LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON HEALTH AND DISABILITY

(Reference: appropriate housing for people living with mental illness)

Members:

MS K MacDONALD (The Chair)
MS M PORTER (The Deputy Chair)
MRS J BURKE

TRANSCRIPT OF EVIDENCE

CANBERRA

WEDNESDAY, 15 MARCH 2006

Secretary to the committee:
Ms E Eggerking (Ph: 6205 0129)

By authority of the Legislative Assembly for the Australian Capital Territory

Submissions, answers to questions on notice and other documents relevant to this inquiry which have been authorised for publication by the committee may be obtained from the committee office of the Legislative Assembly (Ph: 6205 0127).

The committee met at 9.31 am.

DEBORAH PIPPEN was called.

THE CHAIR: Good morning. I will just read this statement to you, as required. You should understand that these hearings are legal proceedings of the Legislative Assembly, protected by parliamentary privilege. That gives you certain protections but also certain responsibilities. It means that you are protected from certain legal action, such as being sued for defamation, for what you say at this public hearing. It also means that you have a responsibility to tell the committee the truth. Giving false or misleading evidence will be treated by the Assembly as a serious matter. Do you understand that?

Ms Pippen: Yes, I do.

THE CHAIR: Thank you. For the *Hansard* record, please state your name and the capacity in which you are appearing today.

Ms Pippen: My name is Deborah Pippen. I am the executive officer of Tenants Union ACT.

THE CHAIR: We do not have a submission from Tenants Union ACT. Would you like to make an opening statement?

Ms Pippen: Yes. We hadn't put in a submission because, when we looked at this, we thought that we did not have the expertise with issues to deal with mental illness; but, once we were invited to attend and I looked into it, what we are looking at is the more generic tenancy issues and systemic issues. I have to say up front that the tenants union does not keep any statistics or figures in relation to mental health issues or even disability, so we could not provide any figures in relation to that. As I said, our contribution would be in relation to issues we have been made aware of through contact with other groups, with individuals and with systemic tenancy issues.

There are a couple of things in relation to the terms of reference. In the first instance, when looking at support issues, we would have to say up front that where support and housing are being offered by the same provider or organisation, as well as other issues that have been identified, we would see that there is a conflict of interest where you are looking at a provider assisting a tenant, and there is no way that those interests can always be exactly the same. There is also the implicit threat, whether it is just perceived or not, that the loss of tenancy would mean the loss of support or vice versa.

Also in relation to support, we have been concerned about training for people providing support in relation to tenancy issues. Much of the assumed knowledge that people have about tenancy matters is quite often incorrect, and that is what we see right the way through any advice that we give when we are talking to people from whatever background, even lawyers. Having spoken to support workers in different organisations, they do give tenancy advice without knowledge of tenancy law and there can be misleading representations about things like responsibility in particular. I know that this is something that does come to pass or is shown a lot in relation to mental illness and episodes with tenant responsible maintenance. Even with the ACT manual that people might look at to see what they are responsible for, we would not actually agree with some of the things that they say the tenants are responsible for.

When it comes to the issue of other housing providers, again we would be looking at the training that people have in different organisations in relation to managing tenancies. Often we have seen with different community housing organisations, if they have a different area of expertise, there isn't always any expertise in tenancy management, let alone tenancy law. Lots of people think that they can just take it on, but the effects of this lack of knowledge and experience can be quite dramatic and quite upsetting for people.

We have, over the years, had some concerns about the way that some community housing organisations do run their tenancies and manage their tenancies. In particular, in the last few weeks we have been hearing about a community housing provider as to the way that they are trying to deal with issues of behaviour. They are issuing tenants with a notice to remedy regarding a breach in relation to their behaviour and, at the same time as they are issuing a notice to remedy, they are issuing a 26 weeks notice to vacate.

They then talk to the tenants and might talk to the support workers and say, "Okay, we have resolved the issue, but we are not taking away that 26 weeks notice to vacate." The tenants do not understand that this notice sits over them and they do not have to be given another notice. They can just be told at the end of that 26 weeks that they are out. It also sits over the top of them if they do understand it as a threat that if they do not behave themselves they will be out in 26 weeks, and it is over their heads. This is a community housing organisation that is not offering them alternative accommodation and is not talking about alternative accommodation; it is just talking about being out if you do not behave yourself. I really do not think that that is the way that we would want to be seeing community organisations managing tenancies.

In relation to other housing providers also there is a concern that we have in relation to appeals and dispute resolution with the providers in that community housing tenants do not have access to review in the same way as public housing tenants do. Therefore, there is inequity between public housing tenants and community housing tenants. Public housing tenants can go to the Housing Review Committee about decisions without having to go to the tenancy tribunal and in relation to matters that the tenancy tribunal does not deal with. Community housing tenants do not have those options. Similarly, with recourse for tenants regarding complaints, there is no consistency throughout community housing, whereas you can make complaints through public housing and, even if people have real estate agents, there is somewhere that they can go in relation to real estate agents for complaints.

In general, many tenants, even tenants who are quite comfortable about their ability to manage things, quite secure, holding great jobs and having lots of security and great education, do not assert their rights and do not even confirm them because of fear of retaliation, loss of housing, loss of being able to rent in the future. If you are looking particularly at disadvantaged groups, then this is even more complex and more strongly felt.

As to other issues that we looked at in particular, something that has been talked about is the behavioural contracts that housing has been talking about that have started operating in New South Wales. Although in New South Wales the change was legislated, the public housing authority has been loath to put them in place. There are many reasons for that. The prime reason and the thing that we have so much concern about is that when you are looking at behavioural issues, you are looking at social issues and community issues and they are not actually and should not be tenancy issues. If someone owns a house, any social issues or behavioural issues are dealt with in a completely different way and their security of tenure and their house, their home, is not at risk. There are other ways to deal with these sorts of matters.

We are aware of the Shelter and ACTCOSS reports that have just been released in relation to housing issues and I am aware that Shelter have appeared before this committee and I support the things that they were talking about. Also the human rights issues, I know, have already been addressed.

THE CHAIR: Thank you for that. Are there any questions?

MS PORTER: Would you like to talk a little bit more about the conflict of interest with regard to the provider assisting the tenant? The other question I have before you go into that is: will you be thinking about keeping some stats in the future about the number of people who come forward to ask for your assistance and who do have a disability or who identify as a having mental illness? That may be useful information for you to use in your submissions to government in future inquiries or on any other occasion that you might want to communicate that information to government. I think that it would have been fantastic for us to have got that information from you, but you obviously do not have it. When people ring in to ask, you must collect a certain amount of information about them.

Ms Pippen: Yes, we have a database system which was set up by the federal government.

MS PORTER: Okay, so it does not allow that.

Ms Pippen: It was recently changed; it actually collects a whole lot less information than what it had in the past.

MRS BURKE: Is that to do with the privacy act?

Ms Pippen: No. I think complexity has got something to do with it. It is actually a national system that goes through all community legal centres right throughout the country. It was a system that fell down quite often and I think they tried to simplify it, but the problem with the simplifying of it is that we get less information.

MS PORTER: It should not be to do with privacy because the name would not be attached to the data once it went in; it would be collated data.

Ms Pippen: It is, actually. It is legal advice we give. The information that we collect is in relation to each specific client. We can pull things out and get generic details, but when we first talk to somebody we have to get their name and a contact number so we have to have contact with people. It is something that I could take back and say that it would be a useful statistic, although I don’t know how useful it would be in relation to figuring out and seeing the number of people who contact us. People do find it very difficult to contact us as it is. A lot of the things that I do through my work with the tenants union are about talking to groups in a more general sort of way. But it is something that I can take back and talk to the centre about.

MS PORTER: Really, the substantive question is around that conflict of interest that you mentioned, if you could enlarge on that a little.

Ms Pippen: When you are looking specifically at repairs and maintenance issues, there is nothing in a tenancy agreement that says that a tenant will not fix things or will not repair things, even if they are not liable for it, and it is in the interests of a provider who is trying to minimise costs to put costs on a tenant rather than bearing those costs themselves. We see that right throughout. We see community housing organisations doing it, public housing doing it, real estate agents doing it and private landlords doing it.

The most recent thing I heard was about someone at the shopfront there who said that some kids had come along and broken her letter box and she could not get any mail and the person at the shopfront said, “Well, that’s your responsibility; it is not our responsibility.” Often the first response when a tenant says that there is some damage is that they will say, “It’s your responsibility to fix it.” If the tenant then says, “No, I don’t agree that it is as I was not responsible for it. I did not do the damage maliciously or negligently. It was an accident or was outside my control,” if the tenant has the ability and the confidence to do that, often you will find that a provider of housing, whoever they are, will then step back and say, “Okay, we are not going to get the tenant to pay that cost; we will pay that cost.”

That is a really common thing that we see and it is persistent. It is something that ACT Housing has done for years and years. If a tenant reports a maintenance need, often they will just get a letter back saying that they are responsible for it. If they question it, then it is likely that it will get looked into with a lot more thoroughness and often it isn’t the tenant who is responsible. So that is one instance. If there is a difficulty with behavioural issues, neighbourhood issues, it is much easier for a landlord to say that they will just get rid of that tenant and say that that tenant has to go rather than dealing with the issue or saying that it is not a tenancy issue, that it is something that the people in the neighbourhood have to deal with themselves. I do acknowledge that there are lots of good landlords and lots of good providers who will act in the interests of and are concerned about their tenants, but there is that underlying conflict that they are there for two different reasons.

