

FAMILY AND COMMUNITY

DEVELOPMENT COMMITTEE

MR J. PERERA MLA, Chair
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**INQUIRY INTO SUPPORTED ACCOMMODATION
FOR VICTORIANS WITH A DISABILITY OR
MENTAL ILLNESS**

Witnesses:

MRS BERNADETTE RANSOM
Parent Carer

MRS KATHERINE HAGGARTY
Parent Carer

BENDIGO

WEDNESDAY, 19 NOVEMBER 2008

THE CHAIR: All right. Thank you very much. I'd like to call upon Mrs Bernadette Ransom, and I believe Mrs Katherine Haggarty is coming together?

MS RANSOM: Yes.

THE CHAIR: Good afternoon. Thank you very much for giving evidence. I'm not going to go through the introduction because you were here for some time. So I will get you to make your verbal submission. Before that, please introduce yourself for the Hansard.

MS RANSOM: I am Bernadette Ransom. I'm a parent of a 19 year old son who has Down's syndrome. I'm also involved with Centacare here in Bendigo. We are looking at accommodation for adults with intellectual disability. A lot of the issues have been covered. How I first came to be involved – when Andrew was only a couple of years old, I read an article in a magazine about L'Arche communities. (L'Arche is a French word that means ark, a place of refuge) L'Arche communities were founded by Jean Vanier, a French Canadian in the 1960s where he took two adults from an institution into his home to live with him as family. From that decision he made, L'Arche communities have grown and there are hundreds of communities all over the world. There are a few communities in Australia; one in Hobart, Sydney, Canberra, Brisbane, and a community is being established in Melbourne.

And although Andrew was a very small child, you always have such things as accommodation in your mind as a parent. I thought what they were doing in L'Arche communities was living life as a family with adults with intellectual disability in a home environment. When our other children leave home, they would go to their own homes, and that is what I would like for our son. So in 1999, another parent – a friend of mine who had a son with a disability and I thought: well, what can we do in Bendigo? She was a nurse visiting elderly in their homes and noticing that there were a lot of elderly parents still caring for their children with intellectual disability - some in their 30s, 40s, and 50s still living with their parents.

So that was the impetus for us to see what we could do in Bendigo. I went to DHS and then found that for each one place that was available – and this was eight years ago – I think there were 170 people on the waiting list. So it's probably changed so much since then. There may be more accommodation available, but still I'm sure the numbers on the waiting list would have risen since then. We then approached Centacare because we thought as just two parents we needed more help to see what we could do. L'Arche communities are faith-based. They started off as being Catholic, but it can be any faith, whether you're a Jewish person, or of any other faith but there is that faith base. We were Catholics, and we thought: that this is what we wanted for our children so that they could live the faith into their adulthood.

Centacare were interested. It was a new thing for them to take on, but in their caring role, thought perhaps this would be something that they would be happy to be involved in. The few issues that we've come up against – the list, as it's called. We, too, have had differing opinions about the list. Andrew our son –has been registered with DHS since he was born, but we haven't needed any services, but they know he's around. So one time we were told, "Yes, you must all go and register." You go along

and they say, “No, you don’t need to be on this list until the time that you are ready for your son to go into accommodation.”

So that is our understanding at the moment, and with Centacare’s inquiries, we were thinking: yes, we’ll put up a submission to the Department of Human Services, about the accommodation project that they were interested in getting together, but their reaction is, “Well, a lot of the people that you have involved are not on our list.” And then our parents will say, “No way is our son or daughter’s name going on that list, because we want to know where they’re going first.” We don’t want to be in the position that – when the name comes up, your son or daughter can end up perhaps anywhere else in Victoria, in a place where you’re not happy for them to be going. So that is the reason, it’s a bit of a catch 22, why they’re not on the list.

