

**FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE**

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

Melbourne— 22 October 2008

Members

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Deputy Chair: Mrs E. J. Powell

Staff

Acting Executive Officer: Mr M. Bromley

Witness

Mrs N. McNamara, parent carer.

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**Mrs McNAMARA** — Good morning, folk. I doubt that I will need the speaker, but I will make sure you can hear.

**The CHAIR** — Thank you, Mrs McNamara, you can take a seat.

**Mrs McNAMARA** — I happen to be disabled. It is a bit more comfortable here at the moment, thank you. My son has a syndrome which approximately 1 in 25 000 are born with. He is in a DHS CRU with people who cannot speak, and he cannot hold a conversation. Therefore his skills, which he has had, have gone down the pipe. As late as last night — because my son will be home with me over the Melbourne Cup weekend — I drove him to the doctor, but I could not go in. I said, ‘Of course I can go in’. ‘Oh, no, you can’t!’. I said, ‘You have got the medical sheet, but I can still go in’ — absolutely dictating to me, despite the freedom that we fought for from 1942 to 1945. I said, ‘I can go anywhere I like. Surely you have got a waiting room while you go in with my son’.

Look, I have gotten my son down in his weight, because the hypothalamus of the brain absolutely governs their eating and their temperature. The hypothalamus of the brain is about the size of a peanut, but it has got a hell of a big governing factor. He has been carted to three different weight loss clinics — Melbourne, Monash and now repatriation. They have got the wrong diet. And yet mum can get the weight down from 21 stone 6 pounds to 8 stone in 30 months, because I have a routine and timing — something the staff do not know and will not abide by. The staff believe in saying, ‘Go and sit down and leave us alone’. They always say that they look after people. In other words, they are a minder service and they could not care a stuff — pardon my language — whether the person is well or not well.

They got my son sacked — after 19 years and 4 months service at the same place. He is now allowed to go three mornings a week for 4 hours, because I kicked up. I did not go to the war and go around the block for 80-odd years for them to stand over me. They are public servants. I was a civil servant long before they were born, and we had to be both — civil and servants. They say, ‘We look after people’. How the hell can they look after the person when they do not even keep to the diet that is there? Their goods — they can lose things. Where they go, God only knows — and I do not know whether He is there or not. ‘We can’t find them,’ they say.

When my son was working his peers at work tried to ring me on the Friday night. Saturday morning they got me and said my son was off colour again with a temperature. That was a Saturday morning. I sat tight. I thought, ‘Wait, and if anything happens to him, my God, I will be after you’. Monday night they took him to the local doctor; he had to wait. The doctor said, ‘I think he has got hypothermia’, so the doctor rang for a MICA. Sure he had hypothermia — because of the loss of his job after 19 years and 4 months. He was left alone in his room to pore over the farewell card. He finished up having a breakdown and had to be certified to be restrained. My son has never had to be restrained in this life, and he turned 45 last April. I was lied to, to get him in there, so that the then house supervisor could get a cluster manager — and she could not manage a cluster of pins without doing the wrong thing; and she has had no more promotions, if she is still there. They are still lying like pegs in a store, and they think I cannot see a hole in a barbed wire fence.

When the department had house committees I was on several — but my son was not then in a CRU — and they were absolutely fantastic, bar a couple. My son’s former music teacher lived opposite a CRU. When you can see drugs and sex on the front lawn, you wonder what the hell you have hit. I did. When I mentioned it to a committee on which I served, they said, ‘But it does not go on’. I said, ‘But do you know? Have you seen it?’. They said no.

I said, ‘Well, I have’. I said, ‘We are going to get a petition and my name will head the list’. A few months later a new house supervisor came. Blimey Teddy, it was the same one who was at the other place that had drugs and sex on the front lawn. There is a lot to be desired in the integrity of the staff. With my son, I told you I had gotten the weight down, but in the Hume region,

Mr Sainsbury — I hope he doesn't mind me mentioning his name — has got a person suffering from Prader-Willi syndrome, which is where the hypothalamus governs eating and temperature, from 100-odd — 105 or 106 kilograms — down to 60.

I think it is wondered by the staff where my son is why I praise people. I will give praise to a gatepost if it does the right thing. But where the staff will not do the right thing, I will condemn them from here to kingdom come if there is a place. I have nothing but absolute abhorrence for that staff, and I want my son out of there as quickly as possible. The people with whom he is are older than me, and I am 83. They cannot speak. Some cannot speak any more than that glass of water. My son's skills have been diminished. He was offered, with his fares paid and everything paid, to play in America. How many persons would get the opportunity to play in America for a worldwide conference? And it was said in VCAT that I have taken my son to every Prader-Willi syndrome conference ever had. Funny that I have only been to four — two in New Zealand, one in South Australia and one in Melbourne.

**The CHAIR** — Mrs McNamara, I am conscious of the time.

**Mrs McNAMARA** — Time's up? Thank you, and thank you for listening. I hope sincerely that other parents do not have the fun and trouble I am having.

**The CHAIR** — Thank you.

**Witness withdrew.**