MS PORTER: How would you see that addressed?

Ms Pippen: In separating it. If you are providing support to somebody, even when you are talking about training being offered by a provider organisation, it can always be tailored in a specific way about how someone is managing a tenancy and then, if the support people are sitting in on that, there is a different way of looking at things rather than looking at things from a tenant’s perspective first and about what the tenant’s rights are first. The most important thing there is the separation. I suppose one of the other things is that it all comes back to what you have been talking about—training, and proper training and independent training. In relation to this, I have just been talking to the Office of Fair Trading, because we have some issues with the way that some real estate agencies are trained, and we are now going to be talking to the providers of training about how they actually do it to see that it is done thoroughly and properly.

MS PORTER: I am still not quite sure of what you mean by separation? I am sure you know what you mean, but I do not.

Ms Pippen: I am just talking about where you are looking at, say, housing. The workers within Housing are looking after the interests of the organisation as well as looking after the interests of the tenant, and those two interests are not always the same.

MS PORTER: What would you see happening instead?

Ms Pippen: I had always thought that the role of these particular workers would be to refer to outside organisations, independent organisations, organisations that are not linked to the provider of the housing, and I think that that is really important. And whether the workers themselves feel that they are completely independent and believe they are acting in the interests of the tenant. It is always there that they know how hard it is for the provider. They know the limits on the provider and sometimes they can tailor the way that they give assistance to people without meaning to, but they can do that.

MRS BURKE: Good morning, Deborah. Thank you for being with us today. You talked about community housing and you talked about the notice to remedy, along with the 26 weeks, and there seems to be, perhaps, an anomaly there that you are giving two warnings, if that is what we want to perceive them as, or notices to put something right in the one hit. I am picking up something there that I do not feel is right. How would you like to see community housing dealing with tenants with ongoing behaviour problems? What would you see as being the best approach to that?

Ms Pippen: Again, there has to be some split. Community housing is there to provide the housing and to manage the housing and then to refer issues to other organisations or support organisations if there are outside issues. The community housing sector is very small in the ACT and we really should never be seeing any issues from tenants with the community housing providers, but we do. We will see a handful of issues. When we see the issues, that means that there must be so many more issues out there because so many people cannot get through to us, don't know about us, and that is an issue of concern for us. I think, again, it comes down to knowledge and an understanding of what their role is as a tenancy manager and not moving into trying to manage people as well as managing a tenancy, separating that.

There is, again, that conflict that I was talking about and we do see that, and what they think the benefit is of moving people out and not assisting people. So I think a lot more transparency in community housing providers is needed. I am quite aware of the size of the sector and the limitations with resources for the sector, but we cannot talk about growing the sector until we have these sorts of issues resolved. Putting in place something where the tenants can go if there are issues with them as tenancy managers is something that should be there before anything else happens. There really should be somewhere that they can go to question a decision where they think that something is not fair, an appeals mechanism that will relate to all of the providers. Some providers do have appeals mechanisms, but some of them don't.

MRS BURKE: So there is a need for consistency.

Ms Pippen: Yes. If you are looking at a smaller provider, it is likely that those things are not in place. So we need something. There has been talk about broadening the scope of the Housing Review Committee to cover issues relating to community housing and I think that that would be a really good idea. We are talking about public housing stock, regardless, and there is equity then between the tenants. Again, the same with complaint mechanisms. If you are in a little community housing organisation and there is an issue and you want to make a complaint, and it is a very small organisation, everybody knows each other, people aren't going to make complaints. Organisations learn from complaints, but a lot of the small organisations that feel under threat don't like hearing complaints.

MRS BURKE: Perhaps the consistency may need to come with the head leasing arrangements. What are your thoughts on that? Therefore, it needs to be set from the top once head leasing starts and it filters down the line that these are the guidelines. I don't know. It seems to be that you are saying to us here that there is one rule for someone and another one for somebody else. Clearly, that is what you are saying. But looking specifically at people with mental health issues, they need support. Would it be fair to say that you do not believe that that support is out there at the moment? So, in turn, what does public housing, the department, do per se, or community housing or private landlords for that matter? They cannot allow the situation to continue. Going back to my first question, what would you see would be a process, or how could we improve that? What do we need to do to make the system more robust?

Ms Pippen: Support mechanisms are not in my area and I do not know what is out there but, from reading the transcripts, I have seen that there are lots of support providers out there and there is a lot of assistance out there. I think that something that is an issue right throughout anything to do with the housing sector is that there are lots of programs, issues, supports and whatever and there is no one place that people can go to find out. I know that Shelter have been talking for quite a few years about the idea of a provider of information and referral on services, anything to do with housing, a shopfront or something like that where you can go.

MRS BURKE: We already have stuff there, haven't we? I think it is probably just a matter of utilising things like the government shopfronts or Shelter itself.

Ms Pippen: Yes, and it would be somewhere that people can go when they think there is an issue and need to see how they could resolve the issue. Again, it is training for the providers of the accommodation, giving them that knowledge, first of all, about what tenancies actually mean, what they can do and what they cannot do. If you are looking at community housing providers, I think they have an extra layer, they are not there to make a profit, that is not the way that they are set up. They need to be able to continue to operate, but there is that community obligation that they have and have to always take into account. That is something that we don't see sometimes.

MRS BURKE: We talk a lot about rights, but there is the corresponding responsibility side of it. It needs to be very clear both ways, doesn't it?

Ms Pippen: Most definitely, yes, it does, and sometimes either side tends to lose focus of that.

MRS BURKE: That is right, yes; well said.

THE CHAIR: I think I already know the answer to my question but I will ask it anyway because you might prove me wrong. Do you have any contact with mental health services at all when you are dealing with tenants who are having problems?

Ms Pippen: No, we do not. The way that our service operates is that we are an advice service only, so we have phone contact with people and that's it. If there is any need for any other type of referral, if it is developing into a case and a matter that needs more follow-up, we would then refer them to Welfare Rights or somewhere else. We do not have case management of any sort. Our advice service is strictly that; it is advice. If someone calls up, we will fill out a sheet, take details and give them advice. Sometimes they will call back on specific issues, but we only advise on tenancy legislation and again that is it. So we do not have that one-to-one client sitting down in a room, case contact with people.

THE CHAIR: I just thought that it might be that sometimes you might refer them on, you might actually ask them whether they have thought about getting in contact with someone.

Ms Pippen: It is not something that would come up that often with us. I suppose a lot of it has to do with the fact that Welfare Rights exists and, specifically with ACT Housing matters, tenants know that Welfare Rights deals with housing matters, that they have had a long history of dealing with housing matters, that they do have case workers and people can come in and make appointments with them. So there is that knowledge that there is that service. We do public housing matters but only one per cent, if that, of our calls are ever public housing matters.

THE CHAIR: That was the answer that I was expecting, but I thought I should check anyway.

Ms Pippen: Yes, I would ask Welfare Rights what contact they would have.

MS PORTER: I have a question about how we can make our approaches to community organisations clearer in that when you first saw the information you thought that it had nothing to do with you, but today you have given us lots of information and it has been really good to be able to ask these questions and get this background from you, and your suggestions. I am really grateful that you are here today. Initially, you thought that it had nothing to do with you, but when you looked at the terms of reference you could see—

Ms Pippen: There are specific things.

MS PORTER: How could we have made that more clear to you in the first instance?

Ms Pippen: We got the information about it and it is a housing issue. If I had more staff rather than just myself—

MS PORTER: So it is a resource issue for you?

Ms Pippen: Yes. We get papers and whatever when anything happens either in the ACT or nationally. We will get invited to participate, write discussion papers and responses, and we also run our service and we do community legal education and train people. It is just a resource issue. We did look at it and I had spoken to Welfare Rights' disability discrimination lawyer and we had thought of putting in a brief submission, but unfortunately it went by the wayside. I don't think that there is anything really different that could have been done. It was highlighted that it was a housing thing. But I suppose, because of your particular target audience, it was something that we thought you were looking at more generic stuff.

MRS BURKE: I have a quick question that you may not be able to answer. What percentage of the people, in your estimation, would present with a mental health problem? Do you have any ideas?

Ms Pippen: No.

THE CHAIR: We appreciate that you have come along to speak to us. You have provided us with some valuable information. I thank you for making the time available. We will be back in contact with you when we provide the proof transcript to you to check. We will advise you of the progress of the inquiry and let you know once we have got a report ready to go. Thank you for your time.

LEILA CORMICK and

KERRY ODDY were called.

THE CHAIR: You should understand that these hearings are legal proceedings of the Legislative Assembly, protected by parliamentary privilege. That gives you certain protections but also certain responsibilities. It means that you are protected from certain legal action, such as being sued for defamation, for what you say at this public hearing. It also means that you have a responsibility to tell the committee the truth. Giving false or misleading evidence will be treated by the Assembly as a serious matter. Do you both understand that? For the transcript, heads are nodding. Please state your names and the capacities in which you appear today for the *Hansard*.

Ms Cormick: Leila Cormick. I am a program manager for Connections Volunteers at Volunteering ACT.

Ms Oddy: Kerry Oddy. I am a customer service manager at Volunteering ACT. I work closely with Leila but I am here under several different capacities.

THE CHAIR: Thank you. Would you like to start by making an opening statement.

