

FAMILY AND COMMUNITY

DEVELOPMENT COMMITTEE

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**INQUIRY INTO SUPPORTED ACCOMMODATION
FOR VICTORIANS WITH A DISABILITY OR
MENTAL ILLNESS**

MORWELL

THURSDAY, 21 OCTOBER 2008

MS DOUGLAS: Thank you. I'm Lynne Douglas, as has just been said. I have a son who has a mental illness. He's been ill for 25 years. His diagnosis is of chronic schizophrenia, which means he has symptoms all of the time, and that was – he had a motor bike accident, so I must admit this part of me is a little bit mental health snob. His was through a trauma, not through self-induced drugs. He has a loss of cognitive function due to his illness, to his medication, to the trauma, possibly all of the above.

I manage all of my son's financial affairs, because my biggest fear is on him becoming homeless, which has nearly happened many times. He's been in debt, writing bad cheques, behind in his house payments, no money for food, etcetera. My husband and I brought him back into our home five times where we had to re-outfit him in clothes, in goods for his house, when it was time for him to go back to his house because everything just gets trashed. And of the things that happens when they're unwell is that – he's very fastidious in his person, about his house and everything else.

In fact, I have to clean up my house when he's – well, for him to come and visit me because he'll have something to say about it. Dear, I should have just been reading. What I want to say is, I know you said that the hospital and secure extended care is not to be included in the submission. But I'm going to say, I really don't see how you can exclude them because of the very nature of mental illness. The very nature of it disqualifies them being not included. It is known that the sooner an episode is treated with a change of medication and the safe environment for this to take place, the better the outcome.

And that unless this happens, the more ingrained the paranoia becomes, which is exactly what has happened in my son's case. The fact that we only have 25 acute care beds, six CQ beds and two adolescent beds in the whole of Greater Gippsland, from San Remo to the Coast, dictates to the conditions that they live in when they are unwell, and are unable to take care of themselves and unable to get into hospital. And I mean, unable to care for themselves in an appropriate manner with or without support, and that's why they need a safe place to go, because mental illness isn't just, we're unwell here and then we're better. It goes in cycles.

The need is getting – is great and getting greater. It's not something that's disappearing. Numbers of mentally ill are increasing. And even when they're in hospitals there are times that they sleep in caravan parks, motels and then come on the ward during the day. My son has had his illness, as I said, for 25 years and, over those years, has got steadily worse because of the lack of intervention or, dare I say, lack of hospital beds. And I so admire my son, because it really takes real guts to live with this illness.

Even when Hobsons Park was opened, and before that was sort of drawing to its final stage, there was one time when he was admitted by a GP and the nurses. Those that knew him because he was unwell. But when he was seen by a psychiatrist the next day he was deemed not to meet all the criteria of needing treatment, or restrained treatment, and so he got sent home. When he went home he smashed all the windows in his house. When, again, we couldn't get him into hospital, even though that had happened. When we finally did get him in I was the one who had to go and wash all the blood off his walls. I did kick up a big stink about that.

I wrote to the Minister, I had public advocates involved and everything else. But, guess what, the system did all the right things. There was no-one who would take the responsibility for my son to be treated. We have struggled for years with the ups and downs of his illness, and with the system. There is a lot of anger and frustration among both the clients and the carers in not being able to get help. And I mean appropriate, well timed help when it's needed. To be told, Lynne, I know he is unwell, but we have people who are much sicker than he is and we can't get them into hospital.

That went on for six months with my son declining in health. He went from being 120 kg person to 69 kilograms because he thought his food was – because of his delusions and paranoia – he thought his food was poisoned, smelt and – and you could prove it by how it smelt and how it tasted. The water in his taps was so contaminated he couldn't wash his floors, and, in fact, couldn't wash himself because it was so contaminated. He was unable to care for himself. In fact, in the end of the six months, he became such a danger to himself he was placed on a community treatment order, and they had to hospitalise him.

When we rang the hospital to see, even then, if there was a bed, we were told there wasn't even a bed in the State. Someone did have to go home because we did get him in, but someone had to go home for him to get in. I had been told the hospital is only for acute care to get them over the crisis stage. They are then to be discharged and the community has to pick them up and get them well. The community is the PDRSS services – Psychiatric Disability Rehab Support Services, and their case manager who are worked into the ground having 15 to 25 clients depending on experience.

You have someone who is sick and they have to pick up other clients. A policeman came and spoke to a group of us. He said they will pick up people knowing that they are unwell, they're walking the street, or getting into trouble. They would take them to hospital only to be told they are not well enough to be admitted. They don't meet the criteria. The police's role is to take them to the hospital, but not to shop for a doctor. The police know they need help, but don't have anywhere to take them themselves.

So what do they do except be ready for the next time they're called or to pick them up. My son, a couple of times, had to be picked up in the streets because he's just gone wandering and they're – he's done well. It's no secret that the homeless situation has increased dramatically among the mentally ill. And nor is it a secret that some of our mentally ill are in our presence. I have spoken to a worker from another service who deals with the homeless, many of whom have a mental illness. Those who, for whatever reason, don't have anyone to support them. These are the ones who fall through the cracks.

