

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into the provision of supported accommodation for Victorians with a disability or mental illness

Melbourne — 5 November 2008

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Witnesses

Ms A. Burgess, secretary,

Ms N. Lindner, member, and

Ms C. Jackson, member, Peninsula Carer Council; and carer consultant, Peninsula Health; and

Associate Professor R. Newton, member, Peninsula Carer Council; and director, mental health services, Peninsula Health.

The CHAIR — Welcome to the public hearing. I invite you to give a brief description about your organisation and what you do, and then to make your verbal submission.

Ms BURGESS — I am Aline Burgess. I have been a carer for 25 years, and I am the secretary of the Peninsula Carer Council (PCC)

Ms JACKSON — I am Carmel Jackson. I have been a carer for over 25 years, caring for three people, and I am currently carer consultant for Peninsula Health.

Ms LINDNER — My name is Nyorie Lindner. I have been a carer for eight years, and I am a member of the Peninsula Carer Council.

Assoc. Prof. NEWTON — My name is Richard Newton and I have been a psychiatrist for almost 20 years. I am the director of mental health services at Peninsula Health; it is a state-funded area of mental health services attached to Peninsula Health.

The CHAIR — Thank you very much. Who wants to start?

Ms BURGESS — I have been a carer of a son with mental illness for over 25 years, and we go back to the days when you had to travel almost 2 hours across from the peninsula to the big hospitals — you know, the Mont Park, Larundel and Plenty hospitals. We know the situation has changed, and since deinstitutionalisation these services have been set up, but the thing that has not changed, the biggest disappointment, is the lack of affordable, quality accommodation for people with mental illness.

I think one of the saddest consequences of this is the increase in homelessness, and it is noticeable in Victoria. I know the jury is out as to whether mental illness causes homelessness or homelessness causes mental illness, but there is no argument that homelessness has increased, and also there has been an increase in our jail population. We have carers whose sons, daughters and husbands have been involved in the criminal system when it is an illness.

We are reaching the stage, I think, when we know there is a high percentage of people with mental illness, and we are horrified when we see that there are plans afoot by the government to build new prisons. You know, we are almost going back to the days of 18th century England when they were looking for the hulks and somewhere to send the convicts instead of tackling the issue that was there.

I know from the director of operations at Peninsula Health, who was working in London before, that when the Institutions for the mentally ill closed in England it was mandatory — whether or not it was carried out completely we do not know, but it was supposed to be mandatory — that an equal number of beds would be provided in the communities so that there was somewhere for those people to go. Here so many of them returned to carers — I am talking about the seriously mentally ill — or to the streets, becoming homeless, or to jails. That is a big worry.

The Peninsula Carer Council was launched four years ago as a result of an initiative by the mental health services. They wanted to hear about the situation from the perspective of carers. Our initial equipment came from a state government grant that was given to us when Bronwyn Pike was Minister for Health; the equipment was first used in our garage at home.

But now we have a monthly Support Meeting; we have a referral service; we have a very small office; and we have all volunteer workers. We have swelled to 102 members. The outline of how it has developed is there in the appendix to your material. It is those 102 members and also the other carers who asked us and pleaded with us to come today; they are listening to know what we are saying, because every time we go to conferences and forums and the mandatory sort of butcher paper comes out the first issue is always the lack of available accommodation. We believe in a country like Australia it is really unacceptable that that should be so.

The Peninsula Carer council has been involved for the last three years, in collaboration with Peninsula Health and Monash University in Frankston, in providing statistics relating to the lack of accommodation for people with mental illness in Frankston. We can do the anecdotal evidence easily, but for the DHS and for your purposes we have to get the actual statistics, and when you are working with a university it takes a long time because they, probably rightly, dot every i and cross every t, and it has to be done properly.

The mapping exercise has been done. The result is as was expected, that there is a deplorable lack of supported accommodation for people with a mental illness, and we are working hard now to work out and provide the next step, which is establishing the gaps that are there. As you will hear from the case studies in a moment, the number of homeless people in the area would be even greater if carers did not take on that 24/7 sort of responsibility for their people.