Ms Cormick: Connections Volunteers is a friendship-based program that links people living with mental illness with volunteers. Most of what I will talk about today is based on the lives of clients of Connections Volunteers. I am the program manager there and I am also on the executive committee of the ACT Mental Health Consumer Network. I am a mental health consumer. I am also a carer for my 19-year-old daughter.

Ms Oddy: The reason I am here is that, because I used to work for ACT Housing, I have a large knowledge of what happened in ACT Housing with mental health clients. I worked a lot with them there. I was also a consumer of mental health services and my current partner is highly involved with mental health at the moment. He is a consumer and I am a carer. That is why I am here today.

Ms Cormick: I want to talk briefly about some issues to do with housing that I can see are affecting people with mental illness. One is that there is a lack of mental health support. That is evident especially for people who suffer from mental illness as well as physical illness or drug and alcohol problems. We match clients to volunteers but we also have social programs. We have a coffee club that meets once a week, we have picnics once a month and there is a bowling corps. So we also meet people socially.

For example, there is an older middle-aged woman who suffers from bipolar who also has a lot of physical health problems. She has been in and out of hospital lately because of physical health problems. A couple of months ago I heard that she no longer has a clinical manager with Mental Health ACT. I found that appalling. At the coffee club we meet and talk about anything, including mental illness. Once I asked her what medications she is on and she showed me a list this long of her medications. She hasn't got a clinical manager to look after her mental health problems to help and support her in that way. She is not getting any younger. Her physical health problems are not going to get any better. What on earth is Mental Health ACT thinking when they say she does not need a clinical manager anymore?

THE CHAIR: She has had to spend a lot of time in hospital recently because of physical ill health. Has she expressed frustration or mentioned any issues with one area of the health system not understanding her mental illness issues as well, and the need to keep those in mind?

Ms Cormick: Yes. One thing she has mentioned is that she goes to a doctor—I do not know exactly whether it was her GP or psychiatrist—who looks after her medication for bipolar. One of the medications she takes is lithium. When she had blood tests done somewhere else, they found out that she was toxic. The doctor had not ordered regular blood tests for her. If you are on that many medications and you are given too much lithium, that is not going to help you with those other illnesses. There needs to be more co-ordination. There is supposed to be. There is collaborative therapy happening in Mental Health ACT. GPs, psychiatrists and clinical managers are supposed to be communicating better. I don't think that is happening. They are trying but there is definitely a lack of resources. They think she does not need a clinical manager. If you have diabetes you are encouraged to see a diabetes educator regularly. You are told, "Please come and see us." If you are a mental health consumer, as soon as it looks like you are managing on your own, you are told, "You're on your own now." But mental health problems go up and down. A lot of them are for the rest of your life. A person with a lot of physical health problems is not going to get better mentally.

Another example is that a middle-aged woman who had been living in a public housing complex for several years—I don't know how many years—was constantly harassed by neighbours, usually men. She chose to leave her home for several years and moved into some kind of group house. She told me this, but I don't know what the group house was. Later on, when I happened to see her, she said the other women there were younger and she didn't really fit in. A couple of weeks ago I heard that she was no longer there and was living in a women's refuge. You can stay there for three months. I know that they can sometimes stretch that further. I don't think she has a clinical manager. I don't know—that is not my job. I don't manage the people. I don't necessarily know exactly what their mental health problems are either.

I think it's very difficult for people with mental illness to feel safe in their homes. They often already suffer from anxiety, paranoia or something like that, so it's even more important for them to be in a very safe environment. Often it is worse in bigger complexes because there are people who live there for a while. There are people who are drug users or other mental health consumers who often don't get appropriate care. There is another middle-aged woman who lives in a suburban house which was broken into just before Christmas. She suffers from bipolar and severe anxiety. She couldn't get anybody to fix the sliding door. She couldn't close and lock it for at least a couple of days. That is not safe.

Another thing that I think affects people with mental illness is isolation and lack of social support. Often this is to do with the fact that they either have other physical health problems or anxiety, for example, so they cannot catch public transport. They cannot afford to have their own car. Some do, but it depends on whether you used to work before or whether you have always been struggling with mental health problems and whether you've got a government pension or whether you are on a work pension. Lack of money is also a problem because you don't have money for leisure activities.

Transport is a huge issue. That is often the final thing. Some of the clients have told me that, if we didn't pick them up for activities like the coffee club or something, that would be the final hurdle. They say, "That's just too much. I just can't go there." They might have the $5 for bowling but can't get there if they have to use public transport. Some are happy to use public transport. I am not saying that everybody is like this but there are several people who have difficulty. Even though there are problems living in the public housing complexes, those are often close to shopping centres. That's good for getting your shopping done, visiting a GP or visiting friends but it may not be a safe environment otherwise. Living in the suburbs may feel safer, but then there is the problem of visiting your friends and getting anywhere. For example, on weekends public transport is not great.

There is a client who luckily now has a volunteer who is willing to do much more than we would expect a volunteer to do. Often the volunteer visits their friend once a week. It is a social visit. You might stay at the client's house and have a cup of coffee; or you might go for a walk, go to the shops, go to see a movie or whatever. This volunteer has been visiting maybe two or three times a week. He has taken him to hospital when he has needed to go, taken him to see a doctor and taken him to the Rainbow for some sort of social contact with other people. He also brings this person to the coffee club. This client has many physical health problems. He has had a stroke, he has diabetes and he is a heavy smoker. Being a heavy smoker you don't have money for anything else. If you live on a pension, you buy food. He was telling me that he can't buy good, healthy bread; he can only afford cheap white bread. Of course you could tell him to stop smoking but it's not that easy. A lot of people with severe mental health problems smoke. In a way, it's self-medication. I think that's about it, briefly.

MS PORTER: Thank you. Perhaps Kerry would like to talk about her experiences.

Ms Oddy: I will be brief with mine. I worked for ACT Housing in the sense that I was a housing manager and dealt with a lot of housing sites that had multiple tenants. I also dealt with singular situations. I had a lot of experience with particular clients who had mental health illnesses. I found that a lot of the housing staff didn't give a damn. They said they did, they pretended they did, but behind closed doors there was very little care factor. I found that very disturbing. I respect anybody in this world and I try to help as many as possible. A lot of the clients I helped were mental health clients. I went to a lot of trouble to work with them to get them out of places and all. I got nowhere because of the procedures in ACT Housing. To get just one thing done there is a pile of paperwork that big. It's ridiculous. Mental health clients can't handle one thing, let alone the number of forms they have to fill in. That's a quick overview of my housing experience.

I worked for the YWCA for a year and was involved with many mental health clients there as well. It was the same thing. I had to deal with housing as well as other mental health issues and the mental health team. I found that the mental health team were very unresponsive to the clients at the Y. You couldn't get them out there if you needed them, you couldn't get housing out there if you needed them, and at one stage you couldn't even get the police out there if there was a problem. That was a big issue in my way and I see that as a big issue for everybody in a mental health situation.

On a personal basis, I was a mental health client several years ago. It's pretty insignificant today. That was back when the system was a lot different. My current partner is a mental health client. He has been in PSU twice in the past three years. They let him out of PSU when I didn't think he was fit enough to come out. The problem is that I couldn't comment because I wasn't his carer. That made life very difficult. I had no say in it. There has been no follow-up care at all on him since he left PSU. He has threatened on several occasions to do himself in. I have had to deal with that in my own way because Mental Health won't touch it. If I ring the crisis team and say, "Look, this is the situation he is in," they say, "You're not down as his primary carer so we can't do anything about it."

He was in an abusive relationship and Mental Health didn't look into the whole situation properly. The reason he was in the situation in PSU was because he wasn't coping with the violent relationship he was in. He didn't have the guts to tell anybody about it except me. When I went to them and said, "Look, this is why he is there; this is the situation; we need to get him out of there," they put him straight back in. He's not there at the moment but he keeps going back to see her to say hi and all that. He still goes back but he is terrified of her. That's my situation. That's where I'm coming from. I am here to give you an inside story about housing more than anything, and also to explain my situation.

MS PORTER: For how long did you work for Housing ACT?

Ms Oddy: Six months.

MS PORTER: Which particular area did you work in?

Ms Oddy: I had Downer and Owen Flats, and I looked after all of Lyneham.

MS PORTER: What was your exact responsibility?

Ms Oddy: I was the housing manager for all the properties in those suburbs. There were a couple of others but I can't remember them.

MS PORTER: I just want to get a clearer picture of what you were doing there.

Ms Oddy: I had four massive suburbs to look after.

MS PORTER: What was your role at the Y? How long did you work there?

Ms Oddy: I was a community development worker. I was there for 14 months. In that role I went out to housing complexes. We provided activities for the housing clients, to give them support and offer them any advice we could.

MS PORTER: What do you see as the alternative for your partner when he was well enough to come out of PSU, rather than being thrown back into the same situation?

Ms Oddy: I like the idea of them coming into a halfway situation where they are monitored but can still go out into the real world. I think it should be both ways—going in and going out. Then they may have seen the real situation and what was going on. He was in PSU for two weeks. In that time he had no clothes, no toothbrush—nothing. I had to go and buy all those for him and take them in. She didn't take any of that in for him. I had to go and buy new clothes and everything so he had clothes in PSU.

MS PORTER: Thank you for that.

