and layout of the unit; staff are well aware of its shortcomings. If anyone has the right to be critical, it is staff rather than an outsider such as myself. Did staff have an active part in the design?

What do patients see other than TV? In my home I can see the trees and their movement with the breeze. It is peaceful.

Compare this with the sterile environment of the ward. Sterile but not restful. Nothing green and natural. No grass. No plants. No water.

4. A cautionary tale

What I have found these last few years when the New South Wales Government has invited expressions of interest from non-government organisations is the emphasis on something innovative (and that surely has a place for many communities of carers). But the mundane, the friendly ear and guiding hand that is the underlying aim and strength of my organisation that cares for carers, takes a lowly place. What government sees is not in the hierarchy of needs as carers see it.

Thus the likelihood of any inquiry (it is my own feeling and cannot be substantiated by any solid fact) is that it will create more paper, more courses and education (everyone is falling over themselves to design courses), but nothing that directly helps carers and families.

The ever increasing amount of information, and the reports and intentions and plans and inquiries and committees. A competition in volume, but even if of the highest quality and with the best intentions, there is about all this a lack of real progress that – to the misfortune of many – can be extrapolated well into the future.

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From the past. Extracts from the submission of May 2005 to the Senate Select Committee on Mental Health (submission 185):

5. The importance of sensitive admission to a mental health unit

The date is mid-1994. Since then, the procedure has much improved, but much is to be learned from this experience. Without vigilance and without the continuing training of hospital staff in the finer aspects of life beyond the purely clinical (of which more later), the same will happen again. In this anecdote the name of the hospital has been deleted. This is the text of a letter to the Director of Mental Health Services at the time.

Quote:

I hope that you will not take too much exception to my comments on the admission to ----- Hospital Psychiatric Unit which I experienced when I took my wife to the Hospital yesterday. When one is thankful - as I am - that a service is able to accommodate a patient at short notice, it is tempting to let the matter pass, and to accept the probable claim that staff are overworked. What is far more likely, however, is that staff are simply not aware of the impression which they give - however good the intentions - on a husband and wife already under great stress. However, let me start from the beginning.

My wife suffers from manic-depression, and the depressive phase hits her hard at uncertain intervals and for uncertain duration; and it did so again two or three weeks ago culminating in a telephone call yesterday to the Mobile Treatment Team, a service which we had not previously used.

The Team's response on the telephone was friendly, and we were heartened by their support. Two members quickly arrived at our house to listen to us, and to make an appointment with the visiting psychiatrist who agreed to hospital treatment and found a bed at short notice in ----- Psychiatric Unit. We are thankful for the prompt and considerate manner in which the Team responded.

2008: There is no Mobile Treatment Team. Access to treatment is a haphazard affair and may have to involve the police (and in our case has done so).

We arrived at ----- sometime after one o'clock and gained entry to the locked ward (we had been there before at a time when the ward was not locked). Someone was found to recognise that we existed, and we were asked to sit down and wait; and wait we did; and wait, and wait.

I found it interesting as an observer with a reasonably developed sense of humour nevertheless with some impatience, how my wife would receive attention (indeed some recognition that she existed at all). People passed hither and thither. Most ignored us completely; some looked at us fleetingly in the manner of "look what the cat's brought in". There was not a hint of acceptance or welcome. The more comical aspect was that everyone rushing from door to door was waving keys on a the end of a thong or a piece of string, sometimes twirling, sometimes aiming for the next door, but always the key and the lock, and the hope that we would keep out of the way and keep ourselves to ourselves so as not to interrupt the purposeful hurry of the staff. Had we been forgotten? "I'll go and find out. What's your name?" "The doctor is in conference (why don't they give the man a name?)"

Then suddenly the happy voices of people going off duty. Will we now be forgotten?. We need a cup of tea. The turnkey was summoned to release me, and summoned again to let me in.

