LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON HEALTH, COMMUNITY AND SOCIAL SERVICES

(Reference: Respite care services)

Members:

MR S DOSZPOT (The Chair)
MS A BRESNAN (The Deputy Chair)
MS M PORTER

TRANSCRIPT OF EVIDENCE

CANBERRA

WEDNESDAY, 1 SEPTEMBER 2010

Secretary to the committee:
Ms G Concannon (Ph: 6205 0129)

By authority of the Legislative Assembly for the Australian Capital Territory

Submissions, answers to questions on notice and other documents, including requests for clarification of the transcript of evidence, relevant to this inquiry that have been authorised for publication by the committee may be obtained from the Legislative Assembly website.

WITNESSES

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Amended 21 January 2009

The committee met at 9.33 am.

GORDON, MS ANITA, community member

THE CHAIR: Good morning, Ms Gordon. Welcome to the fourth public hearing of the Standing Committee on Health, Community and Social Services inquiry into respite care services in the ACT. We look forward to hearing your statement. You have read the privilege card, have you not? Okay. Do you have any questions on that? Are you comfortable with that?

Ms Gordon: My only concern is that I went through one of these in 1998 for the disabled taxis and the agreement that came out of that has not stayed in place.

THE CHAIR: Basically, a hearing does not constitute an agreement. What a hearing does is hear evidence by people coming forward and giving us information—

Ms Gordon: Yes, but the ACT Assembly then took it to the Assembly—

THE CHAIR: You are referring to the—

Ms Gordon: Yes, and it was agreed on, that every new plate that was issued to a taxi driver had to be a disabled plate for the first five years and then it could swap over to a normal plate to deal with the increased transport problem that we were having in the ACT. But I believe from Les Wassell, who was involved and in charge of the six disabled cabs at that stage, that that has fallen through and it is just in turmoil.

THE CHAIR: We have had a number of people bringing up the issues of taxis and problems for people with a disability. We have had some submissions on that. You wish to raise that as part of your—

Ms Gordon: A concern about what I am raising today is: what is going to come of it? Are you guys going to really listen to it? Are you guys going to hear what we and our families and our carers are enduring? Is there going to be accreditation and accountability towards the agency and also the government towards us?

THE CHAIR: Speaking from the point of view of this inquiry, our role is to listen to the evidence and the submissions put before us. We will then make recommendations to the Assembly. We can only make recommendations to the government on the issues that come before us. It is up to the government to deliver on the recommendations or make comment on the recommendations that we put before it. I note your concern about a previous report. I am not aware of it. We will note that. Perhaps this committee will look into what that agreement, as you say, was about. I am not sure if we can incorporate it into our recommendations, but we certainly note your comment. We will move on from there at the moment.

Ms Gordon: Okay.

THE CHAIR: Before the committee asks you any questions, obviously you are here to give us some report. The floor is yours, if you would care to tell us your issues.

Ms Gordon: Yes. I am 43—I think! The years go too quickly. In 2007, I had my first small stroke and was warned that within 12 months I would probably suffer a major one. Eleven months to the day my life and my family's completely changed for good. The sentence, as I call it, was not just to me but also to my husband, child, family and those friends that have stayed close and supported me.

I remembered the people in rehab telling me that I could achieve quality of life. Wow, do those words haunt me now. Whilst you are in hospital and rehab you feel you are achieving and beating this disability, but once you walk out those doors your real, new, frightening, discriminative and insufficient life begins. At the beginning, as an injured, disabled person you have the spirit and fight to survive. After 10 years you have the fight to die as you watch your partner, children and family crumble before you.

The major problems are funding, carers and agencies, lack of funding and being unable to fill the requirement needs and the equipment to give quality of life, no accreditation within the agencies, no accountability by government or agencies, no confidentiality between agencies and carers.

Recently I placed an ad for carers as part of a pilot that I am doing for the ACT disability department. The ad clearly indicated current first aid and manual handling certificates. Out of 50 calls, only one had a current first aid certificate. The others, even by phone stating they had certificates, had none at interviews.

One in particular caught my eye and my carer's who has worked for me since 1998. She saw one that was meaningful, dedicated, professional standard of care. This particular lady had no credentials since 1986, no manual handling—in fact, she did not even know what it meant—no first aid certificate. She was shocked that I requested them, as she had worked in every nursing home in Canberra, through an agency she refused to name, and did not require any of these documents.

As an advocate for the aged and disabled in Queensland and here in the ACT, the people that I have met, the situations that I have confronted, no-one could stomach. Some incidents have been like being in a Third World country. Certain pets are treated with better care. The tears that I have shed, thinking, "How can anybody treat a person in this way?"

The Bribie Island issue was a nightmare, not to mention the brain injury unit at Bracken Ridge in Brisbane. Patients were thrown on a slab and washed by a bucket of hot, soapy water over them, with no privacy or dignity, enabling visitors to see. I was actually in this incident. I was requested by family members to attend while I was running for state parliament as an independent.

If one had hidden cameras in certain homes, one would faint or their jaws would be fixed to the ground at some of what we experience. As is often heard, it is me against four or six of them. We are the brain damaged. Who will believe us? And they continue to sit in silence.

Approximately three weeks ago, I was listening to radio 106.3, Cam and Lisa. The discussion was over public art funding. One listener rang in and stated she was struggling as an artist, that they received little funding and that it was a large struggle. “My God,” I thought, “struggle! What struggle? You have two arms, two legs. You breathe on your own, you toilet, you shower, you feed, whilst others lie in silence in solid beds, with no water or food until someone, anyone, comes in.”

The ACT government feels that $75,000—these figures are just what I have heard—for Al Grassby, $750,000 for the soggy steel chips in Gungahlin and $1 million for windmills have priority over human life. Let us see: $75,000 in total would mean 75 commode-toilet-shower chairs for the disabled at home; $750,000, 15,000 electric wheelchairs; $1 million, twenty $50,000 care packages for the disabled.

Then we have got double-dipping, as I call it. The agency gains in most cases a 10 per cent brokerage fee. On top of that, the carer may, for example, receive $20 per hour and the government or insurance company is being charged $49 on top of the 10 per cent that they are taking from our packages. These are old figures. I am sure they have increased. Still the carer receives a measly $20 per hour for giving someone quality of life.

Disability ACT contracts an agency for a contract for an individual. That agency agrees that they have the capacity to fulfil the agreement but they, in turn, subcontract another agency so that they can fulfil the agreement. The client becomes confused, frustrated, insecure, and fears set in. Agencies need to be accountable. Fear of retribution for speaking out, fear of being harmed, fear of losing funding and care being removed, the vicious circle goes round and round.

I state that some of these problems can be cured by bringing back the nursing to the hospital system, with the 12-week rotation all levels. They will become better experienced and equipped nurses.

Housing places restrictions now. Any new homes being built are required by law to be constructed to allow space in one bathroom, one bedroom, one lounge, kitchen and front door to accommodate a wheelchair of any size.

The system has failed so badly that we now have the family carers needing to be cared for, either due to injury or just outright physical and mental exhaustion and breakdown.

THE CHAIR: Ms Gordon, we are just discussing the amount of time and the amount of information you have in written form. Do you have more information in written form there?

At the direction of the committee, recording was suspended.

THE CHAIR: What we will do is we will now resume the proper hearing. How far have you got through your written statement?

Ms Gordon: I am done.

THE CHAIR: You are done?

Ms Gordon: Yes. I was just going to expand on what the pilot was that I was doing with the ACT government.

THE CHAIR: I am sure my colleagues and I would like to ask some questions, and I just wanted to make sure that it was time for that. That is what our discussion was about. Okay, thank you.

THE CHAIR: We will resume now. Thank you very much for the statement you have given us. We will take that on record as well. Obviously, everything you have said will be recorded in the *Hansard*.

You expressed concern about, I guess, the certification of carers. Is that correct?

Ms Gordon: Yes.

THE CHAIR: Do you want to elaborate on that?