They must be pretty big cracks for them to fall through, and my son falls through the cracks and I fight 24/7 for him. They have trashed their rented places of residence, and don't have their – they don't have their mum's to go in and clean up for them. They go into hospital and then have no place to go when they are released. They try to advocate for their clients with the landlord to pay rent arrears etcetera. They will

be having to pay rent in advance if that doesn't work. And if that doesn't work then they seek to find transitional housing for them.

Elderly persons units is one of the first bases they try, which I hope you will agree is totally inappropriate for both the aged and the mentally ill. Or caravan parks - they have to give them money to buy food and clothes. As I said, one of the symptoms of the illness, they just lose all interest in keeping themselves right. They just so totally neglect themselves. I have bought clothes for my son when he's gone into hospital and he won't even take them because they're not his, or he'll wear them once and wash them and then won't go and get them because they're not his. He doesn't identify them. These are some of the things that we have to work through.

I asked this worker, if given a wish list, what would she want. The answer was that there would be appropriate housing be available. Not three bedroom places for someone who has a mental illness. Don't just lump them all in together in one street without assistance, and please don't put them in the same area as those just released from prison, because another aspect is that these are very vulnerable people and very often so easily taken advantage of.

My son was admitted into hospital on Boxing Day – and I'm – this is abbreviated, so you'll be glad about that, because the whole of '06 was traumatic. There's no other word to describe it. He was admitted on Boxing Day on '06, after the worst Christmas of my life, by his case manager because he was so unwell. We had been promised a bed in the secure extended care unit early September '06 for a change of medication that was urgently needed. Medication that required constant monitoring and still requires monitoring.

It was his psychiatrist who wanted the change of medication. And even though his psychiatrist wanted it, even though it was very obviously needed, we still could not get him into hospital. Why? Because there were no hospital beds. And my son was the one who was suffering in the community. And, I mean, suffering, really suffering. Hearing voices constantly all of the time. Again, the food and all of these symptoms are now set because he didn't have treatment when it was needed. Because the hospital beds weren't available, and because he couldn't go into hospital and have the change of medication.

You know, I was reading this out and I thought, who can I sue over this. That would be nice if I could but, you see, you can't. But that's criminal that that has happened. Sorry, I'm a little emotive about it. Anyway, he actually spent three months in Flynn, then he was put into CQ for another six months, and then he has just spent 12 months in the new CRCU units, where, I must say, the care was excellent. And with assistance on a day to day basis, it was 24/7 care, that they were there available in the office.

They had their own units, their own TV, own cooking – they pay rent which covers their electricity, and their rent. They go and buy their own food. But because they lose all their social skills it can even include sitting down and making recipe – thinking what we're going to have for a meal, making shopping lists, budgets, how to wash a fridge out. Even though I know that I have taught my son all these things, they lose their skills when they're unwell and untreated.

The program that they have at the CRCU is called Stepping Stones, and the staff there got to know the strengths of each client. And this goes into what sort of appropriate support they really need. They got to know the strength of each client and the areas that they needed extra help. Remember the loss of cognitive function is one of my son's disabilities. Social skills was very important for him to learn. How to say hello to somebody. He'd lost the skill to do that because he was hiding from people. He didn't want anyone – he went home one time and played his music really loud and waited for three weeks for the police to come and pick him up.

This was all a time while we were waiting for him to get into hospital. He's been discharged, and that was about six weeks ago. He's not cured. He still has all of his delusions. The medication that he's on is the last one that we can try, but because he almost had a heart attack on it we can only go up to 250 milligrams and not the 350 that they would like to be, but there's nothing else that we can have. So pray for another medication. There is one PDRSS service that visits my son in his home three quarters of an hour a week, but if they, again, have one or two staff ill then a spanner gets thrown in the works.

His case manager visits once a fortnight or more if I ring him and tell him I'm concerned about him. He has a blood test and sees the doctor once a month. So from 24/7, his direct care now from services is one hour a week, with another possible PDRSS support of six hours if he is well enough to go and attend their activities. They say that they have to choose to go there, but it's more – always not a choice. It's if they feel they can cope with their illness at that time.

There are 14 CRC units, but that's hardly a drop in the bucket. It's not enough. 14, again, for the greater area of Gippsland. When David was ready to go into the units we were told we had to make up our mind because there was - I wrote high – because they already had a waiting list and they were just newly done. I asked my son what was the best thing about the village, and he – about the CRCU, and he said it was a village like atmosphere. You had your own personal space, and had a garden area, but also had supervision and plenty of support. He felt safe.

The hospital, you know, received the funding for the units before the units were built. So rather creatively they decided to use the staff by going into the community and provided some extra support in clients own homes. At that time they were visiting 130 clients, but that ceased once the units were built, and they went back. I wasn't happy about that ceasing, I must admit, because, once again, they were using the same program of going into the homes and helping with budgets. Doing simple things like getting music from a computer, or putting it on a little MP player, and that sort of thing for them.

It was a genuine help of life skills. Those services are needed. You can't have one and the other. So I'll just go back now. All right. Can I just do this one half page or not? Or you want me to just give it to you?

MR SCHEFFER: Just give it to me.

MRS POWELL: Probably give it to us, yes.

MS DOUGLAS: Okay. All right, then. Thank you.