It then became evident that this doctor without a name was seeing patients first before he would see us. No one told us this, but it became evident as patients and escort made their way towards the consulting rooms. The doctor appeared from time to time; we hoped that he would look at us just to give us a feeling that we existed; but he did not. New arrivals are left in no-man's land.

In due course the doctor appeared. I was ignored, but I tagged along. The family unit of man and wife had become a patient and an appendage. We entered the room. Then ominous silence for a while. No introductions; the doctor without a name. No introduction or explanation who might have been the unknown young observer sitting in on the consultation. The patient had become an item on the conveyor belt.

2008: I must interject that such an impersonal attitude has given way to better. I am now recognised as my wife's carer, and that I can explain her episodes more accurately than she can.

I have some reservations too on the use of the first name by anyone on the staff when first confronting a mature woman. Of course it puts her in her place as the patient now being controlled by powerful others. Why not recognise that people deserve the recognition of dignity, and allow the natural process of adopting first names between people who respect each other? Perhaps my sensitiveness on this subject derives from my experiences when sitting as a member of the Guardianship Board [now the Tribunal] when I would hear or read such matters spoken or written by hospital staff as "Nelly wets her bed at night". Why, for heaven's sake not give the old lady the dignity of the title and name?

Truly, my comments derive from a single visit; yet I feel that the impression gained by patient and family on admission is important; it may raise fears; it may calm. It is not my first experience of the Psychiatric Unit at ----- Hospital. Once it was not a locked ward, and there were not as many people rushing hither and thither waving keys and evidently hoping that no patient would impede their progress.

What is the impression of all this on a disturbed person already in fear. I know what it is because my wife told me; it is darkly threatening. I am also sensitive enough to know what it is without being told. I fear that staff and the service, however well meaning and dedicated to their duties, may not see the situation as a patient, already disturbed and frightened, will see it. A powerful system and powerful people have taken control.

End of quote.

6. The patient interview - a 1994 anecdote

That morning, I was a visitor sitting with my wife in the ward. A member of the staff appeared; he addressed her but ignored me, and collected her for her interview with the professionals. I rose to go with her. Even then, there was the hint of an objection as I did so; and at the door of the consulting room: "Not you; only your wife" - "Why not? We have been married for over 40 years. Why should we be separated now?" - "Hospital policy!". Frightening for both of us. The marriage vows have no meaning. We have lost control.

I can understand that a husband can be a nuisance when the psychiatrist wants to hear only the patient's response in order to assess the patient's progress, but such a problem can be overcome by sensitive treatment of husband and wife as a family unit. In our own case, I am my wife's carer, and that care continues after discharge from hospital. Yet in that past event, the value of that continuing care was ignored, and I had no role in her treatment and in the discussions in the hospital. Once admitted, my wife was controlled by powerful others.

When I was eventually allowed into the room, we both appeared to be the subject of a court hearing. A room full of people, strangers, students, no introductions, no dignity. The patient had become an exhibit.

Here then were two people, a very disturbed woman and her husband - both frightened - who were then expected to welcome the intrusion into their life of a host of total strangers to analyse her, judge her and control her.

That was in 1994. It is in the past. The story is stale, It is out-of-date and merely a reminder of how things were, and how we felt. Why then have I told it? Because I want to emphasise the need for the Service to recognise the value of others who care for, and who have a role in the treatment of the patient. Don't lock us out.

In these last few years, attitudes have changed dramatically; from our point of view for the better; but it helps, from time to time, to recall and to be critical of the past.

7. The health of the family - mental ill health and domestic violence

Excerpts from a submission of 14 November 1999 to Dr Jim Hyde, NSW Health. A commentary on: Review of NSW Health Domestic Violence Policy Discussion Paper - October 1999

Although written more than eight years ago, family conflict where there is mental illness persist for ever. What to do about it is likely to be a problem for ever.