It seems with DHS, the only way to get accommodation is if there is a crisis in the family - death of parents, ill health, or other extreme circumstances. From our experience, and from a lot of the families that we are dealing with, the parents are middle-aged to elderly. One of our parents is 87, still caring for her 43 or 44 year old son because there is nowhere that she would be happy for him to go. I think it should be a choice of the parent at what time you think is appropriate for their son or daughter to leave home. I would like to think that my son would be going to live independently when he’s late 20s to early 30s, and as my other son says, “Poor Andrew, he’s still living with you and Dad.” We’re in our 60s, and I think it would be more appropriate for him to be living with people his own age.

Another issue that we found with DHS was – that we want 24 hour supported care for Andrew. Andrew – he is able in many ways, but we would not leave him by himself overnight, and as has been pointed out before, if he was sick or for any reason couldn’t go to work, that there would need to be supervision. For instance, if there is a bad thunderstorm in the night, he is quite afraid of that. If someone would come to the door, he would not know how to deal with an issue. If all the power went out or the gas didn’t work, or anything like that, I don’t think he would be capable of coping with such a situation or knowing what to do. He can shop, but he would need assistance as he has no understanding of money. All our parents feel that 24 hour supported care is the only way that we would like our children to live.

It was suggested from DHS that perhaps he could go and live in a unit either by himself or with someone else and just have perhaps care in the morning and the evening, but for me, I don’t think that is really appropriate. I would like Andrew to be part of a family which, to me, means say three, four, five others. It means being able to celebrate as it was mentioned before, birthdays, family activities, and to live life as a family. And I know we’ve come a long way since the institution days, but I would like to see him living in accommodation with others. At the moment, we have a little community which is called Faith and Light, where we all meet once a month. There are a lot of common threads among our community members, with our parents and with our sons and daughters, who might be attending a lot of the same day programs, sporting programs, school and other things. We are looking at this as a little community and would like to think one day that we could establish accommodation for our little group.

The ages vary from the 40s down to the teens at the moment. We would like to think that there would be a transitional period where our sons and daughters might be able to stay one day a week, then two, and have that opportunity to slowly leave home so it's not such a dramatic loss of family like it is when there is a crisis in the family. I think it's just a parent's right to choose the time for their son and daughter to leave home. The funding at the moment seems to be very inadequate to give our children the same lifestyle that they're used to. I think it would have to be doubled or tripled to enable that.

Another issue, I think, was when I mentioned to DHS that we were looking at having a faith-based community. That was another issue because it was looked at as being discriminatory. So I don't know how we could address that situation as well.

Another issue – I know another parent who has given us another reason for us looking into accommodation - the constant changing of staff and the staff not listening to the parents. These friends have a son who is in high care and the high changeover in staff is very unsettling. I think they seem to be quite well paid and perhaps a lot of people may take on the position because it is well paid, but not necessarily because they have the heart or the interest in the job at hand. You just get used to talking about the needs of your son or daughter, and then that person moves on.

I guess we can't do anything about that, but especially these days in any sort of job, people seem to be there for a short time and then move on, but with our people, continuity is everything. Understanding the person involved and listening to parents, I think they were two major issues that she always felt and there was not a lot of flexibility.

THE CHAIR: I'm conscious of the time. Can you conclude that, your submission?

MS RANSOM: Sorry?

THE CHAIR: I'm conscious of the time.

MS RANSOM: Okay, then. Well, I think I'm just about the end of - - -

THE CHAIR: Yes, sure.

MS RANSOM: - - - my list of things I had, so – okay, would you care to - - -

THE CHAIR: Please introduce yourself.

MS HAGGARTY: Katherine Haggarty. I've been sitting around tables like this for 37 plus years. I have a box full of state government plans, the 10 year plan, the two year plan, the one year plan, the three year plan. We have seen services improve enormously over those years. I've probably held positions in most areas of disability I'm here today as a mother. It is the raw emotion of a mother that has been the driving force which has improved services over 40 years, so it's not a negative force, it's a very positive force. Too long have we listened to professionals say, "She's just an emotional mother."