MS BURKE: Thank you, ladies, for being with us today and giving us some insight into your respective cases. That has been my observance through being shadow for disability, housing and community services and it certainly supports what you are saying. I don't know how we make the situation better. Maybe you have some ideas. I have people presenting as a one-page problem and they become an A4 folder nightmare. I don't know how they cope. They have a folder similar to that.

Ms Oddy: I'd say there is more than that folder.

MS BURKE: Yes. It was interesting to get your perspective, Kerry. Whilst I know that you were not there long, you were there long enough to understand the machinations of what goes on and how we are pressuring people. How can the government improve things when working with people with a mental health disorder or issue? How can we help? Is it resources; is it support; is it money; is it training; or is it all of the above?

Ms Oddy: I have an idea but I don't know whether it's worth it—to have a middleman who works with both housing and with the mental health client. But the mental health client doesn't have to work with housing the whole time and housing don't have to work with the mental health client all the time. With housing, the clients have to keep an appointment on a certain day or they miss the property altogether. That is hard for a mental health client who may be sick, not sure what they are up to or what they are doing. Why can't we have a middleman who takes the property and waits until the mental health client is well enough to take it on, sign the documents and all that and then help them hand it over? That's the way I see it working better. The middleman would then deal with a lot of the paperwork.

Honestly, I have never seen so much paperwork in all my life—and there are so many dramas to get to one spot. There are too many procedures for one little event. Just to get something fixed in your home you have to fill in two forms, then you sometimes have to wait two weeks. Sometimes you have to wait three months, depending on what the situation is. You have to make a phone call to get it done. You may have to make three or four calls to follow up on it. It's a nightmare.

MS BURKE: That is right; I have experienced it, so you are expressing no more than my belief and experience. You talk about a middleman. We have heard from people before about conflicts of interest, so we have to be careful who that would be. Are we at the point now where perhaps separate case managers—not housing managers—need to be established within housing for people with acute problems?

Ms Oddy: If you were going to do that, you would have to do it so that each case manager had a suburb.

MS BURKE: Yes, much like the area manager.

Ms Oddy: Not an individual person.

MS BURKE: Yes.

Ms Oddy: Each manager would have an individual suburb. The way housing is divided at the moment, they have five or six suburbs. There are so many mental health clients in each suburb that you could not do it. A housing manager can't even manage the portfolio they are under. It's a nightmare. It's a great idea but you would have to do it so that each individual suburb had a manager who could deal with that area. I believe a great way of managing that program would be to have someone who has not only already been through the mental health system and has insight into it who is stable enough to run it but also can communicate with housing on their level. The middleman should be someone who has been both ways. I see that as the best way to manage it. I don't think you should get someone who hasn't been a mental health client, because they won't understand the mental health clients properly. I have no objection to people studying at uni or anything like that but, even if they've studied it, they still don't have the personal experience. That is what I see as the main endeavour of it.

Ms Cormick: Mental health clients can study too. That is what I have done. That is why I have changed from computing to mental health.

MS BURKE: Thank you.

MS PORTER: I wanted to ask you about the number of Connections clients who are utilising the service at the moment, if you know off the top of your head, or the approximate number if you don't. Approximately, from that number, how many of them would have housing and accommodation issues? How many are expressing to you that they are feeling isolated or are not in suitable accommodation? Do you have an idea?

Ms Cormick: We have about 40 clients that are matched with volunteers. There are also a lot of people on the waiting list, but then we have 60 people who come to our social gatherings.

MS PORTER: About 100 in total?

Ms Cormick: Yes, probably about 100. I haven't necessarily met them all because there is no time to do so. I know there are at least half a dozen who definitely have issues with their housing. There are some middle-aged people who still live with their parents. That will be another housing problem in the future when those parents are no longer here. Some of our volunteers are mental health consumers.

I know that one volunteer has a son with schizophrenia living with her. Not only are there housing problems but it is also a matter of whether the housing is appropriate. They may have a place to live, but is it appropriate for a son in his 40s to live with his mother who is in her 70s? It doesn't always work out. It can go up and down. What happens to that son when the mother is too old? I don't know the numbers and I don't have the time to look into it and help people. That is not my role. There is definitely a lack of mental health support. Whether you have housing problems or not, you need that. It's not good enough just to have a place to live in.

MS PORTER: You are saying it's not good enough just to have a place where you are housed, you need to have the mental health support in addition to that housing?

Ms Cormick: Yes. You need continuous support. Sometimes people need more support. They might need weekly visits or maybe they need somebody to support them even a couple of times a week. When they get better they shouldn't be thrown out of the system but maybe should be seen less often. When they get unwell again—and most of them do—then they should be seen more often. There are not enough ACT mental health workers. They easily tell people that they don't need a mental health worker anymore because their case loads are far too big. I don't think that is the proper way to manage mental health problems.

Ms Oddy: On top of that, when a client wants to see a support worker or anything like that for any reason, they have to go to them. They have to make an appointment and turn up to that appointment. Why isn't the worker going out to the home and having a look at the situation? They are not doing that. That has been happening with my partner. They are not going out into the situation, they are bringing them away from it. That is great if they have to bring them away from it, but there's just not that extracurricular activity where they are going and having a look at the whole situation; they are looking at half of it.

Ms Cormick: A lot of people can't get a worker. They don't even try because they know they won't be able to get one when they need support.

MS PORTER: Do you mean that they can't contact them on the phone? Is that what you are saying?

Ms Cormick: They don't have one at all. They are not even on the books of Mental Health ACT or other community agencies that Mental Health ACT funds. They don't have anyone. They hear about it from friends, and sometimes it is inadequate anyway.

MS BURKE: You have mentioned step-up, step-down facilities. A few people have mentioned to us that that would be a good idea. What would be another form? I think we have got scared about the word "institution, " so I don't want to go there. Call it by another name. Do you think it is appropriate that those sorts of constructs are in our community where people can go for safe refuge for extended periods of time?

Ms Cormick: Definitely. We have a client who lives in public housing—this was the woman whose house was broken into. She has a son who has a brain injury because of a car accident, and he also has a mental illness. When he was in the remand centre he wasn't getting his medication. That is a woman who has a mental illness already and she has all the worry of not being able to help her son much. It took a long time before they were willing to give him his medication. She goes into respite at times because she needs to get away from that situation.

THE CHAIR: Thank you very much for your attendance today. We will be in contact with you with the proof transcript of today's hearing so you can check it for accuracy. We will also keep you informed of the progress of the inquiry and let you know when we are likely to have a report, but that is looking as though it is further and further into the future.

MS BURKE: The more evidence we gather the better.

THE CHAIR: Yes, that is right. More people keep coming out of the woodwork, but that is a good thing. Thank you very much for your input.

Ms Cormick: I hope there will be some results as well, not just reports.

JAMES HENRY SNOW and

AMANDA JANE SNOW

were called.

THE CHAIR: You should understand that these hearings are legal proceedings of the Legislative Assembly, protected by parliamentary privilege. That gives you certain protections but also certain responsibilities. It means that you are protected from certain legal actions such as being sued for defamation for what you say at this public hearing. It also means that you have a responsibility to tell the committee the truth. Giving false or misleading evidence will be treated by the Assembly as a serious matter. Do you understand that?

Ms Snow: Yes.

Mr Snow: I do.

THE CHAIR: I know that you have been advised of the ability for us to hold this as an in camera hearing. Do you wish for it to be held in camera or are you happy for it to go ahead as a public hearing?

Mr Snow: I am happy for it to go ahead as a public hearing.

Ms Snow: I am happy for it, too, yes.

THE CHAIR: Can you state your names and the capacities in which you appear today, for Hansard, please?

Mr Snow: James Henry Snow. I am a parent of a deceased mental health patient and I am patron of Winnunga Aboriginal medical service where I have had some experience with mental health patients.

Ms Snow: Amanda Jane Snow, sister of a deceased mental health patient.

THE CHAIR: Amanda, it is good to see you here today because I know that you, as well as Jim, assisted with Natasha over a long period of time while she suffered schizophrenia. Thank you for the submission that you put together, Jim. Would you like to make an opening statement and we might move on to questions.

Mr Snow: I am sure the members of the committee are all aware of what happened following the well-known Richmond report when mental health institutions were very unsatisfactory. He pointed that out but pointed out at the same time that there needs to be strong community support if people who do not need to be in a service are not in an institution of some sort. There needs to be very strong community support. It is my belief that that has not really happened.

If I can briefly point out what the Human Rights Commissioner, Brian Burdekin, said in October 1993. He delivered a scathing report on the care of the mentally ill, a thousand-page litany of tragedy, neglect, abuse and ignorance of the squalid housing, jails and living conditions on the streets. At that time, 1993, the federal government said that an interdepartmental committee would examine the report. The health minister at the time said more funds were inevitable.

There have been quite a lot of problems. I have made a few suggestions here. They relate to Natasha mostly. If I could briefly mention that, in the case of Winnunga Nimmityjah Aboriginal medical service, there have been a few incidents where there have been real problems. People have been put into flats or neighbourhoods and there have been very bad behavioural problems, with mental health breakdown, and people have been shunted from place to place. For that reason, it is quite clear that the type of accommodation that is being provided at the moment is not satisfactory.

This problem is nation wide, not just in the ACT. Julie Tongs, who is the CEO of the medical service, wishes that she had made a submission. She would have liked to have given some evidence. I do not know whether the committee has time for that. I won't expand on that greatly, but she would like to make contact because of the problems that they have experienced. As well as being on the national Aboriginal community-controlled health organisation board, she is quite an expert on and is aware of the nationwide problem to some extent.