I quote from parts of my 1999 text:

Some years ago, when sitting as a class (c) member of the Guardianship Board (now the Guardianship Tribunal), I was accused by the professional class (b) member of condoning domestic violence, an accusation that I have never forgotten. How did this come about?

The case before the Board concerned a woman with an acquired intellectual disability, her habits unpredictable, her speech limited and generally aggressive (whether she was aware if it or not). The application to the Board for the hearing had been made by a son and daughter-in-law who wanted their mother to be confined in a nursing home and her movements restricted for her safety; the husband, also present at the hearing, wanted his wife to remain with him at home. In this conflict, there was an accusation that the husband was violent towards his wife, which he denied.

Why was I a class (c) member of the Board? Because I have a son with an intellectual disability, and a wife with a manic-depressive disorder, a situation that has been with us since the birth of our son more than 40 years ago. With our other children - all now adults - we remain a close and happy family. In my situation, I was able to see the predicament of the people before the Board with an understanding of their situation which I tried to explain to the other two members of the Board at its deliberation after the parties had withdrawn. I was able to stand in the shoes of the husband.

Something that I had said provoked the rejoinder by the class (b) member, a qualified psychologist, that I condone domestic violence. I do not condone it, but I understand it, and have experienced the tension in a family when one partner may be depressed and irrational, frightened of any situation, panic at the simplest task, and at times very aggressive; at other times manic, irrational and aggressive. Provocation, loss of control, and violence is, in the acute phase of the disorder - either manic or depressive - often just under the surface. It showed me too, how much a professional person, a qualified psychologist, lacked an experience of real life, yet passed judgement.

How many women with a mental illness suffer their husband's violence because of their own change of mood. The husbands bear their mocking and their ridicule, their often irrational criticism, their temper and even their physical assault. I have learned to shut off; to let whatever is said pass through me without effect, and to respond as best I can.

How much of our situation need I explain to you without conveying the impression that I may have been guilty of assault on my wife (which has not happened), or that I am some sort of saint able to cope with a situation which has torn many families apart? When my wife is in her depressed phase, I do everything for her in our home. When she is in her manic phase, I have to guard her against her excesses. In the periods between - of uncertain duration - life changes so dramatically for the better that we can catch up with living again, and with friends whom we shed (or they shed us) whenever we withdraw.

Some of the sadness and the frustration of the person who is mentally healthy in a home where, for long periods all is gloom and silence, or anger and lack of reason, are of such a private nature that I do not wish to dwell on them in detail; they had best be put aside until the clouds of gloom magically vanish. Tomorrow will be a better day.

End of quote.

8. The elimination of stigma against people with mental illness and their families

Quote from a 2003 paper (perhaps somewhat philosophical):

The stigma surrounding mental illness is so strong, it places a wall of silence around the issue (quoted from a discussion paper 'Eliminate Stigma Plan' Illawarra Mental Health Community Partnership Committee - 2003).

And yet we speak about it often enough. It may not be a wall of silence; but a wall of uncertainty what to do about it. We cannot legislate against stigma and against opinions.

What follows may be a view of stigma somewhat different from what we usually read.

Consider some elements that influence people and thereby promote stigma against people with mental illness and their families. These elements are agencies composed of people and controlled by people; they are three components of the law.

The first is legislation, argued and written by people that might or might not have a good understanding of mental illness. It is written and it is the law. It is the *Mental Health Act* (NSW) 1990 which - in the manner in which it is written - so puts people with mental illness into a category apart from the rest of us that it creates a relationship between people with mental illness and the community that is stigma.

The *Act* promotes social stigma. The words in the *Act* alone promote stigma: 'Control', 'detention', 'to apprehend', 'the court', 'the magistrate', 'police', 'forensic patients', the association of the *Act* with the *Mental Health (Criminal Procedure) Act* (NSW) 1990 that leads to a perception that people with mental illness are criminals or likely to be criminals. And if the *Act* were better known by the community (I am glad that it is not), it would promote the association with criminality by a community always sensitive to aberrant behaviour and ready to lay blame on that disadvantaged group.