Ms Gordon: Well, the thing that annoys me the most is that, when anybody gets accreditation, nursing homes or hospitals, the government warns the agency or the nursing home that they are arriving. Anybody with common sense would be able to tell you that they are going to make sure that they have full staff on, the place is spotless, everything is clean and tidy and everything. If you are going to actually go and accredit these institutions and nursing homes and everything, you do it without warning. You walk in and see what it is like, there and then, at that time—not giving them warning that you are coming to do an inspection.

There is no accreditation here in the ACT of carers' agencies. There is nobody monitoring whether the staff have got manual handling certificates, whether they have got first aid certificates, whether they have got aged care certificates, disabled certificates—none whatsoever. We are getting so many different qualities of staff that come through that it is just unbelievable. Something that somebody who is disabled needs is consistency—and quality of care—because we are damaged goods. And a carer can damage us so easily.

I have a scar from one hip right across to the other side of my hip, because a staff member came to my home, transferred me from one wheelchair to a swimming pool wheelchair, was not trained in how to transfer me, dropped me, dropped my bladder, my uterus, and everything had to be tied back on. I was in bed for six months, in hospital for eight weeks, with infections and everything, because of this staff member. And I don't know what would have happened had it not been for my son, who is autistic, intellectually, and epileptic, if he did not have the common sense that day to grab me and come running out of the house when my husband was not there and throw me into the pool and float with me, to take the pain off me. The carer just freaked out and collapsed.

THE CHAIR: Have you made any formal complaints on any of these issues to anyone?

Ms Gordon: Yes. But they go to the back door. They go to the back door. This is why we as disabled people have got fear, because we are not heard. We are classified as whingers, as complainers, but all we are asking for is quality of care. Most of us who have got the ability to communicate know whether somebody is doing something incorrectly with us. It is like a doctor or a nurse being in hospital as a patient: they know when somebody else is doing something wrong.

THE CHAIR: Can I just ask: do you remember who you made the formal complaint to?

Ms Gordon: It has gone through the agencies. I have actually put complaints through the commission. There have been several complaints that have gone through. I have got carers who can verify the complaint that we put through. And, do you know what: we come out as the bad ones, not them.

MS BRESNAN: I was going to ask about the pilot that you mentioned.

Ms Gordon: Okay. What is happening at the moment is I am doing a pilot for the ACT department of disability services. We were looking at the figures for what it costs for insurance of holding a carer in your home, all the costs that the so-called agencies say that they have to endure when they take on a package for us.

I am doing a pilot for a self-managed ISP—individual support package. I have been doing it since June. A month or six weeks ago I had a meeting with the people involved—Leanne Power and Leigh Hares—on the figures and the costs. Everything has been monitored to the dollar. They were just overwhelmed. I had duplicated 2½ times my care hours and I had reduced by half the amount I was paying to the agency to have a carer in my home. From 20 weeks of care per week that I was receiving, because that is all I could afford—we are now paying an agency, supervising my funding, paying the carers, paying the insurance for the carers, superannuation, tax and everything—I am now on 45 hours a week.

This is not possible for everybody, but there are people out there that have got intelligent family members that can also do this and other individuals that are like me that are capable of doing it. There are a lot of securities that we put in place, such as if something happens to me who can enter. There are people that know the access to certain codes. It is a trial.

At the last conversation that we had with Leanne Power and Leigh we showed them the figures and everything. I have doubled my care hours and reduced my funding, which was lasting probably half a year. It now goes into the complete year, plus equipment. I have been able to install a security system in my home. I can press a button from my bedroom or the kitchen and it releases the front door to allow people inside if I am stuck in bed and sick. I have been able to purchase a chair from overseas, which Australia does not have, to put in my shower, which gives me that little bit more independence.

The other thing that I have realised is that, for some reason, when you put the word “disability” in front of something, the zeros add up, and vice versa: when you put “government” in front of something, the zeros add up. I do not tell people now when I am purchasing things that the funding is from my package. I do it as a test. I get a carer to ring up and say, “I’m from the government. I’m inquiring about such and such. How much is this chair going to cost?" She gets a figure. I ring up two or three weeks later saying, "I'm after such and such. How much is it going to cost me?" and there is a reduction of about 50 per cent. It is a joke.

THE CHAIR: You mentioned that this is a pilot. Has the pilot got a duration, a specific time frame?

Ms Gordon: It goes for 12 months. I understand that if everything is working successfully, as it is at the moment—

THE CHAIR: You will be able to maintain that?

Ms Gordon: Then I will maintain it. At the same time, I am doing the paperwork at my own cost, which the department would be paying thousands for a consultant to do. In that paperwork it shows how easy it is to do something. It will come out as a package that the next person will have everything right there in their face. They will know exactly who to go to for their insurance, how to set up their taxation files, who to contact in taxation to give them assistance if they need it and who to contact in super if they need assistance. So far they are absolutely delighted with what I have proven to them.

THE CHAIR: Ms Porter?

MS PORTER: I do not have any substantive questions. I just wanted to know when you moved from Queensland to the ACT.

Ms Gordon: I moved in 2007. It was a struggle because the ACT government would not accept my individual support package that I had in Queensland and I had to fight for it.

THE CHAIR: I have one other question regarding this pilot study. Are you aware of whether this is being conducted under a particular title from the government? Is it to develop a particular system or is it part of future plans?

Ms Gordon: It is part of the future plan. Apparently it has been requested by several people because their money is not going far enough. There does not seem to be clarity on this brokerage fee that the agency asks for and why it is adding on this extra amount. With the government it is not too bad, but if there is an insurance company involved the agencies are taking them to the till. The government and the insurance company need to sit down together and say, "Stop. This is what we will pay for hourly care and that is it."

THE CHAIR: Ms Gordon, we are very impressed with the evidence you have given us. Obviously we will take on board the questions you asked at the outset as well. Thank you. We will also provide you with a copy of the transcript of what has taken place here. We can hear back from you on that if there is any privacy issue concerned. I thank you on behalf of our committee for taking the time to come in. We hope that we can look at the recommendations that will do justice to your request.

Ms Gordon: Thank you. I am not sure if you are aware of Youngcare and the thong day. Youngcare is a facility that they have built in Brisbane. They are building another one in Queensland. I have some information here that I got for you. It is specifically to cater for people under the age of 55 being put in housing and accommodation and not thrown into nursing homes. They are asking that each state and territory come together and build these facilities to assist, because Queensland has not got enough room for everybody.

MS BRESNAN: Thank you. That would be great.

THE CHAIR: We will take that as a submission from you as well. The committee may want to ask you further questions after we have considered some of the submissions that you have given us. So we may be in touch, if that is okay.

Ms Gordon: That is fine.

THE CHAIR: Thank you very much.

MOWBRAY, MR GLENN, community member
MOWBRAY, MRS PATRICIA, community member

THE CHAIR: Thank you very much for joining us this morning, Mr and Mrs Mowbray, for the fourth public hearing of the Standing Committee on Health, Community and Social Services inquiry into respite care services in the ACT.

Mr Mowbray: This is Luke, our eldest son; Peter, our second son; and Paul, our third son.

THE CHAIR: Are you aware of the privilege card? Have you read the information on it?

Mr Mowbray: Yes.

THE CHAIR: So you are aware that information you give is given under privilege?

Mr Mowbray: Certainly.

THE CHAIR: We would like to clear up something. You cannot say it is confidential information. The information you give will be published in *Hansard* and in the committee's report and will be available for the public to see.

Mr Mowbray: Yes.

THE CHAIR: Are you comfortable with that?

Mr Mowbray: Yes. We understand it is under privilege and we must tell the truth, which we will.

THE CHAIR: We have received your submission and the committee will be wanting to ask some questions, but would you like to make an introductory statement regarding your submission?

Mr Mowbray: Yes, thank you. You have our submission. Just as an opening statement, the critical issue for our family is being able to access sufficient hours of respite care to enable us to continue the voluntary work that we are involved with, mainly with our church but also with outside organisations.

You would have read in the submission that we came to the ACT in 2002 and the experience we have had in the ACT was very different from the experience we had in New South Wales, from the point of view of provision of respite care services. This has changed. We have now been here for nearly nine years and it has changed quite substantially in that time.