At the same time the Mornington Peninsula Shire, with its offices in Mornington, Rosebud and Hastings, has been conducting a survey on the homeless in its area. This has been a case of signs down for Victoria because there have been comments even from tourists in the area about the number of homeless who are quite obvious on the Mornington Peninsula. The report the shire council has written is titled *Speaking Hard Truths* — I have put extracts of it as an appendix in the material you have been given — has not yet been published, but we had permission from the shire to present those extracts to you today; in fact, the shire was delighted they would get publicity.

As you will see there, the shire interviewed 50-plus homeless people and the services that were going in to support them. Even on the foreshores of the peninsula there are tents set up that are obviously used by the homeless. It is a situation that I think, again, is completely unacceptable. As one of the studies from our own carers will show, a mother of a 27-year-old son who was seriously mentally ill was discharged from hospital several times. It was no longer possible for him to go back home — it was not a tenable position for him to go back with his mother — and he became homeless. He was referred to the Frankston Crisis Centre for accommodation, and the accommodation that was offered to him, which he took, was a tent on Sorrento beach. So the situation is really very serious. Carmel will tell us about further case studies.

Ms JACKSON — The impact on carers is huge, to say the least. Their own health suffers; it is usually blood pressure, heart problems, stroke, and all sorts of problems from stress for the carer; and their personal wellness suffers from caring for someone 24 hours a day, in some cases seven days a week. People with mental illness may be socially withdrawn and depressed; they may be alienated from their carers, suicidal and psychotic. They have periods of wellness as well, but episodes of unwellness, and that is really hard on the families, especially on the main carers.

Many carers are getting older and are greatly concerned about what will happen to their loved one when they are unable to do that any longer. Many people do not have someone to care for them. They are not all fortunate to have carers like ourselves to support them.

A percentage of mentally ill people cannot support and look after themselves. There is virtually no supported accommodation on the peninsula for people with mental illness. I would like to relate some case studies of some of the carers who come along to the monthly Carer Council Support Group. I will read these for you because there are quite a few — if it seems overwhelming or too many, I will just stop.

The first is the case of a young man in his late 20s suffering paranoid schizophrenia. He was evicted when he was behind in his rent payments. Carers made sure the unit was in a pristine state when he had to leave, but the agent warned the carer and son that neither of them would ever be able to rent again in the Frankston area.

The second one is of carers both in their 80s who found supported accommodation for their middle-aged daughter with chronic mental illness. The accommodation is inappropriate, but the cost exceeds her disability pension. The parents, aged pensioners themselves, are struggling to meet the balance of the accommodation costs.

Another case is that of a family with a young teenager that is finding it increasingly difficult to cope with the behaviour of their son who is in his early 20s. He suffers severe depression and schizo-affective illness. The family has become dysfunctional, verging on break-up. There is no appropriate accommodation available.

Another one is the case of a parent in their late 70s who has sought for years some quality, affordable accommodation for their son. He has a dual diagnosis: an intellectual handicap, plus chronic paranoid schizophrenia. He is now in his mid-40s. No appropriate accommodation was found. The parents finally set up a granny flat on their own property.

Another case is that of a man in his 30s who suffers from bipolar plus drug addiction. He was hospitalised after a suicide attempt. He keeps returning to his single mother, requesting accommodation — like, to come back home.

The mother, afraid of his outbursts et cetera, refused to provide accommodation. He sleeps in his car in various places. Do you want me to go on with some more? Shall I keep going?

The CHAIR — Yes, you may continue.

Ms JACKSON — This one is the case of parents in their 90s who moved to a unit. The son, who suffers bipolar and schizo-affective disorder, was moved to a nursing home after discharge from a psychiatric ward. His aged parents paid the balance of the accommodation.