If I could also add briefly to what I have said, people I know who have been in ACT Housing have told me that quite often they have been told that they are to look after the patient from Mental Health insofar as housing was concerned. Natasha, my daughter, herself experienced problems. She was in ACT Housing in Lyneham. There was another mental health patient who was in the room next door. After some time she noticed a smell coming from the room. They found the person had died in his accommodation provided by Housing. No-one knew; no-one was seeing the person. Of course, it could be the patients themselves not wanting to be seen, which can often happen, but there needs to be some way of dealing with it. She was very distressed by that and then felt she had to move from that housing.

When I was the member for Eden-Monaro, I had a call from a lady in Sutton who said that her son was attacking her, was violent on occasions, and that she needed to do something about it. There is all this confusion about cross-border problems, too. A person might be in Canberra occasionally and then back in Sutton occasionally. Which mental health should be dealing with the problem? Mental health said, "No, it is a police matter. If he is attacking you, it is violence." You had the person being shunted from one agency to the other, and the poor old lady was having to deal with that problem.

As far as Natasha was concerned, I have mentioned the need for a type of accommodation where the person would voluntarily be admitted and where a professional says the person needs to be admitted, as was her case, where the psychiatrist said she needed to be admitted. The registrar of the hospital at Woden—and Natasha was an ACT resident at the time—said no, she did not really need to be admitted. But he had not made contact or had not been able to make contact with her psychiatrist.

Both her psychiatrist and her caseworker felt that she should be admitted but, when the registrar made a decision, they accepted that decision. It was probably on professional, ethical grounds of being a colleague of the registrar. They did say they understood completely the registrar's decision when we had a coroner's hearing on the matter. Nevertheless, beforehand they recommended that she be admitted to the hospital.

I know that part of the problem is hospital accommodation—and this is a huge problem not only with the mentally ill but with the ageing—but the high cost of hospital accommodation means that it is tempting for the hospital to try to reduce the numbers, the intake. There again, if there was a hostel—not modelled on the frail-aged hostels but on the approach where you have one constant person, not half a dozen, because they are voluntary patients and they want to be there—there could be a type of accommodation where people could have longer term and respite-type accommodation. That is what I have mentioned here.

You could have graded and properly provided services, going from forced attention through to voluntary accommodation, but not just a house of two or three people. Natasha went into a Richmond Fellowship house, which was quite good, but the other patients were not accepting. There was no constant supervisor there. They were friendly to themselves, and she noticed immediately that no, it would take some time. I might have said, "It will take a while to get used to the place and people get used to you." But she was not prepared to tolerate that.

I would envisage a place where you would have 15 or 20, maybe, patients available and being more accommodating and where the manager—and there is a person there—is more accommodating. I could understand that there needs to be some assessment of the person. Just as you have ACAT assessments of people, there needs to be some assessment of a person and there needs to be a professional recommendation about the person going in. But I would see it as being a little bit cheaper and I would see the assessment being a bit more accommodating than the registrar of a hospital might be. For that reason, I have suggested that approach.

It could be feasible, preferably on a national basis, if there was an assessment done. The person could pay for the accommodation, maybe after an initial period, and the person could have assigned their pension or a part of their pension, as they do in frail-aged hostels if they are on a pension or a benefit, so that the costs could be reduced somewhat. I could see it happening in just one territory or state, if they are prepared to take the initiative. They could afford to do it. Perhaps it could be more affordable by doing that. A national approach would be better because of cross-border problems. People are constantly moving across the border to and from the ACT. I could see that it would be better if there were national standards.

That briefly covers what I have said and added a little bit more to the submission I have made.

THE CHAIR: Amanda, did you want to say anything?

Ms Snow: Just from a sister's perspective on, most specifically, Natasha because she is the one I have had to deal with the most: a lot of the time the mentally ill think that their family do not care about them or else they do not want to see us, for some other reasons and stuff like that. Whilst our doors are always open for them, they will often shun us and seek other accommodation away from us. We had probably 18 months to two years where she said, "Don't call us; we'll call you." Whilst I would continue to send her cards for her birthday and stuff, I respected that. During that time I know she had difficulties with accommodation. I always went and saw her when she was in hospital. She was always more than happy to see me.

The other thing about family is that we would offer and she would come and stay with us and she would be happy with that but she would feel like she was imposing. She wanted to be independent. Because of that feeling, she would often leave after a day or two.

THE CHAIR: Natasha went into a Richmond Fellowship house but did not stay there, as you have said. Ms Heide Seaman from the Richmond Fellowship has suggested that there needs to be more funding whereby there can be small clusters of housing for groups of four to six, with one bedroom each, so that people who have mental health issues can stay there, because the whole concept of having to share accommodation is not necessarily conducive to good mental health, even if you do not have a diagnosed illness. Do you have a comment to make about that?

Mr Snow: I am no expert on it but my impression in Natasha's case was that, when she thought she should go into hospital, she wanted to go into some sort of protection. I have seen people in frail-aged hostels. There are common meals and there is common protection. It is something between the housing she had in Mawson, which had been satisfactory, and the hospital protection that she had. She was prepared to accept that type of protection. I am not arguing against the cluster-type housing.

What happened in her case was that she had gone from hearing voices and had improved. The big problem with her was that she had improved under medication and suddenly became incredibly lonely in her home in Mawson. She missed the voices, the delusions. The psychiatrist said to the family afterwards, and unfortunately it was afterwards, "If only she could have lasted for a while after that, she would have got used to living." She had been 14 or 15 years with these voices. She said, "I am incredibly lonely. I have to move. I need to be with other people."

Ideally, there would be a variety of spaces. Cluster housing may have helped. It would have suited her at some stage, probably. But at this stage I would have thought that a hostel-type arrangement would have been better. The closest—and she would have liked to have gone into it—would have been Hennessey House, which was at Calvary. She had applied for that at one stage.

THE CHAIR: You mentioned now and in the submission how the Respiradone medication was helping with the voices. She was improving but then she became lonely and was not used to it. You have mentioned in your submission that you have a qualification in pharmacy. You have an understanding, beyond what some other carers would have, of the pharmacological effects of certain medications. How do you feel that was handled in terms of the medication that was given to Natasha and the potential effects of it?

Mr Snow: It seems to me that there needs to be a lot of counselling available. Maybe it was partly the psychiatrist and partly the patient in that she wanted no communication between the psychiatrist and her family. At the same time she was not hostile to the family for most of the time. There was a time, as Amanda said, when she suspected the family of—

Ms Snow: Plotting.

Mr Snow: Plotting, and she was paranoid about the family. Part of her problem was the family's motives and that sort of thing. She was very suspicious about the family for some time. But there seemed to be a lack of counselling on the fact that she was coping with the Respiradone. She began to invent physical illnesses. She rang me in desperation and said, "Can you help me?" She had suspected me of some rather outrageous things before that. She rang and said, "Can you help me?" I said yes.

She was being tested at Queanbeyan Hospital, even though she was living in the ACT, because she could get in earlier for a hernia operation, which she needed. This has complicated things, too. She needed it. But she suspected that she had all sorts of other illnesses. She told them that at the hospital, and they said, "We will have to test you for the urinary tract infection which you say you have got; so we will put your operation off for a month." That absolutely devastated her. She was going to stay with us, my wife and I, for a while after her operation and convalesce.

We said, "We will still do that when you go in; that is all right." Then I realised she was at her home in Mawson. I went over and stayed with her for a night or two. But it turned out she did not have a urinary tract infection at all. We did not realise what had happened until we heard, indirectly from the psychiatrist through the caseworker after her death, that she was imagining physical illnesses.

Yes, the Respiradone was working but there should have been much better counselling. I was not aware that she was inventing physical illnesses, even with my knowledge, at the time. I could easily have said to her, and I did say to her, "Things are now working, so you are probably getting better. If we can sort out the physical problems you should be right." She said, "I can't keep going on. First of all, I have mental health problems and now I have got physical problems. Am I going to have this for the rest of my life?" When the registrar ordered her Valium, which she had never had except under hospital supervision, if we and they had known that that may have affected her mind so that she could do something she had thought of doing for quite a while, which was take her life, because I felt that it had probably relaxed her mind so that she could take that act, then we might have acted differently.

That is all associated with her treatment, the success of the treatment and the poor follow-up following that treatment. She should have been accommodated then. If the registrar had said, "No, it does not warrant you going into hospital, but we are giving you Valium; you should be under supervision all the time. How about going over to this hostel for a night or two," instead of saying, "We will give you Valium. You are going to be with your father tonight. We will come and see you there and give you another Valium then," the story might have been different. My own knowledge shows that, when people reach the age of 40 or 50, they quite often learn to accommodate their illness anyway. That may not have happened. She was quite successful academically in some ways, but she would give it up when everything overcame her.

MS PORTER: Many people have talked about what they perceive to be a lack of coordination between different service deliverers or arms, whatever you like to call them. Would you like to comment about that?

Mr Snow: Yes. It is complicated by the border, too. People in places like Sutton, Queanbeyan, Murrumbateman and Yass are under New South Wales mental health and are then transferred to ACT mental health. I know that is complicated by the arrangements between the ACT and New South Wales.