We have mainly dealt with an organisation called Tandem, which was called FaBRiC. They seem to constantly have funding issues and fairly regularly change what sort of services they can provide. So the situation we are in at the moment with Tandem is that they do not wish to offer us, or they can't offer us, any weekend respite care, which is a big problem for us because a big part of our voluntary work involves four weekends a year away, at a weekend conference—four separate conferences.

We have been working quite well with Disability ACT. That has been working very well. Unfortunately, the respite centres that are run by Disability ACT have not been a good solution for us. We have had ongoing problems.

So that you can understand the sort of problem we had, our three boys are used to in-house respite, in familiar surroundings, and that is what they have grown up with. So going to another house for respite has been a huge step. The first time we undertook to do that was at the Hughes respite centre. When we turned up, no bookings had been made, they were not expecting us at all and we were turned away. So it started off on the wrong foot. We have actually experienced that—going to the respite centre and being told, "No, you're not booked in." That has happened three times. So there are real issues with how the government respite centres are run. It probably needs to be addressed.

Where we are at now is that there is a respite centre run by Carers ACT called Fraser House. It was established, I understand, specifically for ageing parents. But they have told us they are willing to offer us weekend respite care because we have three children. We have not tried that yet but we are booked in in October, so we are hoping that might work better. We have been out there, and we have really noticed a stark difference, just in the surrounds and in how the house is presented, between the government-run place and this privately run place. It is more like a home. The government-run place is like a clinic. When we took the boys there, they did not really feel at home, whereas we went to Fraser House just to show them the house and look around, and they were much more comfortable there. I did have some notes here but I have talked without referring to them.

Mrs Mowbray: Just to let you know, our plan for the boys for the future is that they will actually stay in our home and we will leave. So we are setting up the house for them. That is why it is important to have in-house support—so that, while we are having respite, they are learning how to cope with us not being there.

Our eldest son, Luke, has a mental illness. We spoke to his psychiatrist at length about the difference between putting him into a respite centre and having in-house support. Our second son, Peter, was very resistant to going into another house. We spoke to him about strategies and how we could do this. He said, "Why are you making them do it when your plan is for them to stay at home and for you to leave?" In the long run, support workers will be there for them, so perhaps we should be looking at planning for the future and support workers coming in for those four weekends and then gradually increasing it. The ACT government are aware of our plan because we are in an unusual situation. In a couple of weeks time we are doing the PATH program that is offered to people who have families with disability. I think that needs to be looked at for our situation as well.

Mr Mowbray: The person we deal with in the Disability ACT office, Simone Provost, has been fantastic. We cannot speak highly enough of that higher level in the department—very helpful and trying to do as much as they can. I think the problems occur lower down, at the delivery level, rather than higher up.

THE CHAIR: You mentioned at the outset that conditions have changed since your arrival. I presume conditions have changed for the better. Is that what you were saying?

Mr Mowbray: No.

THE CHAIR: For the worse?

Mr Mowbray: No, for the worse.

THE CHAIR: Would you like to elaborate on that?

Mr Mowbray: Certainly. When we first arrived, we found out from the respite service that we used to be involved with in the Wollongong area, Interchange, who to look up down here, and FaBRiC was the organisation at the time—Family Based Respite Care. So we looked them up. I guess the first change for us was that they had a very strict policy of a set number of hours per month. You could not bank hours. They came out and assessed our family. I think they gave us 24 hours a month. So every month we could access 24 hours of respite care. Obviously, that was not enough for us to continue with our weekend voluntary work. So at the time we had to pull out from that. With 24 hours, we could not even go away for a weekend or anything like that.

After some time and discussion, they then decided that we would be able to bank our hours. So we basically did not access the hours for several months until we had a weekend’s worth. That seemed to work quite well. However, the arrangement was different from what we were used to. They would have different support workers who would come into the house, but they operated on shifts. They were probably eight-hour shifts or something like that. The boys were not used to that. We had, as we set out in our submission, a family in Wollongong and they would come into our house. So it was the same family every time. In fact, we provided respite care for one of their children as well, so it was a really great arrangement. So that was something that was not as good for our family.

Then, I think it was probably a year or 18 months ago, they told us that, because of funding issues, they could no longer provide us with weekend care or overnight care at all. They could not afford to pay their support workers on a weekend, so it had to be Monday to Friday, and it had to be something like a three-hour stint. So they said they might come in and do cooking with them or something like that. So that really was not very helpful for our family.

Since that decision was made, we have had a couple of weekends. That has been made possible by Carers ACT actually providing the gap funding to Tandem. So they have given gap funding to Tandem so that they can then provide overnight care. But it is a temporary resolution to an ongoing problem. We had extensive discussions with Disability ACT and Simone about this, and their resolution was for us to access the respite centres, which, as I have already explained, really has not worked.

MS BRESNAN: The interchange service you mentioned that you used in the Illawarra, was that something that was run by government?

Mr Mowbray: No.

MS BRESNAN: Or funded by government, I should say?

Mr Mowbray: Yes, it is funded by government. It is a community organisation—pretty well the same as Tandem or Carers ACT—and it pretty well works similarly, but it was families providing the care. So they would link families up.

So there was one particular family that lived in the same suburb we did, who would provide the care for our three children, and they had one foster child with a disability, and we would provide care for her as well. And then there were three other families we provided care for as well.

MS BRESNAN: So were they families in a similar situation to you?

Mr Mowbray: Yes.

MS BRESNAN: And then they link up families to provide, so as to enable people so their children can stay in the home if they need to go away or that sort of situation?

Mr Mowbray: Yes, that is right. But it was not just linking families together. It was run through the organisation. You had to be registered. When we provided care, we were paid an allowance to do that, and we paid for the care as well.

MS BRESNAN: I was just interested, with the registration, in terms of ensuring that the family who you might be linked up with are able to provide the care—and those things about checking that people not necessarily have qualifications but are able to actually perform those tasks—what that process was?

Mr Mowbray: Well you had to have a first aid certificate and police checks and all that.

MR BRESNAN: So there were police checks.

Mr Mowbray: The suitability was handled by sitting down and being interviewed, and the organisation would say, “They are suited to providing care for these children.”

MS BRESNAN: Were they the stand-alone organisation, or were they run through another body?

Mr Mowbray: No, it is a stand-alone, not for profit community organisation.

MS BRESNAN: And that was basically the basis of the care—or the sort of system they had? Linking you up with other families, that was the basis of it?

Mr Mowbray: That is correct.

MS PORTER: The government is about to commence a feasibility study around the replacement of centre-based respite houses. If you were to have your druthers and say what you would like to see as the key features of what future respite might be in terms of the physical environment and the service model—I think I know what you are going to say—is there any more that you would like to say about the service model and the physical environment for respite?

Mrs Mowbray: I would like to see choice in respite. A lot of the problems or challenges we have had with our respite are to do with the fact of what sort of respite it is and why we are choosing that. Part of the volunteer work is actually my paid work as well, and I am required as part of my part-time work to go away to these conferences and support the councils we are dealing with. So it is part of my work, but Glenn is on the same council, so, for us both to attend, that is the sort of respite that we need. We do not access any other respite, except for these four work weekends. We probably would like another two, just for ourselves, to regenerate and, you know, just have time for ourselves.

So I think it is choice—and I am hearing this from a lot of other families: they would like choice in how they access it. We just do not want a set six hours a week where someone comes into our home and I actually have to leave. Because that is what happens: If the boys are doing cooking, then that is my respite time, so I have three hours to do something. At five o'clock in the afternoon, I cannot go into the office. I mean, I suppose I could, but it is not practical from five to eight. They say, "You two can go out to a movie or something." That is not really respite. It is great for the boys to be learning a new skill, but it is not helping us. So it is real choice—and letting the boys have a choice too in how they want to spend this time, whether it is learning or recreation. So "choice" is the word.

Mr Mowbray: I would just add two things. I would repeat that choice is important, not from the point of view of simply having a choice, but the fact that different families have different needs. Obviously, in our family situation, in-house respite makes perfect sense, given that there are three boys living together as brothers and given the future that is planned for them. But that would not be the case with all families. So obviously respite centre style respite would be appropriate in some cases. But often government is not the best deliverer of a service. Government is a good funder of a service, but often services are better delivered by a community or a private organisation. We have not experienced Fraser House yet, but certainly, from what we have seen, they seem to be able to do a better job of it.