The second is the courts, the judges, the magistrates, the courthouse staff, any jury and any public present. The fact that a person having committed no crime appears before a magistrate because the Mental Health Act determines that it shall be done puts the person into a category apart from us, judged and controlled no matter what provisions the Act makes with the aim that the person with mental illness is not set apart, is not drugged, is dressed in ordinary clothes.

The person with mental illness accused of a crime, stands in a court of law not as would the rest of us. The courts have their own way of putting the person in his place no matter how diligently judge or magistrate follows the rules whether at a hearing in a hospital or in a courthouse. The person with mental illness is likely to be confused, and may be ill dressed and ill kempt. And even if the magistrate is unaffected by behaviour and looks, the public will see the person as different from the rest of us.

The third is the police, who, while servants of the law and the courts, are closest to the person with mental illness as one human being is to another. Their behaviour is a personal matter of tolerance. I believe that, in the relationship between individual officers and the person with mental illness, stigma and loss of dignity is no different for the person with mental illness than between police and any other.

There may be confrontation; but the stigma and loss of dignity is as the outsider observes the scene of confrontation between police and the person with mental illness, not as the police see it.

I must interject again when, in 2006, we had to call the NSW Ambulance Service to our home. The police were also present. I cannot speak too highly of the attitude and friendliness of the officer and his female companion. Their understanding of a fragile situation, their presence in the hospital until they departed with a handshake. I tried to express my thanks to the Wollongong Superintendent and to the Public Relations Officer. Neither were available. Neither call was returned.

Acceptance and inclusion is a very narrow band in the spectrum of behaviour and relationship that allows a person with mental illness (or with any disability) to be seen as normal; in other words to be accepted by those that see themselves as normal and worthy.

On one side of that narrow band of acceptance, the person with mental illness or disability may show great dignity, but I may be sorry for him because I know his problems. I may also be afraid to offend; and hence I behave towards him in a manner different from my behaviour towards someone who is like me. It is stigma.

On the other side of that narrow band of acceptance is the person with mental illness who might offend me by looks, dress, aggression and manner; and so I may not want to get too close.

The spectrum of acceptance is very narrow indeed. Every relationship on one side or the other is stigma, fear, rejection.

At any instance of time we cannot alter the person with mental illness. So how can we broaden the band of acceptance and inclusion by changing attitudes?

Language

We have made a start in writing and speaking about mental health rather than psychiatric illness. Even the change of order of words that puts the person first (it started with intellectual disability) will make a difference. Even so, the language of mental ill health hangs on and we cannot easily get rid of it.

We are saddled with labels. The tyranny of language; a language which follow us like the tail follows a dog. And this tail is wagging the dog.

Schizophrenia, itself a frightening word. Paranoid schizophrenia with all sorts of connotations. Electro-convulsive therapy. Involuntary admission. The Mental Health Act. Magistrates hearings. The Mental Health (Criminal Procedures) Act. Psychiatric hospitals.

the whole scene of mental ill health is full of argument and contradiction. We ask that people with metal illness not be stigmatised. We ask that families where there is mental illness not be excluded. But the whole scene sets us apart: locked wards, the paddy wagon, police at the door. What do the neighbours think?

Where does this argument lead: I wish that I had an answer to that. It can mean that that any plan to eliminate stigma can make some very strong proposals. It means educating (if that is the right word) those not already touched. Dedicated community educators for the dedicated purpose of alleviating stigma, prepared to roam the as yet untouched audiences. It could be non-government appointment or project; but I believe that such an appointment has a place in all area mental health services.

End of quote.

9. Forgotten people - dual diagnosis

They are alcoholics, perhaps because of some mental condition.