There is a lack of communication—I have mentioned one between housing and mental health—and a bit of buck-passing as well. Do not for a minute deny that it is often partly due to the patients themselves rejecting a particular caseworker or not thinking they need it. They also do not think they need treatment.

It seemed pretty evident that there was a total lack of consultation between the private sector and the public sector—between her private psychiatrist and the public sector. It is partly complicated by the rules of privacy in that you cannot break that privacy and talk to family without the permission of the patient in a lot of cases and tell the family, "I have to tell you that Natasha is now imagining she has got physical illnesses and she has not."

There is a lack of consultation, even if it is permission for a registrar of a hospital to communicate with the private psychiatrist or the staff of a private psychiatrist and get the records and what it is all about so that there could be a little bit more care there. If that had happened, she may have been accommodated, even for a night. When she wanted accommodation at Calvary previously, she had been given it. There was none at Calvary and none at Woden on this occasion. And that is understandable.

Ms Snow: And she only spent a couple of days in there. The previous time I visited her in Calvary was only a month or two earlier or something. I visited her the morning after she went in. She was really quite positive but bored. She was ready to go out again. But she just needed that time somewhere.

THE CHAIR: Somewhere she felt safe?

Ms Snow: Yes.

THE CHAIR: Safe, I suppose, in a sense, from herself?

Ms Snow: Yes, that is it.

Mr Snow: She felt there was a danger of her doing what she eventually did and took what she thought was a sensible act: "I had better go into hospital again for a couple of nights where they will watch me and they will talk to me and listen to me."

Ms Snow: "And then I will get better and I will leave." Yes, it definitely did her good to get into that sort of situation. As dad said, a hostel situation would probably be equally as good as long as there was some supervision as well, yes.

THE CHAIR: I suppose the issue—and this is a comment not a question—is that Natasha was aware of when she needed to do that but there are a lot of clients out there who won't and do not.

Ms Snow: She certainly did not initially but, yes, after 15 years she had certainly learnt to understand herself quite well.

MRS BURKE: Ms Porter asked my question. We are pushing for time.

THE CHAIR: Is there anything else you wanted to add before we finish up?

MS PORTER: I wanted to reflect on the fact that you think that this is a national issue and that the ACT—maybe I am putting words in your mouths; so correct me if I am—going it alone is probably not a good idea. Do you think that the ACT could lead the way?

Mr Snow: I think the ACT could lead the way as long as they feel they can finance something. It may be that something developed from the Hennessey House idea could be done. If you could make sure you got a proportion of the pension—it might be five-eighths or seven-eighths of a pension or allowance, maybe after they have been there a time—that might help finance it. I think they could do it.

The ACT should raise it at the Council of Australian Governments where there is a mental health inquiry—there is also a Senate inquiry at the moment—and say to them, "There needs to be a national approach on mental health, including accommodation." There are two ways the territory can go about it.

MS PORTER: Thank you very much.

THE CHAIR: Thank you.

MRS BURKE: Thank you very much.

THE CHAIR: Thank you, Jim. As I said, I am glad that you came along as well, Amanda. Thank you for your submission and for appearing today. We will be in contact, with a copy of the transcript so that you can check it for accuracy. We will also keep in contact with you on the progress of the inquiry. As I said earlier to another witness, the more publicity we get about it, the more people are coming out of the woodwork and wanting to submit information. It is extending a bit longer than we had anticipated, but that is okay. The committee is happy with that. We will also get in contact with Julie Tongs and say that we would be happy to accept a submission. I am speaking up without having spoken about it in private to the committee, but I am pretty sure that we will be happy to do that. We will let you know when we have a report. Thank you very much for your valuable contribution.

MS PORTER: Thank you.

MRS BURKE: Thank you.

Mr Snow: Thank you all for your attention.

PATRICIA MARY DANIELS was called

THE CHAIR: You should understand that these hearings are legal proceedings of the Legislative Assembly, protected by parliamentary privilege. That gives you certain protections but also certain responsibilities. It means that you are protected from certain legal action such as being sued for defamation for what you say at this public hearing. It also means that you have a responsibility to tell the committee the truth. Giving false or misleading evidence will be treated by the Assembly as a serious matter. Do you understand that?

Mrs Daniels: Yes.

THE CHAIR: Before we go any further, Pat, we can have this as an in-camera hearing so that it is not open, as is a public hearing.

Mrs Daniels: That might be better.

THE CHAIR: You would prefer that; okay, we will do that. What happens now is that the proceedings will be recorded but not circulated around the building. Members of the public will not be able to come in.

Evidence was then taken in camera.

ANDREA SIMMONS and

MICHAEL WOODHEAD were called.

THE CHAIR: You should understand that these hearings are legal proceedings of the Legislative Assembly protected by parliamentary privilege. That gives you certain protections but also certain responsibilities. It means that you are protected from certain legal actions, such as being sued for defamation, for what you say at this public hearing. It also means that you have a responsibility to tell the committee the truth. Giving false or misleading evidence will be treated by the Assembly as a serious matter. Do you both understand that?

Ms Simmons: Yes.

Mr Woodhead: Yes.

THE CHAIR: Could you please state your names and the capacity in which you appear today, for the record.

Ms Simmons: My name is Andrea Simmons and I am the Manager at the ACT Disability, Aged and Carer Advocacy Service.

Mr Woodhead: My name is Michael Woodhead and I am an advocate for people with a psychiatric disability with the ACT Disability, Aged and Carer Advocacy Service.

THE CHAIR: I would like to start by welcoming you and thanking you for appearing today before the inquiry. We have discovered that, since we have been talking about it out in the media, a lot of people, like you, have come to us and said, "Hang on; we are involved with this in this way." So we don't want to stop people from coming in and giving us their experiences for the sake of a deadline; we would rather have a quality report. So thank you. Would you like to make an opening statement?

Ms Simmons: I appreciate very much the opportunity to be able to speak to you today. I know we were a last-minute ring-in, so thank you for making the space. I will say a little bit about ADACAS before we start. You know that we are an advocacy service for people with disability and people who are ageing, and that people with disability include people with a psychiatric disability.

We get funding for our advocacy work from both the commonwealth government and the ACT government and specifically we get funding from the commonwealth government for an advocate for people with psychiatric disability. We have been the only independent advocacy agency in the ACT funded to provide people with psychiatric disability with advocacy, and we have had over 11 years experience now in providing this form of advocacy.

The advocacy that ADACAS provides for people with mental illness can cover a really broad range of issues. These, obviously, include things like housing, which is why we are here, but also things to do with the legal system, with education, with people's finances and their relationships with family, neighbours, service providers and doctors. In the past few months—and in fact right now—ADACAS is providing advocacy to more than 15 people with mental illness whose mental health has been significantly impacted upon by poor responses from Housing ACT.

That is why we were very keen to come. We felt we had some information that it was important to put forward. We also feel that better and different kinds of responses from Housing ACT would considerably diminish the need for other services to play a role with some of these people, and we know that, as soon as you get a whole lot of services involved, this creates a quite considerable additional cost for the community.

I have got a range of key messages that I thought I would put upfront so that you know what I am talking about on the way through. One of the key messages is that for people with mental illness access to safe, secure and affordable housing is vital to their health and wellbeing—and probably more so for that group than almost anyone else in the community. Public housing is the most accessible option for many people with mental illness as, because of their illness, they often don’t have the financial capacity to enter the private market or, indeed, they frequently don’t have the necessary positive rental history to put forward in order to get into the private rental market.

Another key message is that to gain access to public housing today—you already know all this—is very difficult for anyone; but we would say that it is often even more difficult for someone because of their mental illness. To achieve a positive housing situation for a person with mental illness often requires considerable ongoing external support. That is a key message that we want to get across here today. The provision of housing that is compatible with the mental health and other needs of the person is vital to their mental health and often their physical health. In other words, it is no good having ordinary housing; you have to have housing that is specific to the person’s needs—and that will be different depending on their particular issues. The usual ACT Housing processes might occasionally need modification to accommodate the disabilities of tenants with mental illness.

I suppose the final and key point to that is that we don’t believe the ACT needs more institutions or group homes. What we do need is better support for people to live ordinary lives in the community. So, as I said before, the health and wellbeing of people with mental illness is more susceptible than most people’s to fluctuations in the safety and security of their housing. When someone’s internal life is chaotic, confused or depressed, it is even more important that their external surroundings be appropriate to their needs. Yet the capacity of people with mental illness to access appropriate housing in the ACT is at an all-time low due to the lengthy waiting lists for access to ACT public housing.

I know some of you, perhaps all of you, may be aware of the report that was recently put out by ACT Shelter and ACTCOSS titled *The wealth of home*. In that report they said that the number of applicants for early allocation category 1, which is basically the only way you get into public housing now—and that is the group which are deemed to be functionally homeless and in urgent need of housing—has tripled in the last four years, and the average waiting time for each allocation in that group is 189 days. In some areas this has meant a waiting period for people who are acknowledged to be without safe or affordable housing of over a year.

In situations where a person has a mental illness, the stopgap measures that are likely to be available to them in the community will almost certainly lead to a deterioration of their mental health. So the mere fact of not having proper housing is going to, in all likelihood, lead to the need for a whole range of other services for this group of people. Yet, because they don't have permanent housing, it is often much harder for that group of people to access the services that they need and for services to find them.