Mrs Mowbray: The coordinator of Fraser House has been just wonderful in her support and welcoming and in the way she treats us as a family and in her respect. What I have noticed in the government respite houses is sort of an attitude of "people are a bit precious" I am a bit reluctant to look at them again for the boys, when one of the coordinators said, "Well, some of the clients are a bit precious." I would not want to go to a house where I am told I have to eat this and do this at a particular time. It is supposed to be a time of recreation for the people going to the respite house.

I know there are lots of different clients they need to look at but, when you get a comment like "these people are a bit precious" it worries me a bit, because we have tried to bring up the boys to be socially able in all sorts of situations, but there are certain things, like all of us, that they do not like. Luke has phobias. It is not about being precious; it is part of his disability. So I think perhaps some really good solid training for some of our workers and paying them better, I think. We need a career path for our support workers. They do a fantastic job, a lot of them. A lot of them are young uni students. But we need a good solid career path for them, so that they can keep on going with this work, because our kids love their support workers, but they are not encouraged to go further and their pay is not very good, so I think that is another issue that could be looked at as well.

THE CHAIR: We are unfortunately getting very close to running out of time. One final question—you have touched upon this a couple of times, but perhaps just a little bit of clarification, before we conclude our submission from you. You were talking in your submission about finding it hard to understand the financial justification of eliminating the provision of in-home respite care for your family specifically. When you get carers coming in, do you need one carer per child or—

Mr Mowbray: No, one for the three of them. If I can briefly clarify that: when we have in-house respite, it is always one carer for the three of them, and, as far as I can see, the only cost of providing that respite, apart from the administrative cost, of course, is paying the carer. If we go to a respite centre, there is always a minimum of two carers there, plus they provide all the food, they have to maintain the house, and everything that goes with that. The discussion I have had with Disability ACT is that I cannot understand, if you look at it in purely financial terms, the justification for saying the respite centre is a more financial appropriate way to go. It has to be cheaper to provide in-house respite care. It has to be.

Mrs Mowbray: We provide all the meals. They are prepared and ready. We go shopping.

THE CHAIR: Have you been able to take this further within the department, to get further clarification on this cost justification?

Mr Mowbray: Yes. The response is—and I do understand the response—that it is not an issue of what is more cost-effective or not, it is an issue of the funds having been made available for that and we cannot use them for anything else. So Disability ACT says, “We have funding to run our respite centres, and that cannot be used for anything else.”

THE CHAIR: We have run out of time. I apologise for that. Thank you for your submission. The committee may ask for further information from you as it goes on.

Mr Mowbray: Of course. More than happy.

THE CHAIR: A transcript of what has taken place will be provided to you and, if you have any comments, we would love to hear further from you. So, even though you have given your evidence or your submission, you are quite entitled to submit any other thoughts back to the committee for consideration. We thank you for coming in and all the best in pursuing the objectives that you have set out.

Mr Mowbray: Thank you. Thank you very much to the committee for doing this. It is marvellous.

McGREGOR, MS ALISON, Coordinator, ACT Community Living Project Inc.
WOODBURY, MS ESTHER, President, Community Living Project Inc.

THE CHAIR: Welcome to the fourth public hearing of the Standing Committee on Health, Community and Social Services inquiry into respite care services in the ACT. You are aware of the privilege card that is before you? Have you had an opportunity to read that?

Ms McGregor: Yes.

THE CHAIR: You are comfortable with the contents?

Ms McGregor: Yes.

THE CHAIR: We do have a submission from the Community Living Project. Would you like to make some opening remarks regarding your submission?

Ms McGregor: We were wondering whether it would be appropriate for us to give you a bit of background about the ACT Community Living Project and where it came from. Essentially, this is a not-for-profit organisation that represents over 250 families who have children with quite a severe disability, who are seeking better accommodation, training, employment and quality lifestyle choices for their family member with an intellectual disability.

It came about from very early conversations between particular families about the lack of quality respite services as young people lived in their family home, and then looked at the problems that arose once the children got to adulthood and families were unable to continue to look after them and the fact there was a very severe lack of any accommodation options for the young people at that point. CLP came about from looking at the problems in the system and trying to find solutions that were going to be positive.

At the outset, in early 2008, there was a meeting at Carers ACT where approximately 30 people from different families came together to discuss the issues. From that, they formed a committee that looked at the various options. In July 2008, over 100 people attended a public meeting that the Community Living Project ran.

The families are very keen for the community to get behind the needs that they have and believe that they are not making any extravagant claims about what they need. It is about the same sorts of choices that people who do not have a disability want, things like a choice of accommodation that suits their needs, access to lifelong learning, education and training, meaningful things to do every day, whether it be paid or unpaid employment, things out in the community on a voluntary basis, adequate and timely medical and dental care and opportunities to mix with their peers and have a social inclusion within the general Canberra community that is genuine inclusion rather than token, walking through the community and not being engaged and not having the community engaging particularly with them.

The people that the Community Living Project represent all have an intellectual disability. Most are going to need significant help throughout their lives in terms of their communication, their self-care and their daily living skills. The majority are going to need help in developing and maintaining their social networks. Few would be able to use public transport on their own. Many have limited reading and writing skills. Most are not able to use sophisticated technology. A large number are going to have health and medical problems.

Looking at that group, the families decided that probably the best way into the future was to develop a village-style accommodation project that would look at a variety of separate buildings that would accommodate the needs, from very high-care needs that require significant levels of medical and physical care assistance through to more independent unit-type accommodation where young people and adults would be using the facilities but would be able to handle a fair amount of their daily living without significant care but would still have a structure around them that would supervise the way things are happening for them and to make sure that they are safe and able to manage their affairs to the best of their ability. Part of the village option is also to include within that community a range of people who do not have disabilities so that it is not just a segregated unit where just people with a disability are going to live but there would be others who would intentionally join that community.

From all of the work that has been done within the Community Living Project, there has been a range of things that have come across our research bases that say what makes a good place, whether it be a respite place or supported accommodation. The best condition that the research is showing is that there needs to be choice, that one size does not fit all. There needs to be quality care provided.

At the moment, only 2.9 per cent of the ACT population that requires supported accommodation is being provided with that accommodation; so there are 97 per cent of the group that are still living at home. The needs of that group are not necessarily known because they are within the family home. There needs to be significant expertise developed along the way into the future so that there are people who are trained and have adequate knowledge of how to care for this group.

Another thing that is required as far as the research goes is that there should be social activity and inclusion opportunities, access to friends and family, being a contributing member of the community rather than just being present in the community so that they are recognised for the contributions that they make. Person-centred planning is the key to all the approaches for people with a disability so that the opportunities that are provided to the person are tailored to the person.

One of the difficulties and the challenges for people providing both respite and supported accommodation services is to have a bank of knowledge about the individual and a real commitment to making sure that the individual who is being catered for is involved in the decision making as far as they are able, that people who really know them are engaged in that planning process and that there is serious monitoring going on of how those individual plans are being implemented.

Part of what the respite inquiry threw up was that, while there were good policies in place in terms of all the things to do with respite, there was a significant difficulty in terms of the way that those policies were implemented and there needed to be a greater monitoring of the services and a greater accountability of the individuals working within the system so that the policies that overarched all the services were actually implemented.

Medical and dental care is a very serious difficulty for families in the ACT and across Australia for people with a disability, particularly those with an intellectual disability. Often the medical and dental treatments that most of us take for granted, the regular checkups and so on, are not carried out or are inadequately accounted for.

Both in terms of respite services and supported accommodation, these are issues that need to be seriously addressed along the way for families to have real choices about what happens for their young people.

THE CHAIR: Thank you, Ms McGregor. Just a couple of questions from me and then I will pass on to my colleagues. You have mentioned in your commentary on the Auditor-General's report—you highlighted some areas there—that the CLP believes that the eligibility criteria for specialist disability services should be defined in the ACT Disability Services Act. Do you have any further comment on that as to where the definition may fall short?