Another is of a son in his mid-30s who was discharged from a psychiatric ward. The mother was subjected to violence and had to take out an intervention order. The son, homeless, attempted suicide and was hospitalised again. When discharged again, the only available quality accommodation was a privately run accommodation lodge, which he could not afford — it was \$330 a week. He was finally organised in lodgings in an unfurnished room in Rosebud, sharing a kitchen and bathroom with seven other males, with no meals and no food provided, at \$110 a week — for virtually a room.

Another case is that of an 84-year-old grandmother who was sole guardian of her grandson, whom she had had since his early teens. He had attention deficit disorder. He was frequently hospitalised. He became very aggressive and dangerous. The grandmother could no longer provide accommodation for him. The grandson became homeless. His violent behaviour caused eviction from a caravan et cetera, and he became homeless. He frequently returns and harasses the grandmother.

The last one is a single parent with a 27-year-old son who has a dual diagnosis. The son refuses to allow his mother to be involved or informed. He is frequently hospitalised, and discharged without the mother being notified. He was sent to the Frankston crisis centre, which turned out to be a tent on Sorrento beach. He was removed from there as well.

These cases are just the tip of the iceberg. We have support meetings once a month, and that is where this data is gathered from. Carers come along for support and talk about their cases. A lot of young people come there too. Carers tells us they come into contact with police and become homeless. Some are in jail. They need more affordable accommodation.

Assoc. Prof. NEWTON — I have been asked to come along and speak a little bit about mental illness as a disability, so far as I understand it, within the definitions of this committee's reference. I would like to thank Peninsula Carer Council for inviting me to participate in this. I would also like to thank the committee for inviting me as well.

It is well understood by everybody who has looked into this area that mental illness and accommodation are closely interlinked. You cannot provide good mental health care and have good mental health in the community without having a system of supported accommodation. It is very obvious when somebody has schizophrenia, bipolar illness, manic depressive psychosis or who is hallucinating or deluded and behaving in a very disorganised way that they have difficulty maintaining accommodation, and often end up losing their accommodation, their job, their occupation et cetera.

I think what is much less obvious to the general public is the impact of long-term psychotic illnesses on somebody's ability to maintain their day-to-day activities of daily living. One per cent of the population has schizophrenia, and of that substantial group of people within the community with schizophrenia at least one-third will have a long-term illness, and the longer they have that illness and the more often they have a relapse of their illness, the more they develop a series of deficits to their ability to maintain their activities of daily living. They lose their motivation progressively as the illness progresses. They lose their ability to think; they have fewer thoughts in their head as their illness develops. They lose their ability to feel and share emotions and empathise with other people.

These things are not obvious in the way that they are in somebody who might be wheelchair-bound or have an obvious physical deformity or disability or obvious cause of a disability, and often even carers struggle to motivate their relative or to understand why they are not cooking or cleaning for themselves and tidying their house. Even simple things like washing become a struggle. If the families struggle then, it is perhaps not surprising that the

community as a whole sometimes struggles with the idea that schizophrenia causes terrible disabilities in these areas of being able to maintain yourself as an able person and maintain your accommodation.

We know that our prison population has increased, probably in direct proportion to the reduction in the number of places in long-term psychiatric hospitals. In some ways we can think of our prisons as being de facto supported accommodation, which is very poor and inappropriate for many people with long-term psychiatric illnesses.

Within Peninsula Health we looked at the factors that led to readmission to the acute ward of people who had previously been treated there and who came back within 28 days. We did this using a very rigorous methodology. The two causes of readmission were substance abuse — usually cannabis or speed and alcohol — and not taking their medication. That is fairly simple stuff to understand. But we then looked at the underlying causes for their non-compliance with the treatment and their substance abuse, and the single important factor that fell out of that analysis was a lack of appropriate, stable accommodation.