I will go on to the eligibility, working my way through the questions that you have. We find that many people with mental illness find it almost impossible on their own to manage the paperwork and communication necessary with ACT Housing to successfully apply for and gain access to public housing. In order to establish their entitlement to be on the early allocation 1 waiting list, a range of documentation needs to be gathered and presented, and this in itself can be an enormous obstacle for people whose lives are somewhat chaotic. Even when people try and get the documentation they need, often the people they need it from don't know what to write and you end up with documentation that is no good and you have to go back again.

These sorts of administrative things can be extraordinarily difficult for people with mental illness—not all people with mental illness, but often the group that we work with. So what we find is that advocacy support is frequently needed to navigate the system, yet ADACAS has one part-time advocate dedicated to providing this kind of advocacy to people with psychiatric disability, and our advocate provides advocacy across the whole range of areas. So housing is just one of a range of things, as I said before, that we advocate on. What we are finding at the moment is that housing issues are chewing up an enormous amount of our advocacy time.

One aspect of the eligibility criteria for public housing that we believe needs further consideration is the way the assets test can be used to deny entry to public housing to people who are functionally homeless but who notionally have assets. This is a group that, in theory, have assets but often cannot get access to them. It might happen, for example, where you have a homeless person who jointly owns a house and the house is lived in by their ex-partner or their ex-wife and some of their children and they are not able to, in any way, access the assets that are tied up in the house. And, in fact, nor do some of them want to; they don't believe they should be turfing their family out of the home so that they can get hold of the assets. But it often leaves them functionally homeless. These might be people who are prohibited from being at the house because of domestic violence orders or just simply because of a marriage breakdown or partnership breakdown.

In terms of the support mechanisms for people who currently live in public housing, we think this is the area of great significance for the government and needs to be paid a lot more attention to. ADACAS's experience in working with people with mental illness in public housing is that the support that is available to them is largely medical, and it is often chemical in nature. Very commonly people who want access to therapy services aren't able to get them, and little attention is paid, in any case, to their social and community living needs.

It is also our experience that most individualised support for people with mental illness occurs in response to crisis situations rather than on the basis that prevention is better than cure. In particular, we think it is vital that appropriate support is available to assist people when they start to become unwell, when other people identify them as becoming unwell or when they identify themselves as being at risk. We know that time and time again people cry out for help because they know their situation is going downhill, and they can't get it.

The support that is provided needs to be individualised, as I said before, so that it focuses on the individual attributes and circumstances of the person, and it should be aimed at creating the kind of environment in which the person is likely to thrive and to have a good life. So we are talking about support that looks at the whole person, at their fundamental needs, and not merely at where they are in the medical scheme of things. This means, in addition to managing the medical aspects of a person's illness, that support needs to be provided to assist the person to identify and create community supports and linkages. That's enormously important.

We know from research into health inequalities that was done in England a little while back that one of the key things to maintain people's health—everybody's health—is their links to other members of the community and their family and friends. People with mental illness will need assistance to manage the requirements of day-to-day living on occasions, and sometimes just to organise the elements that go into that. Sometimes they need help to successfully navigate the outside world, including the responsibilities of being a tenant, of being a friend, of being a neighbour and being a worker. Sometimes the responsibilities that go with those valued roles that we have are very difficult for people to manage without some support and some assistance in knowing how to do that. The support that is provided needs to be timely and responsive to the fluctuating needs of the individual. Many people with mental illness are functioning quite fine today but maybe tomorrow or next week or down the track they are not going to be, so we need very flexible support for this group.

It is vital that ACT Housing, as a housing provider, recognise that they have a role to play in assisting people with mental illness to maintain their tenancies. They're not a landlord in the normal course of events. We believe they have specific additional responsibilities. ADACAS is commonly called upon to prevent the eviction of a person with a mental illness in circumstances where their illness related disabilities have impeded their ability to conform with the usual requirements placed on tenants. In the vast majority of cases, by the time we get to be involved a very complex set of circumstances has arisen, yet we think those circumstances could have largely been avoided by a few key things.

They could be avoided if ACT Housing recognised the flow-on effects of the person's disability and made appropriate early accommodations to manage this. A small example that I can think of is that with certain psychiatric disabilities it is very threatening for people to have someone that they don't know come into their home, and ACT Housing like to do inspections of houses, for good reason, to keep an eye on what maintenance requirements there are. Perhaps different kinds of arrangements for a person that has that sort of issue can be made—maybe they don't have to be there and someone they trust can be there when the inspection takes place, or maybe someone that they trust and that ACT Housing trusts can do the inspection on ACT Housing's behalf.

These are the sorts of accommodations that sometimes need to be made for people with mental illness that we find are not being made at the moment or are not being made unless there is an advocate that says that this needs to happen and explains how it could happen.

We feel that issues could be avoided by ACT Housing taking proper account of the illness related disabilities of the person concerned in determining the original housing allocation. What we commonly find is that even before people get into a house that has been allocated we could say that, because they have this particular psychiatric condition, they are likely to find a particular environment threatening or they are likely to find a particular environment is going to exacerbate their illness. It makes no sense for ACT Housing to treat this group of people in the way they treat ordinary tenants and just say, “Okay, you fit the criteria for this form of housing—away you go.”

ACT Housing could be acting quickly and respectfully to rectify inappropriate housing allocation when it is found, when it is discovered. Sometimes you don’t know when you put someone in a house that it is going to be a problem because of their illness, but you later find out that it is. We find that the time taken to remedy that problem, even though it is accepted that the problem is there, can be huge, and in the meantime the person’s health is falling apart and often the relationships with people around them are falling apart. It can create some very serious problems.

We think ACT Housing ought to take responsibility to ensure that appropriate support is available to a tenant when problems first appear. We know it is not ACT Housing’s responsibility to provide the support, but they are often the first agency to hear about the problems because a tenant will let them know or because they will discover something when they do an inspection. So it should at least be their responsibility to ensure that the appropriate services and supports are engaged at that point.

We think ACT Housing—and I know they don’t agree with me on this—also have a contractual responsibility to ensure the quiet enjoyment by a tenant of their property. We know that is in the contract, yet ACT Housing, to date, take the view that issues with other tenants, even if they’re public housing tenants as well, are not their problem; you go to the police. But looking to the police to handle those sorts of issues is escalating things enormously. We would argue that, if you can find a way to deal with these issues early on in the piece, you end up with far less damage to individuals and usually get a far better outcome.

I would just like to take this opportunity to emphasise the importance of housing that is appropriate to people’s needs. I think it is good to have a few examples of the sorts of things that go wrong when you are making a housing allocation. For some people it is vital that they not be located close to others, or with windows that look directly onto their neighbours. People with paranoid schizophrenia, for example, will often become concerned that people are spying on them if they live in too close proximity to anyone else. For others, the level of noise—maybe a busy street—can be a problem or living near somewhere where there are lots of people can be a problem. For others, relationship building is an issue. If you are in a complex that has a lot of tenants, commonly you will need some skills in terms of connecting with other tenants, and if you don’t have those skills sometimes the other tenants take a very dim view of you and make life difficult for you.

We’ve supported people with mental illness in these sorts of circumstances where they have been subject to threats to their person, to their visitors, to their pets and their property. We've supported people that have had ongoing verbal abuse every time they stepped outside their door and have had their car damaged, their lawnmower—all kinds of things—simply because people did not really understand who they were and what their circumstances were, or, if they did understand, they did not appreciate it.

An individualised approach to housing provision in the first instance, or when changes to housing are made, can avoid illness exacerbations, conflicts with neighbours and conflict with Housing ACT. So we are talking about things that are necessary to keep people well. In circumstances where the housing provided does not take account of the mental health needs of the person, the likely outcome, as I have already mentioned, is increasing unwellness for the tenant and an escalation of tenancy related problems.

I would like to go on to the opportunities for the involvement of non-government stakeholders. This is an area where we would say that you need quite a deal of caution. We would support involvement by community organisations that have a role to play in assisting people to link with their community. There are some really good examples of that in the ACT. I would like to just share one with you, which is what Centacare call their Links program. This currently works with people with physical disabilities and intellectual disabilities, but there is no reason why it wouldn't work well with people with mental illness as well. The program is based on acknowledging that you don't want necessarily for people with disabilities or people who are vulnerable generally to be living all together. But they need assistance to connect with communities and they like, sometimes, to have the possibility of support from other people who share the same kind of difficulties in connecting.

The links program at Centracare basically has a support person who lives in a neighbourhood; they live in their own house, in their own way, and they support maybe up to eight or 10 other people that live in the neighbourhood, but those eight to 10 other people live in their own house. Their house might be an ACT Housing house, it might be a rental property, it might be a property that belongs to a family member—and the people live with whomever they choose in their houses. What is special about it is that there is a person who lives nearby who is designated to support them to connect with the community and to create natural supports.

It is a program that works very well in England. It is something that is tried and we would love to see more of it in Canberra. We're aware of a project in Melbourne called the Macaulay project, which I tried desperately to get you some more information about today but we could not find it. That is another project that is a good example of community organisations working to provide linkages for people with mental illness into the broader community.

The other area that I think might prove to be beneficial in the future involves community housing providers. A community housing provider that has housing in a wide range of areas and of different types—I know one who is probably interested now—might specialise in providing a bit fuller tenancy support to people with mental illness. So, once again, you would have people living in their own home, a home that is provided by a community housing provider, but they would have access to a little bit more support in the sense of someone who knows what their limitations might be in terms of managing tenancies.