Ms McGregor: I think it is mainly in terms of how you actually define the group. Just having a tag does not necessarily define the requirements that the group has. Therefore, it does not lead to a service model that will provide some real way of dealing with the needs that each person has. There does not seem to be any real assessment process that goes on that is consistent across the areas. This would be one of the things that we would have been highlighting in that instance.

THE CHAIR: What I am saying is that if there are specific instances that you think should be catered for, this is an opportunity to bring those forward, either now or perhaps later on if you want to make some further submissions.

Ms McGregor: Maybe if we can just think about that then.

THE CHAIR: Of course. That is what I am saying.

MS BRESNAN: With the CLP project, have you looked at any particular models in Australia or overseas that have worked and how they might apply in the ACT?

Ms Woodbury: We have looked everywhere. We have looked very long and very hard. There is a lot of research on our website. All of our research, basically, is on our website. There are lots of places overseas that are old and have been there for a considerable amount of time.

MS BRESNAN: Is there one in particular that you think has really worked well and could be successful here?

Ms Woodbury: The trouble is, with 97 per cent of people living at home—since the institution has shut down there has not really been any move to do anything particularly, except support the people that have pretty much fallen out of home, their natural supports. That has been almost a major reaction to those that come into the system. We cannot find any particular planning that has gone on over that period about what is expected to happen in future. We still do not see it.

People talk about all the things that they are doing, but it seems to me that they do research and come up with papers and that is where it seems to stay. There is nothing that comes out of that that then says, “Well, let’s go and actually set up something.” Still this week we are looking around and saying, “Everybody keeps on identifying the problems.” There is an endless amount of identifying what is happening. Does anybody actually have an idea about what is going to happen to our children? It is extraordinarily difficult to get any sort of answer about how anybody can plan for what is going to happen to their three sons in future, or however many they have got. It just does not seem to be there.

MS BRESNAN: I have not looked at your website, but are there any particular countries where—I appreciate what you are saying: the planning has not occurred after deinstitutionalisation in a lot of areas—you think it has been a successful way of addressing the issue or there have been similar projects set up somewhere that have worked well?

Ms Woodbury: Overseas there are a lot of farming communities that seem to work well, but it really depends on who you talk to. The communities that put their children there are very supportive of them, but of course there are always the detractors who say, “It’s an enclave. It has groups of people living together who shouldn’t be.” There are lots of different reasons that people have. There are all sorts of things where people are being supported.

Yesterday we looked at the New South Wales institutions that the government has been trying to shut down for the last number of years. It was something that we were going to follow up. They have not shut most of them down; they are redeveloping them. It would be interesting to ask why they are redeveloping them, why they did not shut them down. What do they want to do with the people? Yesterday we found there are lists of all the places in New South Wales. It would be interesting to ask why they did not shut them down and what the problems were. This is ongoing research that we are doing all the time.

While there are places there that some people will say have worked great, you can also find that another bunch of people will tell you that they do not. But when you ask the people who are there they seem to say that they do. That is always an issue when you look at what has been successful—on whose judgement has it been successful? We have found that many of the places did not seem to cater for the very disabled group. They seemed to cater for those that had much more ability to care for themselves or did not have high medical needs. That medical needs group seemed to be going into the nursing homes and being caught up in that 6,500 group.

THE CHAIR: Would you be happy to submit that additional information as part of your submission? It would help us get to some of those issues you have mentioned.

Ms Woodbury: Yes. It is very interesting, actually, and there is a lot of work to follow it up.

THE CHAIR: Thank you. Ms Porter?

MS PORTER: No. The questions that I had have been more or less answered during your presentation. Thank you very much. If we can get hold of a copy of that, it would be really good.

THE CHAIR: Coming back to your submission, you stated that you agreed that access to respite services in the ACT has not increased proportionately to meet the demand for services in recent years. Would you like to elaborate on your findings of the real unmet needs as you have defined them?

Ms Woodbury: Personally or in general?

MR HANSON: Both.

Ms Woodbury: In the ACT, I think there is a huge disparity in the numbers when you look at those that can potentially have respite and those that are actually using respite. So there would be a lot of questions, such as, "Why don't people use respite?" From my own personal experience, as probably everybody else has told you, respite is set to suit the staffing needs and all sorts of other arrangements. They do not say, firstly, "What does the client need?" It is really about saying, "This is the service we've got. You have this service and that's what's available to you."

I think this is an ongoing problem everywhere and it is something we are looking at. Person-centred planning is about what suits the person, not what suits the service provider, such as whether they are on 12-hour shifts, which is an awful long time for anyone to work. By the end of your 12-hour shift you are very tired, distracted and all of those things. The respite places in Canberra are not purpose built. They are homes that have been extended, which is another huge issue for how many people are physically put in the same area.

Then you get kids who may need more support, which sounds like a good idea, but at the end of the day you may have six children at that respite centre and you might have four adults in the area. Normally, nobody would live in that sort of area if there were 10 or 12 people. It is always a make-do situation of the respite that is available in terms of physical space. What if you do not have very good systems of collection of data? Are they going out? What sort of food are they eating? Is there a dietician there? Do the people who are cooking the food for the clients know how to cook? What sort of training have they got?

There are just so many issues that come up. The respite document is appalling. Really, what is happening in those four homes is absolutely appalling. If you went out and said to anybody on the street, "Would you put your child into this sort of place?" I think most people would not say they would do that. But that is what is offered—you take it or you leave it. A lot of people do not take it, so they are just at home with respite.

We have another survey which we are going to ask all the families to do again, which quite comprehensively asks about respite. It asks: do you use it? Does it suit you? Does it suit your child? What are the problems with it? How often do you use it? How much is it costing you? It will be interesting when we get those answers back. It will give us some understanding about people who are not using respite or if they say, “No, I’m too worried about using it.” A lot of families are worried about using it. They are worried about the safety issues of how the children are cared for, whether they are safe from other clients, and—as what happened to Jack—any number of issues.

THE CHAIR: On that point, you mentioned in your submission that some families report that the government respite service is unsafe. Have there been formal complaints made to government agencies, Disability ACT or any other areas regarding how places are unsafe?

Ms Woodbury: In the respite document, it says that the Riskman was appalling. Firstly, the incidents were not logged. How does anybody really know how many incidents there were? Obviously they knew that incidents were not logged but nobody actually has any idea how many incidents were not logged. How could they know if they were not logged?

Firstly, they were not logged. Then they were not followed through. I am a bit rusty at the moment but they said something like “almost two incidents of levels 6 and 7”. Eight is death or permanent injury. You have got two of the very highest levels of incidents. Out of four homes, that was almost two per month or something. I would have to go back and check that but that is a lot of very serious incidents. That means that at least two children out of however many clients there were each month were harmed quite severely in some way. I personally know a number that have had things happen to them.

THE CHAIR: What we would like to establish is: is there a formal mechanism for complaints to be registered over those incidents and, if formal complaints have been registered, has there been any action by the relevant agencies regarding complaints?

Ms Woodbury: I can talk anecdotally but that respite document said that the complaints given to Disability ACT were not followed up and the only complaints that were really followed up were those that were put through the Human Rights Commission. As a parent of a child with a very severe disability, to go to the extent of going to the Human Rights Commission would take a lot of courage, a lot of effort. You have to prove your case. It is not like somebody comes and says, “Okay.” You have to give documentation. You either have to have some paperwork somewhere or have some photos taken or done something to be able to prove that it actually happened. As has personally happened to me, it is your word against the service provider. You are making a complaint and you may have a history, like me, of complaining repeatedly. You become known as a parent that complains. And that is a problem.

It says that those complaints were defended quite fiercely and the only ones that were really dealt with were the ones that went to the Human Rights Commission. You would think, if there were a complaints process, that would inform how you change your way of business, if people complain to you. You would take that as how you then go about moving your business forward and changing things. That does not seem to have happened. Parents that I know and have talked to have said that it has not really changed.

THE CHAIR: Are there any other issues that you wanted to raise briefly? We have gone beyond time, unfortunately. Is there any matter that we have not covered and that you specifically want to bring to our attention?

Ms Woodbury: I put in a complaint. Is that going to be a separate issue?