The taking of alcohol should not bar a person with a mental illness from treatment. A case history recorded some years ago:

A young mother (call her X) presented at Wollongong Casualty wishing to be admitted to the Acute Psychiatric Unit where she had stayed previously. She has a history of mental illness, and is now living away from her family (husband and two children). She told me that she had not been accepted by the casualty doctor because she was drunk, and was taken (by whom?) to the Detox Unit in Dudley Street, where she walked out after ?? days.

[PH: My question is whether the casualty doctor is the right person to form an opinion. The young mother is a friend; and when I saw her, I was not going to question her. Enough that she has a good psychiatrist who has referred her to a psychologist with whom she is happy.]

X had previously been admitted to Wollongong APU. X's mother, who knows of X's bizarre and erratic (even dangerous) behaviour in public, and her broken relationship with her husband, and her lack of sense of responsibility for her children, has tried to persuade X to receive treatment in a hospital; but without success. Mother was very happy that X had been taken by a friend to Casualty, but was distraught that X had not been admitted [hence mother's telephone call to me; the family are old friends].

X is on a pension, and is at times not capable of managing her money, blowing the lot on the pokies. X abuses her mother, but is at times on close terms with us, almost effusive the last time we visited her in her flat (with a bloke). She says (has convinced herself) that her children are all right, and that they can visit her any time in her flat; the older of the two, a 15 year old girl, has walked out of the home and is in the Wollongong City Mission hostel; the younger, a boy, lives with his father.

X took her own life in the year 2002.

10. The need for continuing sensible training of mental health clinicians and staff

This is training in matters beyond the purely clinical and administrative.

In various documents of NSW Health and area health services, families and parents of people with mental illness are recognised as an invaluable resource. But is the full meaning of those words understood?

The understanding is limited to the usefulness of carer and family to take care of a person discharged from acute care. There are still clinicians that do not accept the words of parent or carer as someone who knows the person, has known the person for many years, is able to give a truthful and accurate account of the persons behaviour, more truthful and accurate than the account given by the ill person, and is therefore an invaluable resource for information.

In the real world that one meets in a mental health ward, new staff and a new registrar may not realise this, and may not accept it. But having eventually learnt it and seen its wisdom, they move on to be replaced by new staff and new registrars; and the new registrar may well believe that he knows better than a parent with years of experience of a son or daughter.

So what happens in practice (from a real occurrence)?

There is a disaster in the home, an episode that is violent [not the home of the author of this submission]. The crisis team is called and may turn up or may ask the family to call the police, or the team may turn up with the police. The ill person changes his behaviour to give the impression that he is not ill. The crisis team believes the person and not the family and walks away. Added to this is the difficulty of language, The father's English is difficult; mother has none; the violent son is well able to explain himself to the crisis team and to the police.

If the parent takes the son to emergency, the psychiatric registrar may ignore the parent's views and declare that the son is not mentally ill.

Thus there is a need for continuing forceful orientation (indoctrination) for newly appointed staff to give parents, families and carers the recognition as a source of knowledge and recognition as support for treatment when back home. The family is the person's past and the person's future.

11. Report on a Public Forum of the Select Committee on Mental Health - NSW Parliament House - 7 August 2002

Early in 2002, the New South Wales Legislative Council's Select Committee on Mental Health called for submissions to its inquiry into mental health services in New South Wales. After receiving nearly 300 submissions, a large number from private individuals, the Committee decided to conduct a mental health forum on 7 August at which a selection of people and organisations that had presented submissions would be able to present their concerns.

In the event, more than 20 people made their presentations on the day to a tight schedule of 10 minutes each, most of them parents and relatives of people with mental illness. Only members of the Committee were allowed to question the speakers.

The submission that I had written concerned the *Mental Health Act 1990*, and the *Mental Health (Criminal Procedure) Act 1990*, and the way that these Acts promoted the stigma against people with mental illness. Hence the subject of my presentation on 7 August concerned stigma, its many forms and reasons for it, and what little we had done to alleviate it.