We had 17 discharges a week. Of those 17 discharges half of the people we discharged were discharged to unstable accommodation. We can therefore expect that those people are at much greater risk of having further relapses in the very near future after discharge than people going to stable accommodation. Within the peninsula itself — unlike some areas of the city that are quite well resourced with non-government organisations and supported accommodation — we have very little. We have three supported accommodation special residential services that provide, with persuasion, services to people who can only afford the pension. That is three for a population of a quarter of a million. We have a handful of beds, or places, in the accommodation supported by PDRS, and we have 20 long-term beds in our CCU, and that is really it for the peninsula. I think there is a global issue about disability and mental illness, and there are very specific issues which I wish to highlight around the peninsula as well. Thank you.

Ms LINDNER — I will just quickly mention our suggested options. We believe there should be a range of options available to people with a mental illness. The first one is what we call step-down accommodation following hospitalisation. As Richard mentioned, many people are still very unwell when they leave hospital. Sometimes they have unstable accommodation to go to; sometimes they go back to their carer. But even if they go back to their carer, they are often ill-equipped to handle someone who is still quite unwell. We believe that some kind of step-down accommodation following hospitalisation is essential.

The equivalent of short-term accommodation now is the community care units. They are really required to help some people, who are able to live independently but who do not have those skills currently to learn how to look after themselves and learn how to live independently. But as I said, that is short-term or transition supported accommodation.

One of the areas which really is sorely lacking is permanent supported accommodation. There is very minimal permanent supported accommodation. As mentioned earlier, many carers are getting older and cannot look after people. There are also people who do not have carers. There are a lot of people with a mental illness who would like to be able to live on their own but who do not have either the skills or the financial resources to do that, and that is where permanent supported accommodation is needed.

The other option is where people are actually able to live reasonably independently but may need somebody to call around once a day or once a week just to see how they are getting on, work out if they are showing any signs of a relapse, and help them work out what to do if they are. It is a kind of regular support, but not 24/7. These people may need some kind of rental support to ensure that if they do have some difficult times they can maintain their accommodation. It might be in the private rental market; it may not be government-provided or sponsored accommodation, but it may be underwritten or guaranteed by somebody — by an organisation or by some sort of funding — so that when they cannot support themselves for a short time that safety net kicks in until they are able to look after themselves again.

Ms WOOLDRIDGE — Thank you very much everyone. Richard, you mentioned 17 discharges a week, was it?

Assoc. Prof. NEWTON — Yes.

Ms WOOLDRIDGE — And half into unstable accommodation. How many do not get discharged? What is happening in terms of your acute beds, because you know that unstable accommodation might be the only option?

Assoc. Prof. NEWTON — We use our community care unit as a place for short-term rehab rather than using it for its original intent, which was as long-term accommodation. We have been fortunate in being able to maintain our acute beds for acute need, but I know that in many hospitals many of my colleagues tear their hair out that the beds are becoming progressively with long-term patients.

Ms WOOLDRIDGE — And you are discharging to the CCUs, so instead of them having the six-months experience or whatever they are going there for — or a few weeks — it is operating like a PARC is it? It is operating like the step-down that you have not got? I am just trying to understand — —

Assoc. Prof. NEWTON — I do not think that is quite the case. We have been earmarked for a PARC, and we have just interviewed for an NGO provider to work with us on a PARC, so it will be coming. We use our community care unit — about half of it is used for true long-term support. We have a terrible lack of long-term support on the peninsula, and really we need all of the beds for that. The rest we use for much shorter term stays of between six weeks and six months.

Ms WOOLDRIDGE — And the long-term support would be what sort of period of time?

Assoc. Prof. NEWTON — We have had people who have been there since the CCU opened.

Ms WOOLDRIDGE — Which was? Sorry, just roughly, are we talking 2 years or 10 years?

Assoc. Prof. NEWTON — In 1995.

Ms WOOLDRIDGE — We are talking 13 years.

Assoc. Prof. NEWTON — Yes.