No, an emotional mother will drive services to improve them. Intellectual disability is unique because in most instances the mother is the prime carer. My mother is 95 and she's just been put into care. I have *not* got a maternal instinct about my mother. I have a maternal instinct about my son. In all other care services throughout an adult's life, it is very, very rare that we have to deal with the mother of the adult. You generally deal with the children of the adult. We've seen services improve, but now services have come to a standstill due to "no growth funding"

This has crippled many organisations where the services can no longer expand or improve, because effectively, their funding has gone backward, and so we're watching tight reins be put in place. I'd like to reinforce everything Bernadette said. Certainly, my son is one that needs 24 hour supervision, and I was interested in what Ian said. In fact, he's one of the only people to clearly define the difference between care and support. We as parents are carers. Too long, we've been made to feel guilty because we have not supported our adult to learn more, and frequently, the problem has been put, "Well, it's your fault. You're the emotional parent who has smothered him/her and not let go"..

Ian reinforced this later when he said, "Your role is a parent. You're the carer. You're not the support person." Parents, for lots of reasons give up teaching their adult children – they burn out and become tired. I have two children, one who came out of Duntroon – that's one of the highest institutes in the land, as we know. So clearly, I'm a mother who is capable of letting go of my children and teaching them to move on, set their goals, and so on. The other one is 38, and every morning I shave him and shower him, so my role as a mother can be measured by those two children.

And which type of mother am I? The one with a child at Duntroon, or the one that still has a highly dependant adult child? my skills have not altered in raising my two children. The difference between the role of caring and support is very interesting. It will help your decisions in terms of funding. Are you going to fund care, or are you going to fund support? Governments and politicians always speak from one aspect, and that's the hip pocket. I'm sorry to be cynical, but I was given figures as much as 20 years ago to say that any person in care, that needed 24 hours supervision a day cost the government between \$1500 and \$5000 per head per week. these figures, were for any type of institutional care

Institutions are closed and residential care is now given in CRU's. Parents are keeping their children at home. So we know that governments have gone along the deinstitutionalised path because it saved them heaps of money- There are funding problems, as Bernadette pointed out, with the department again it's emotional stuff, like, "You're queue jumping if you want to build a house and the Department *not Parents* decide how it is to be run.

Surely the government must be pleased that Centacare and a core of parents are prepared to provide the infrastructure for X amount of people. Centacare are talking about not just one house. If they're successful with that, they will do another and another, but the department is saying, "No, you're jumping the queue. Get back on the list." This precious list – half of the people that we're dealing with haven't even got their names on the list. Queue jumping happens in health care all the time. Those with private health cover jump the queue.

My husband recently saw a doctor on the Monday and by the following Monday he was hospitalised for a hip replacement. I have another relative in Melbourne that has been waiting three years for a hip replacement in the public system of health care. . If we are going to privately try and fund care for our, adult children with a disability shouldn't we be encouraged to do that? And then allow parents to put in place the sorts of things like the spirituality and other things parents value. We have a core of parents here that are caring and concerned. They are prepared to work with Centacare and the Maureen Considine Fund locally. They are prepared to put up bricks and mortar to put in place their values, but we need a response from the government that is better than DHS are giving us. And there was - - -

MS RANSOM: Just one other issue, too, was about the respite. It appears at the moment DHS won't entertain any idea of having respite on the same location as permanent accommodation. I can't quite understand what that is about. I mean, one of our ideas was perhaps if we had a four or five-roomed house for our people – could one of those rooms be available for respite care? We thought, in our situation, in our group, we might have four of our older residents who are permanently there, but then say if I wanted to go somewhere for a weekend, I could just ring up and say, "Could Andrew come in this weekend?"

That appears not to be a possibility, and I just don't understand that, because I know down the Hastings group and the various other areas where they're looking into accommodation as well, that respite appears not to be able to be established on the same place. I suppose it might be whether it's different funding or there are people who say, "It causes disruption to those who are there," and that sort of thing, but we're looking at our little community where you would think that everybody has got a common thread somewhere, and so I'd just like to understand what that issue is.

MS HAGGARTY: The department 's policies developed over 40 years; are very rigid in their application., there is no flexibility which is a shame, because they'll lose support from parents like us who are prepared to help develop and monitor residential care options.

MS RANSOM: Thank you. Thank you for listening.