One of the important things to keep in mind is that we think it is incredibly important that the concept of support for people is something different from the tenancy management of people. We think this is vital because what we find is that, if it's not kept separate, people can lose their house because suddenly their support needs change. So that they either need a higher level of support or they need a lower level of support. We believe people with mental illness, just like everybody else, are entitled to security of tenure in their home and the confidence that their home is theirs. So, when you are looking at any sort of long-term accommodation arrangements, we would say that people ought to have an entitlement to stay in their own home and have the support come to them.

Mr Woodhead: This was one of the findings of the Gallop inquiry about people with a disability—the parallels that needs to be there in the mental health area.

Ms Simmons: That was my next point. We also think that that sort of arrangement allows people a far greater choice in how their lives are managed and it allows them a choice to say, "We don't actually like the kind of support we are getting from this service provider, so we can choose another one without being at risk of losing our house." It also can work the other way. It can be that people outgrow a particular living arrangement, like we all do sometimes, and want something different but they like the person that is providing the support and want to take them with them. If people with disabilities of all kinds have made a connection with somebody who is a good support worker in their life, they really want to keep those people beside them, whether they move house or not.

We would also say that it's discriminatory against people with mental illness to insist that if they want support they need to have it in an institutional setting. We don't expect the rest of the world to have to live in an institutional setting if they want particular kinds of support and assistance, yet we tend to say that with people with mental illness.

We have looked at the national mental health strategy and the national mental health standards and they have a real emphasis on recognition of the unique physical, emotional, spiritual and cultural dimensions of a person. We think that those standards give authority to what we are saying; that people with a mental illness should have the same kinds of choices in their lives about where they live as the rest of us have.

I suppose that's the important point to finish on, except to say that it is for those sorts of reasons that we don't think that we need more institutions in the ACT. What we need are better targeted and different kinds of support for people—support that really focuses on how to build a good life, a life that is connected with community and that does not rely necessarily on medical intervention but on having the support around that keeps people's lives running along nicely.

THE CHAIR: Thank you. Ms Simmons has made all the comments; did you want to add something, Mr Woodhead?

Mr Woodhead: I just wanted to add a couple of things, although obviously we cooperated on that. One is the tendency to group people who are marginalised in high-density complexes so that people with a mental illness live next door to people with drug and alcohol issues, people who have long-term unemployment issues or people with personality disorders and such. There is plenty of evidence to show that that leads to an exponential increase in social problems, and many of those lead to the breakdown of housing for our clients. There's a flow-on effect to ACT Health, with the cost of hospitalisation or intervention for people with a mental illness being enormous. Preventative measures are certainly economically wise.

Another issue around support services is that the issues of housing and support services can't be divorced. If we're going to have an aim of allowing a person with a mental illness to have a valued life in which they can thrive, we need to look at some of those support services: do they do their best to ensure that happens, or do they in some ways further stigmatise people with mental illness?

For instance, some support services group people, so you have bowling for people with mental illness, cooking for people with mental illness and all these sort of things. That can work if it is a stepping stone, but very often it is not a stepping stone; it is an end in itself. People go to places like the Rainbow and they stay at the Rainbow. There does not appear to be an exit strategy to move people on.

If there were to be an increase in funding for support services, I think that we would look very closely at what are their values, what are their aims to build true inclusion for people with mental illness. That's all I would like to add. Thank you.

Ms Simmons: One other point is that we are going to have a prison in the ACT soon, and we know that a very large proportion of people in prison have mental illnesses. I think what we should be doing and thinking about in terms of the prison happening is how we are going to support that group of people to re-enter the community in a way that means they are not likely to offend but they have their mental illness addressed and the issues that flow from that addressed in a way that means they can have a proper life.

THE CHAIR: I just want to ask a question, playing the devil's advocate. I would like to preface it by saying that I don't dispute the need for more dollars going into the non-acute end of support for people with mental illness. You made a very interesting statement about the infringement of people's human rights by detaining them in a psychiatric institution. You must surely, though, acknowledge that there will always be a need for some level of psychiatric institution; that people going through a psychotic episode are not the best people to judge what they need and whether they need to be detained.

Ms Simmons: Perhaps I did not express myself well enough either. I think I said that I felt it was discriminatory to expect people with a mental illness, if they needed support, to live in a group home or in an institution. In talking about that, I am thinking of longer-term accommodation. We would recognise, when we are talking about a psychotic episode or something that requires them to go to the hospital, that we never intend that people should stay in hospital long term; they should be there long enough to have their health issues addressed in the way that people who go to hospital generally are there long enough to have their health issues addressed.

So, while I recognise that there is a need on occasions for people to get that kind of level of intervention, I would point out that in some societies, and there are examples of this in Europe and in the US, there's very little locking up of people without their permission. If you have the ready availability of the appropriate supports when people first say they need them, you have people voluntarily choosing to access the support and you have outcomes that are beneficial to people, without having used physical restraint, without having taken away their liberty. They have made a choice to enter the facility or whatever it is that they need to get the assistance from. I would like to see a lot more emphasis in the ACT on making things available to people when they need it so they can make active choices to get what they need and don't need it to be imposed upon them by someone else.

THE CHAIR: Okay, sorry; I misunderstood part of what you said before.

Ms Simmons: No, I did roll a whole lot of things in together, so it would be quite easy for that.

MS PORTER: I realise we're running out of time, but I just wanted to ask this quick question about what you term an institution. A lot of people who have come before us have said that they really would like to see step-down and step-up facilities for people who are wanting, voluntarily perhaps, to enter into some kind of arrangement which is not an acute hospital setting, or when they leave an acute hospital setting are not ready to go back out into the community and would prefer to be in a place where they feel they are safe because they are with other people who can be with and help them while they are going through whatever they are going through.

Another suggestion has been that perhaps we could have clusters of housing together with people not living necessarily with each other but close to one another, which is a different model that we don't have at the moment, with perhaps a supervisor or someone on site who could be there to provide support when needed. Those are a couple of things that have been mentioned to us quite frequently. Would you see those as institutions? I just want to unpick that word and see what it means.

Ms Simmons: It is a good question, because what makes up an institution is not only the buildings that are present but also the way things are done. What you see with an institution is what we would call institutional behaviour, with decisions being taken for people rather than their being able to take them themselves, a regular routine or set of arrangements being imposed on people because it is easier from an administrative point of view for things to happen that way. It is clear that some things very easily fall into that category. So an aged care facility, very clearly, is an institution. A hospital is very clearly an institution. I would say that a step-down facility is very clearly an institution as well.

But, when we talk about institutions not being appropriate, we are saying for people's ordinary living, for their long-term accommodation. If we are talking about a step-down facility as something that lasts for a few weeks in the way of a rehab setting, I'm not arguing against that kind of thing. What I am arguing against is the kind of facility that gets called a step-down facility but where people end up living their lives. We commonly find that something will have one name but it will be used for a different purpose. It's that kind of purpose that we would object to, where people go into something for a short-term set of reasons but they end up being left there because the appropriate supports for them to move into their own home are not there.

I would also have to say, when you look at group home situations, that very commonly group homes that we currently have in the ACT do operate as institutions according to the definition that I gave you before, because they do operate to a standard set of policies, they do operate in ways that limit people's choices, in ways that say, "We are all doing X today, so you will do that because everybody else is and because that is the money we have available to provide a worker to go with you to do that."

Cluster housing is an interesting one because it depends how that operates as to whether you would regard that as an institution. With the City Edge apartments, where you have four or five apartments in a complex of 100 and everybody else living in those apartments is your normal mix of the Canberra community but they are located closely enough that there is a support worker who could live in another apartment even, I would say we are not talking about an institution; we are talking about people living in an environment like the rest of the community does—and it works and they get the support that they need. That sits more like the links model that I was talking about earlier.

If, on the other hand, what you have is a group of houses that are all right next door to each other and everybody in the outside community marks them as different and marks them as being the place where people with mental illness live, and the houses themselves all run according to a schedule and the staff operate according to a schedule in a particular way that takes away the choice of the individuals to control what happens in their lives in those houses, then you are talking about an institution. So it is not just about the bricks and mortar and how they are arranged; it's how the supports are arranged, how the management is done. All of those things are important.

Anne Cross did a very interesting paper on this for the Disability Reform Group a few years ago. She identified those things you look at to see whether what you have is an institutional arrangement or not. I probably should try and dig that out for you because—

MS PORTER: Do you have the name of the paper?

Ms Simmons: She did it for the Disability Reform Group but it was published as one of their sector releases. I can find it for you and send it through. She was a consultant to the government at the time but she did that work and it was very informative.

THE CHAIR: I am aware that we are over time, but Mrs Burke has not had a chance to ask a question.

MRS BURKE: It probably is more of a statement than a question, but I just want to say thankyou for coming today and that you have clearly articulated a message I have been trying to get out there for quite some time. I have been banging my head up and down trying to get people to see the difference between adequate and appropriate. You have clearly given the committee some real further steps forward. It is just not one person crying in the wilderness; we have had a few people say that, and I think that we do need to define what is adequate and what is appropriate.

THE CHAIR: Thank you for your time today. We do appreciate it and we will be in contact with the proof transcript for you to check for accuracy. We will also keep you informed of the progress of the inquiry and let you know when we have the final report to give, but it is looking further away than certainly I had anticipated.

Committee adjourned at 12.11 pm.