Mr NOONAN — Can I draw on your professional experience? We have heard a lot about schizophrenia from a number of witnesses throughout particularly this day. In light of the solutions in terms of the various types of accommodation — step-down, short-term, permanent, individual living — I am just trying to come to terms with the social aspect of a disease like schizophrenia and what might be considered the best type of living arrangement at various stages from a clinical point of view. I am sorry if that is an all-encompassing question. We are talking about accommodation with support, but I am just not sure that I understand it clearly enough from that point of view.

Assoc. Prof. NEWTON — I think the needs of a young person who is newly diagnosed with schizophrenia, who often has multiple comorbidities, with drugs and alcohol, and who is coming off their previous life trajectory, they are losing the ability to hook up with vocational training, they are losing the ability to maintain relationships, their accommodation needs, I think, are quite different to somebody who has had schizophrenia for 30 years, who has a very widespread negative syndrome and needs an awful lot of quite intensive support to maintain themselves. One group needs containment and assistance with medication and really assertive support, and the other group needs a much more long-term residential accommodation option available to them. I think the reason why you might be hearing of all of these different solutions is because different solutions are needed at each stage of the progression of this illness.

Mr NOONAN — I understand clearly where someone might be at will influence what level of support they might need, but to place an individual with two or three others who might be at various stages of their condition, is that detrimental, is that positive in some cases? Can you enlighten us from that point of view?

Assoc. Prof. NEWTON — Sure. I think that there is every reason to believe — and the literature supports this, so there is some literature evidence behind this — that people who have got well-established schizophrenia actually do quite well within a supported accommodation service like the community care unit. In fact, compared to the previous accommodation, the community care unit style of accommodation increases their quality of life and

increases their social networks. Their number of friends increases, and they feel comfortable making friendships within that group.

For younger people I think that the literature again speaks to the need for younger people to be accommodated with people in similar circumstances. The danger of housing somebody at the age of 18 with schizophrenia with somebody who is 50 with schizophrenia is they look at the person who is 50 and lose heart and become quite demoralised for themselves, which is a terrible thing to do, obviously. I think that there are reasons to think that some age-specific or like-specific accommodation is worthwhile and may assist in the recovery process or in maintaining or improving quality of life, depending on which stage you are at.

Mr NOONAN — Just one more brief follow-up then, because we have heard a number of references to this area of mental illness becoming more complex, and I just wonder whether or not that is better diagnosis or whether there is more substance to the condition becoming more complex and therefore needs becoming more complex associated with that diagnosis in more recent times, in the last 5 to 10 years, I would say.

Assoc. Prof. NEWTON — It is a very interesting area, of course. Only 20 years ago people developed schizophrenia, went into a long-term asylum and stayed there, pretty much, so that simplifies everything for everybody.

Mr NOONAN — I think that was Aline's point.

Assoc. Prof. NEWTON — I am not sure — in fact I do not think that was a good thing at all. I think having more complex and rich problems to solve in this area speaks to the success of deinstitutionalisation to a certain extent, but it also brings with it its own problems. We now have a group of people who have never been institutionalised and who probably do not receive the type of containment and support earlier on in their illness that they really need to, so they are moving through to the next stage of the illness still with lots of comorbid substance abuse, lots of accumulated antisocial behaviours that do add a layer of complexity to their situation that once upon a time they would not have been so exposed to because of the previous system of care.

The CHAIR — Finally, do you have any other recommendations to make to the committee, any other models?

Ms BURGESS — We really believe that there needs to be quality living as well. We can sort of patch up and provide accommodation, and obviously there is the need for all these, but there has to be quality. Everybody needs a home, and the rental market is so prohibitive for so many, and gradually the demographic is sort of changing a bit even now, and we are right at the bottom of the heap. They are right at the bottom for discrimination and all the rest of it. But somewhere along the line we wonder as they are getting older — the retirement village for so-called normal people is accepted. Why can there not be something in that type of model available for people as they get older; not necessarily ghetto-type but something that is quality. We do not just want to patch up the things that are wrong; we also believe that everybody is entitled to some quality of life, and that is not happening now.

The CHAIR — Thank you very much.

Committee adjourned.