THE CHAIR: I think you are entitled to make statements to this committee. The only issue—and this is up to you; we have raised it before about people giving evidence—is that personal issues do not remain confidential. The issues that are being raised before us will be published on the website. If you are comfortable with that, you are entitled to make any statement you wish to make to the committee.

Ms Woodbury: I will leave it.

THE CHAIR: Thank you very much for coming in. Thank you for your submission. It has certainly given us a few things to look into. A full transcript of what has taken place will be provided to you. Thank you again for taking the time to come in.

Meeting adjourned from 10.57 to 11.12 am.

CANE, MS MAUREEN ROSE, Chief Executive Officer, Communities@Work
ROWLAND, MRS CAMILLA, Executive Director, Community Services Division, Communities@Work

THE CHAIR: Good morning, Ms Cane and Mrs Rowland. Welcome to our fourth public hearing of the Standing Committee on Health, Community and Social Services inquiry into respite care services in the ACT. I presume you have been to a number of these hearings but I will still ask you the same questions about the privilege statement. You are aware of that and are comfortable with that?

Ms Cane: Yes.

Mrs Rowland: Yes.

THE CHAIR: Before we start asking questions, would you like to make a formal statement?

Ms Cane: Yes, thank you very much. We appreciate the opportunity to make a submission here today. We actually do have a further written submission, which is a reflection of some of our remarks, and we also have some survey material which we mention briefly. So we will certainly provide that to you.

THE CHAIR: That will be very welcome.

Ms Cane: As you will know, Communities@Work is an organisation that involves itself in a whole range of things over the years. We, of course, came to understand, through the work that we did with children, young people and seniors, that there was a significant demand for respite services in the ACT. In recent years, we have become involved with the delivery of two different programs. We mentioned one of those in our first submission to you, and our intention would be to talk about that a little bit more, and also to mention a newer program which we are fortunate to be operating. That is maybe not technically a respite program but certainly it provides respite, both to carers and to care recipients.

The first program we want to talk about briefly is Respite Options ACT, which is a flexible program funded by FaHCSIA, by the federal government, to the tune of about $100,000 a year. It is designed to seek to meet the individual needs of carers and care recipients, and about 1,900 hours of service were provided in 2009-10.

With this particular program, the idea is to provide one-on-one respite and support to the carers of people who are experiencing severe mental illness or intellectual disability. The service basically enables the carers to have a bit of time out for recovery and for their wellbeing.

We actually support a flexible mode of service delivery which really has two strands. One is where other agencies ask us to arrange for a service—in other words, they broker the service with us and we have the funds to get the staff to deliver the service—and the other strand is where we are approached directly. So we have some direct service delivery as well.

I will leave my companion to tell you a little bit more about how we do things and I will say a little bit now about the other program. The other one is called Connections@Cooleman. It is a recent program funded under the HACC program by the ACT government. That is a different model. It is about a life and living skills and leisure program. We have a place where people can come for two days a week to undertake a variety of activities. That might extend through cooking classes to tai chi, music et cetera. That enables the people who attend that program to participate in these various activities, which of course is done to reflect what they wish. We do not just decide what we are going to put on; it is what they wish to have put on. At the same time it means that the person usually caring for that person can have a break as well. So although that is really called a life skills program under HACC, it also basically does have a respite focus, in practice.

For example, under that program, we have arts and crafts on Tuesday mornings, cooking on Tuesday afternoons, music and dance and exercise on Wednesday mornings. I might add that we recently got a grant of $2,000 from the MECU bank to buy some African drums. So the whole idea is to provide some creative, interesting, engaging and diverting activities for the people in that program. That program is aimed at people who are between 25 and 40 years of age who have a disability.

Would you like to add a bit more about some of our experience?

Mrs Rowland: I would. The FaHCSIA funded program, Respite Options, is extremely interesting in that it is $141 million across Australia, and they fund over 130 different services across Australia, but mostly these services are delivered through brokerage moneys.

When we first received the funding, the funding was purely for coordination. We would provide services through brokerage moneys that we receive from the commonwealth carers respite centres. We found that we were tending to be providing crisis respite to families and carers through the commonwealth carers respite centres when they were contacting us. We had a number of other people in the ACT community who wanted some regular respite. So we requested to FaHCSIA that we could quarantine some moneys in one of the financial years to, in a sense, pilot doing direct service provision through our trained support work staff, who all have training in mental health as part of their background.

That request was agreed to and very successfully undertaken. We did manage to provide some 1,900 hours of service through both the brokered services through the commonwealth carers respite centres and that direct service provision. We would like to be able to continue to do that. At the moment there are discussions in FaHCSIA about the way forward for the whole program.

One of the things that we found was that, in addition to the services we were providing, we were always at a point where we could not meet total demand. At any one time we had somewhere between 25 and 30 families who were on waiting lists or who had requested respite service and we could not meet that demand. We also found that there were so many families that were requesting crisis respite, whether it be in home or taking that person out for companionship or to appointments or whatever it might be, that most of our respite services ended up being short term, one-offs, or for a few weeks. We have not been able to provide, for the majority of clients, ongoing respite for more than 12 weeks, meaning perhaps a few hours once a week.

However, we have had really good feedback on our services and a really positive response in our surveys for Respite Options. That is right across the ACT and can go across the border into Queanbeyan as well.

With Connections@Cooleman, although it is funded by HACC as a living skills and leisure program, all of our clients in Connections@Cooleman have carers and it is providing all of those carers with a break when those adults with disabilities are coming along to our day programs. So it is indirect respite, in a sense, that we are providing. In fact, some of those carers actually see it as an opportunity to provide themselves with respite or a break from that care.

We find that about 50 per cent of our clients have intellectual disabilities and about 50 per cent have a variety of different physical and physiological disabilities. The majority of our clients are in their 30s; we do have some in their 20s and one in their early 40s. We only started that in December. Although we have said in our report that we had 12 clients, we now have 15, as at this week. So that is gradually building. Our greatest issue there is that, through the HACC funding, we are only funded for one staff member and the rest is provided by some of our casual workers through other pools of funding and through volunteers.

If we take on clients who have higher needs, very complex needs, we require a higher staffing ratio, and we do not have funding to be able to fulfil that need in the longer term. That is something we would be looking at with the HACC program.

Ms Cane: I would just like to mention a couple of other things Camilla has alluded to. From our experience, there is no doubt that carers require ongoing respite—respite on an ongoing basis—to assist them to sustain themselves and the loved ones that they are caring for in the longer term. It is a huge frustration, I am sure—it certainly is for us, and definitely for other people working in this area—that we can often only meet emergencies or do things on a short-term basis, when really it is needed long term. This is understood, incidentally, in the HACC program for older people. People think in terms of episodes of service—quite frankly, it is often years of service.

So that is one important thing. I have mentioned the word “flexible” a couple of times, and we also find it is very important for a service to be able to respond to the particular requirements of particular families and individuals. Sometime the things that we do are very, very simple. It is simply a matter of perhaps taking someone out for a walk for an hour or so. It just gives either the carer or the care recipient that particularly useful break at that particular point in time. That is very helpful.

We have also found, for example, with a young woman who used to have to come accompanied by a support worker to Connections@Cooleman, that, even though we have only been going a short time, she has now found that, because of the atmosphere in the group and the welcome and the support that there is there, she now has the confidence and the independence to be dropped off at the group, and her support worker, her carer, can now have a break. All these things take time, and they are subtle, but they are often quite simple as well.

Mrs Rowland: And sometimes there are longer term indirect benefits. We have, and this is noted in the submission, one lady who was housebound. Her husband was caring for her, and she would not go out of her house. But we have a trained support worker who was going in to visit her for companionship, and she will now actually go outside the house and go for walks and actually go into community activities and community centres with that worker. That, at the same time, is giving her husband a break once a week, so that he can actually go and play golf. He was at risk himself of actually developing depression. He is probably an undiagnosed person with depression at this stage. But he had not been having a break at all for a number of years and was at the point of not being able to cope. So this regular assistance has been able to change that whole household in terms of their ongoing ability to be able to cope in the situation.

THE CHAIR: You mentioned something, I think, Mrs Rowland, about the Connections@Cooleman having 15 clients now?

Mrs Rowland: Yes.