Report on the Forum of 7 August 2002

Committee members present at the forum: Dr Brian Pezzutti MLC (Chair), Peter Breen MLC, Dr Arthur Chesterfield-Evans MLC, Amanda Fazio MLC, John Jobling MLC.

In this summary of the day, I cannot portray the intensity of presentations by more than 20 speakers, the great majority being parents telling their personal stories of sons and daughters, some that had ended their lives by suicide, others were in prison, others on the streets. The day was one of emotion and - I believe - that this emotion was shared by members of the Select Committee.

My own presentation on Stigma (and what little we have done so far to tackle seriously its alleviation) would have made little impact had it immediately followed the real life story of a family in crisis. Fortunately there was an unscheduled break before my presentation.

If I were to analyse all that was said, and so present a list of issues, concerns, and unmet need, this would be a cold and sterile list in no way expressing the feelings of parents and others at the forum, and in no way expressing the severe stress and sorrow in which families are placed. I, therefore, give you what was said, unidentified and shortened; hoping that the force of individual presentations is not lost.

I have omitted my own presentation.

What was said

- No open disclosure of adverse events. The mental health service cannot be seen to be at fault. The need to redefine 'negligence'.

- The value of Clubhouse: but its survival depends on lobbying for funds each year with uncertainty that the service will continue. Lack of funding keeps the community at a distance.
- Money allocated to areas is not open. How much money does each area get? Lack of funding for long term support in the community.
- Need for early intervention. Family support. Lack of response by local doctors in country areas. A brick wall. Lack of knowledge by doctors.
- Parents not consulted. Confidentiality; "none of your business".
- No help with D&A. No treatment of mental illness because of drug addiction. The boundaries between mental ill health and drug addiction.
- Struggling families. Privacy keeps the family at a distance. Families not informed. "We cannot tell you. Confidential".
- Failure to admit and to keep the person in hospital for an adequate time to stabilise. Need for a separate Mental Health Emergency Department.
- Employment services, the meaningless concept of time when asked to report. The meaningless concept of time for a person with mental illness instructed to keep to time in anything.
- The person's civil rights not to be treated or to discharge himself; this against the need for adequate time for treatment. Services hide behind the civil rights. Discharged or pushed out into the community to satisfy the civil rights.
- Need for police training.
- Reluctance to schedule a person, claiming that this contravenes a person's civil rights. Challenge to the concept of community treatment: Back into the community means back to a family that cannot cope, or to the streets or boarding houses without supervision and support. No case management.
- Country; no professional support from GPs and others. They do not have the knowledge.
- Acute wards far too small, cramped, no private space, too crowded. Son confined in that space for 11 months. How can a person who is ill recover in that cramped ward?.
- Lack of case workers in the community. Need for much more client-case worker interaction. Need for case workers to help the client to find work. Need for easier admission, not to wait until there is a crisis (the client at death's door).
- Departments spent too much time deciding what to cut.
- Son's paranoia that police must be in the conspiracy against him. When the family in crisis asks for help, police and the crisis team never arrive together. Urinating and faeces.
- Carers' rights. Carers' network. People with mental illness treated like criminals. Bad experience with the service. Control by legislation and words. Too many words. Fix it by legislation! Mental health cannot be cured by legislation. Need to review the legislation together with consumers. Carers taken for granted. Carers are too often blamed by professionals for causing the illness. Cost to carers. The hidden costs.

- Carers need information. Carers have no voice. Carers need time out [respite]. We have the right to know how funds are distributed, the right to monitor and to evaluate. Carers are a high priority.
- Son 20 years. Case manager would see him next Wednesday; retreated to his room; four hours later he had committed suicide.
- History of suicide attempts, jumping off the Harbour Bridge. No treatment. Where is the duty of care by the service? Comment from staff to the parent on the suicide "it was bound to happen one day".
- Dropped from a therapy program because he did not turn up for the specified number of meetings while severely depressed. Stayed in bed. No regular monitoring of clients. Compare this with hospital treatment for any other illness.
- Funding cuts to essential day and therapy programs. Cut to arts therapy program.
- Mental Health services, although knowing that a client is at severe risk of suicide, will not admit or treat him and stabilise him. Duty of care mentioned by several speakers.
- Son living in a tent. Refuses medication. "Schizophrenia is a journey that people go through"; "they must be supported".
- From the Country. They have set up a cottage or lodge from their own resources. People out of hospital or institutions, or out of their home district who have no family to which to return are accommodated there. A 6-room building staffed by volunteers, comfort, clothes.
- People in the community: No one to talk to. They live on their own; no one to care for them.
- Daughter: Schizophrenia. Permanently scheduled. Devoted family. The unappealing inside of an institution. Separation of dual diagnosis. Rights in conflict with treatment. Absconding.
- Need for a centralised database accessible to ambulance, police, and professionals (Committee questioned the confidentiality of such a database). Need for a case manager appointed by the State and for a secondary guardian appointed (or chosen) by the person as decision maker.
- Absconding leading to attempts of suicide, jumping off a balcony and jumping in front of a lorry. Discharge planning without involving the family.
- A 27 year old with schizophrenia left home, the law, the court, hospital, released into the care of parents even though not stabilised. No answers from the hospital consumer advocate. Answers avoided by claiming confidentiality. Second boy in prison; intellectual disability dual diagnosis (has been diagnosed with the intellectual ability of a child of 10 years 9 months); has been assaulted; has injured himself and hence labelled by staff as an attention seeker. No counselling in prison, no treatment. On his own in a cell (he is a loner); no TV.
- Confidentiality - no information - send them home.

- Son diagnosed with schizophrenia. Parents had expectations of the mental health service: To be invited and consulted; that son would have hospital care; that son has proper rehabilitation; that rehabilitation means return to the community healed and well. No expectations satisfied.
- Driving a car under the influence of voices and paranoia. Parents' home damaged; call for the crisis team; doctor either on weekend leave or on holiday. Family not informed when taken by police to hospital. Discharged without warning the family. Should have been stabilised before discharge.
- Challenge to the concept of treatment in the community. People with mental illness are isolated in the community; financial loss to the family.
- Country. No mental health service for a son. "Ring the police". Burden on carers. Funding now aimed at children and the young; never at the older patients. Psych episode; damaged a restaurant. Section 27 admission.
- Son, Schizophrenia. Killed by a close friend who also has schizophrenia. When they call the mental health system, parents are told that nothing can be done until they are a danger to themselves or to others; by that time it is too late. Had approached D&A service 8 months before; "nothing can be done". No notice taken by the mental health service of friends and relatives.
- Two sons. One with schizophrenia, the other bi-polar. One lives on the streets of Sydney. Always dirty. Claims to be the Messiah; crucified and with scars on his hands. Salvation Army tried to find him a job. Tried to strangle his brother. Condemnation of CTO. "they are let out before they are well". The service will not act because it is against the person's civil rights.
- Kept in hospital for a few hours, then returned home. Most suicide attempts occur after hours.
- Mother with early dementia. Abused but abuse not admitted by staff. Health Complaints Commission . No accountability. No action and no answer on complaints. Fear of mental health workers. Afraid to speak up. Need for independent advocacy. Scrutiny of professional practice.
- A person with mental illness: Complaints not taken seriously. Depression. Locking her in rather than rehabilitation. Sadistic abuse. Patients not taken seriously. 15 minutes to achieve a misdiagnosis. "You will grow out of it". Glasgow has a stress clinic. Free therapy services in NZ.
- Son stopped going to school. Slept all day. 15 year old boy. Told mother she deserves to be shot. Everyone told me something different. "There is nothing wrong with your son. Get him off marijuana". Mental health service does not listen to the family.

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