THE CHAIR: Are you meeting all the demand currently or do you have a waiting list for the services?

Mrs Rowland: We do not have a waiting list; we are meeting demand, at the moment. But it is about promoting the service. The service took about five months to develop, because it is about—

THE CHAIR: So how are you promoting it at the moment?

Mrs Rowland: Talking to other service providers, sharing information at community hubs. It is for the Weston Creek area, primarily, and the Tuggeranong area, so we have been promoting in the Weston Creek shopping centres and at the Lanyon and Tuggeranong hubs that take place on a regular basis, and we have been going and talking with carer organisations. So promoting the program has meant that carers and care recipients have come and had discussions with our coordinators and said, “This is what we would like to have happen in these programs.” So it actually took about five months to gain full confidence of all the different carers and care recipients and to develop a program that they actually designed themselves of what they would like to have happen in those meaningful activities.

THE CHAIR: Are you at maximum capacity with the 15 you have?

Mrs Rowland: Absolutely. We would require further funding, if we were to take on more clients or if there was a change in the client mix. We have higher needs clients than we anticipated in proportion—

THE CHAIR: And this is all FACSIA-covered, is it?

Mrs Rowland: No, Connections@Cooleman is ACT HACC funded.

Ms Cane: Can I make a comment too? Camilla just mentioned staff in passing there, and an interesting aspect of a program like this is the nature of the labour force that we use. We actually have a number of people who are studying or are graduates or are maybe doing postgraduate study in psychology and social work and so on. They are a terrific type of workforce, because they are very flexible themselves. They find an hour or two in the evenings, which is often a difficult time, or at weekends. They can meet that, and they are very happy to work on a casual basis. That is another really quite interesting aspect of programs like this that tends to be forgotten—the nature of the workforce is quite helpful.

Mrs Rowland: We have a unique opportunity in the ACT to really build on that. I have just come from a two-day FACSIA forum talking about respite across Australia, and most states, particularly in rural and regional areas, were outlining their issues in terms of retention of workforce, trying to recruit people to the workforce who have mental health training and disability training. We have found that, by working with the university students, we are retaining these university students, even those who are graduating—they are developing career paths and so it is giving them valuable experience as well.

THE CHAIR: I have one more question before I hand over to my colleagues. Do you have any thoughts on weekend respite care? Is that something that is on your agenda?

Mrs Rowland: We certainly provide, through respite options, weekend respite care. It is much more expensive to provide, because of the awards and agreements that are in place. Our other concern is that, with the new award that may be coming through with the SACS award, and the rostering information that will come with that around having to roster people for a minimum of two hours, it is not going to be very conducive to being flexible, in terms of how we meet people’s needs as well.

MS BRESNAN: I just want to clarify something you said, Ms Cane, in terms of providing respite for a longer period of time for people. Did you say 12 weeks is the maximum that you are able to provide?

Mrs Rowland: Twelve weeks is almost like a bit of a benchmark. We review each person’s situation with them every 12 weeks. Depending on the resources available, we then may be able to continue that support, or we may need to cease that support for a period of time while we take other clients on whom we consider a higher priority.

MS BRESNAN: I was just interested because you gave that story of the man who is now able to go and have that break. In that instance, would he be someone who would get the 12 weeks and then might have to have a break while other people are provided with some respite, and then he would get another 12-week period? Is that essentially what has been happening?

Mrs Rowland: That is potentially what would happen. I would not say in his situation that that is what has happened, but that is what would be happening for the majority of people.

MS BRESNAN: So, as you said, this is an ongoing thing for people for the rest of their lives, really—

Ms Cane: Yes, for a long period of time, until maybe there is some other change in circumstances, whatever that might be.

MS BRESNAN: That is right. But, in terms of the funding you receive and, as you said, trying to meet the needs of a whole lot of people, is that the best way you have been able to manage providing it?

Ms Cane: Yes, that is right. It is a sort of rationing really.

Mrs Rowland: The federal government works under a recovery model, which works towards providing people with support towards recovery, but the reality is a certain percentage of people will not necessarily recover fully and will continue to have regular episodes, so that they need that ongoing support, and we really support—

MS BRESNAN: And, I guess, particularly with episodic conditions as well—that is where that is going to be, with mental health.

Ms Cane: Yes, that is with the mental health ones, yes, that is right.

THE CHAIR: Ms Porter?

MS PORTER: Thank you, chair. One of my questions has just been asked, around the weekends. Do the respite options also include overnight care?

Mrs Rowland: No.

MS PORTER: No overnight. We had a family here earlier—I think you might have been here when they were here—and one of their needs was to be able to bank the time and then take a whole weekend. That would not be possible under your flexibility?

Ms Cane: Not under these programs, I don’t think. There is insufficient funding at this stage, I would say.

Mrs Rowland: If we were provided with sufficient funding, we could do it.

MS PORTER: You could be that flexible, but at the moment the funding does not allow you to be that flexible to be able to do that.

Ms Cane: Not to do it alone, at least. I think we have had some situations where there has been some care provided, as a joint effort between a variety of different providers, to allow a family to go on holiday, I think. We took on the five to eight stint in the evening, and the preparation of dinner.

MS PORTER: So, in that case, is it the same worker that is staying over—a consistent worker or workers–or is it shifts of different people coming in and out of the house?

Mrs Rowland: In that situation, it was shifts of different people coming in and out. But I do have to say that with our clients we try to match them with a worker and continue that worker with that client for as long as we are providing a service, so that they are not having continual change.

MS PORTER: So this is provided in the client’s home mostly; is some of it provided—apart from the Cooleman program—in centre-based care or mostly at home?

Mrs Rowland: Thank you for raising that, because, in fact, the original intention of our whole proposal to FACSIA was to provide access to a whole range of centre based programs. What we found, in talking to organisations like Carers ACT, was that they said to us, “I think you will find that most people want in-home respite or out in the community,” so companionship, assisting people to go out to activities in the community, not specific disability-based or mental health-based activities. In fact, I believe that, of all the clients we have ever had—this is for respite options—only two of them have requested centre-based activities. The rest have asked for individual support activities, whether that be in the home or assistance with companionship or the shopping or accessing community activities.

THE CHAIR: Can you tell us about the methodology that you have applied to the certification of carers and, I guess, the quality and experience of carers that you provide?

Mrs Rowland: Are you talking about the paid support workers?

THE CHAIR: Yes.

Mrs Rowland: Actually, under FACSIA’s guidelines for this particular funding agreement, we have to have trained workers who have a minimum of certificate IV in community services and mental health training. So we look at that minimum qualification, and we then look at the university students and where they fit with that. We also ensure that all our workers have a two-day mental health first aid training. Other organisations similar to ourselves who provide this across Australia do the same, in terms of that mental health first aid training.

THE CHAIR: Are there relevant ACT regulations that guide this as well?

Mrs Rowland: No.

MS PORTER: Sorry to interrupt, is that because this program is funded through a federal program and you abide by the federal guidelines or do other guidelines apply as well?

Mrs Rowland: There are really no other guidelines at this stage. In terms of the way we are implementing it, we have had a look at the HACC guidelines to make sure that we are abiding by those. We are looking at the national disability guidelines as well to make sure that we abide by those as well.

MS BRESNAN: I have one question which you have probably answered already. You said that the 15 clients going through the Connections project are very much dependent on the level of need of the clients. If you were to get higher needs, does that affect the number of clients you can take in?

Mrs Rowland: Yes. We would really welcome discussions with HACC in order to have a look in the future at how we can increase our staffing ratio to meet the needs of those clients with high needs.

MS BRESNAN: Because of the types of clients that you are taking within that program, that could be a likelihood down the track as the program becomes better known?

Ms Cane: These things do vacillate. There is no doubt about it. We run another program called fun4youth, which is an after-school program for adolescents with moderate to severe disabilities. It varies hugely how many people we are able to take, simply depending on the severity of the disability. The funding will only cover a certain number of staff. In past times, it has gone down to as little as four people up to at least 10 or even more. It is one of those things that we do have to monitor very carefully. It has to be safe. Safety is important for everybody. We have to keep this in mind all the time.

Mrs Rowland: At the moment, that fun4youth is for 12 to 21 years of age. Connections@Cooleman is 25 years-plus. There is that gap between 21 and 25. At the moment, we are trying to look at what we can do to address that and potentially develop another program.

Ms Cane: There are still issues clearly about continuity of care, regularity of care, quite apart from quality. I think we are almost, by inference doing, some of this, quite frankly.

MS PORTER: I have a very quick question. You may want to give us an additional submission about this. The government is about to commence a feasibility study around the replacement of centre-based respite houses. If you had your druthers, what would be the key features of future respite, both in terms of the physical environment and the service model?

Mrs Rowland: This is not quite responding to your question but I do want to mention that Communities@Work has had a proposal with the ACT government for some time about the building of a facility which we envisage would be used in the first stage for day respite services and services for people with a disability. It would be a service delivery building we are talking about. We are not talking about an office. With stage 2, we had envisaged it being a respite house or building which would enable overnight respite.

I am just mentioning that. It is not quite what you were on about there but I just wanted to mention that as well. That is in the process of being considered by government. We hope that could make a significant contribution towards this issue. Maybe my colleague can answer your question.

Ms Cane: In terms of its design, there was certainly a whole list of requirements that we put together. We visited some other centre-based respite services as well to have a look at design issues in terms of wheelchair access, designs of rooms for activities, designs of facilities with living skills activities such as kitchen areas, outdoor areas. It is quite a long list that we would need to have a separate discussion or a separate paper on.

In terms of respite services, individual one-on-one type services, the feedback that we have received and the information that we have received when talking to other service providers in other parts of Australia is that they need to have a very client-focused, individualised plan for each person that meets their needs in terms of regularity, how that might look, whether it is in terms of social support or companionship or escort to shopping or living skills, whether it is assistance to actually attend activities.

For example, we looked at sending a support worker to go with somebody to attend a yoga class that is for everybody in the community. They did not want to attend a yoga class for people with disabilities. They wanted to attend a yoga class that everybody else attends but they did not have the confidence or the social skills to be able to go on their own. Having a support worker go with them was what they saw as their highest and greatest need. At the same time, that also provided that carer with a break to be able to go and do whatever they wanted to do.

It is very much that we are going down that line of seeing that people want flexibility. They want options and choices. They want it to be affordable. They also want to be able to change what those needs are as things progress. We need to remain flexible. If I am hearing correctly, your reference is to the houses where people live.

MS PORTER: We are looking at the whole issue of centre-based respite houses. The reviewers are. Whether or not that is a good model anyway is the whole issue.

Ms Cane: I think we will have to take that on notice because we have not really given very much thought to that. As you can see, our focus has been mainly on the day respite programs. Even with the building with its various modules that we are talking about, we are not envisaging a respite house as such. We would be envisaging some overnight stuff but it would be maybe three or four nights at the most.

THE CHAIR: Your submission mentions that Communities@Work was successful in receiving government approval to quarantine a small amount of allocated management funds for direct service provision to carers to enable a “no wrong door” approach. Is this Australian government funding under the respite development fund? How is this approach working?

Mrs Rowland: I was referring earlier to the fact we were able to quarantine some funds. That was what I was referring to. The original model was that services like ours would provide all our services through brokerage funding through commonwealth care respite centres, which meant that everybody had to come through commonwealth care respite centres in order to get services from us. What we wanted to do was have a “no wrong door approach” so that people could approach us directly. In fact, the majority of clients have come to us directly, not through commonwealth care respite centres. They should be able to request services directly. With that money that we quarantined from that management funding, we were able, for almost two years, to provide direct services.

THE CHAIR: There was mention to the committee by families just recently that they cannot get in-home respite care through Disability ACT. If such a situation occurs, is there any way that you can step into the breach?

Mrs Rowland: Under our funding from FaHCSIA, somebody would need to have a mental illness or a severe intellectual disability. They would have to meet that criterion.

Ms Cane: If Disability ACT wanted to brokerage funding on purchases from us, we would always be open to that.

THE CHAIR: That is exactly what we are trying to find out. I think you were here for the evidence from those people whose children would qualify under that terminology as well.

Ms Cane: Judging by their ages, depending on where they live of course, it would make sense. There is the fun4youth program as well.

THE CHAIR: Thank you. Thank you also for the submission you made. I am thanking you in anticipation of the other submission that you are leaving with us as well as your remarks. If there is anything else, any further thoughts that emerge after this discussion, we are happy to hear from you. The committee may ask you about other things.

Ms Cane: May I add one comment? I just wanted to mention that the research, which is tagged for the committee, was undertaken by Orima for Communities@Work. It is about Communities@Work. In that, the following levels of demand were indicated for these types of services: up to 5,000 households will require in-home care and maintenance service for the frail aged and people with disabilities. Eighteen hundred households require social inclusion and support service for people with disabilities. Up to 800 households require in-home support for people with dementia. We have got an interesting future. There is a long way to go on this. This material is here for you. I just wanted you to know why that was tagged.

THE CHAIR: Thank you for your consideration.

VERICK, MS MARGARET ANNE, Director, Focus ACT Inc

THE CHAIR: Good morning, Ms Verick. Thank you for joining us at this fourth public hearing of the Standing Committee on Health, Community and Social Services inquiry into respite care services in the ACT. Have you read the privilege statement and are you comfortable with the information?

Ms Verick: Yes.

THE CHAIR: Thank you for coming along to give your verbal submission to us this afternoon.

Ms Verick: Thank you. I will start by referring to my notes. I have worked in disability administration, governance and policy for almost 30 years. I thank you for the opportunity to be here today.

For the record, Focus ACT is a non-profit non-government organisation that has operated since 1991. The majority of its funding comes from the ACT government. Focus ACT supports people with a disability to find a place to live, choose how they want to live and manage their daily living. Focus ACT provides those accommodation support services to around 70 people with a mild to moderate intellectual disability.

Focus ACT's values are based on the objects of the ACT Disability Services Act and the belief that people with a disability have the same basic rights as all other members of Australian society. Focus ACT did not make a written submission to this inquiry. However, the inquiry outcomes are likely to affect us. Focus is well aware of the challenges that face providers of services to people with disability and their families. Before coming today, I read through the ACT Auditor-General's Office performance audit report of May 2009 and the ACT government submission of April 2010, as well as some of the other submissions to the inquiry.

Today we are really talking at a much broader level than some of the testimony I have heard this morning that was very informative and much more hands on. This is much broader perspective stuff that I am talking about today, because respite care, and the lack of, does affect Focus ACT.

With respect to some of the main points I want to make, if you can bear with me, I will read some of this. I notice that Disability ACT has developed vision statements, directions and plans, but they have not led to the desired processes and safeguards for effective and efficient respite services, or to an increase in the provision of respite to meet the growth in demand. The positive elements of the ACT government's response to the audit recommendations are welcome. However, when reading through them, all you can say is that many are pending as they wait to be identified, developed, commenced, incorporated, reviewed, conducted, established, formalised, mapped, enhanced, built, finalised and implemented. They agree with most of the recommendations but there is still a long way to go.

In spite of the pressures faced every day by families since institutional living began to be phased out, it is dismaying that timely and regular respite for people with disability and their families has not yet been given the status it deserves in the ACT government's consideration of funding, or, for that matter, other governments'. It is possible that respite care's earlier separation from accommodation support services led to its downgraded importance. But this has happened in spite of the known, very high level of unmet demand, and families' continual pleas for more access and more flexible respite.

Families want to function effectively and need reliable specialist supports to prevent them from reaching crisis points. As we know, a lot of respite is delivered in response to a crisis. Respite care is the major service type that specifically supports carers. The unrelenting and intense nature of caring for a family member with severe disability can lead to carers facing heavy demands on their time, health and finances. Recently, 30,000 carers around Australia were found to have the lowest collective wellbeing of any demographic group encountered by Deakin University researchers conducting the Australian unity wellbeing index survey. Obviously, increased access to regular and timely respite would go some way to offsetting this unhappy distinction.

Carers have a lower workforce participation rate than people with no caring responsibilities. Regular and timely respite could go some way to assisting carers to consider at least part-time employment.

Of course, respite can only make a real difference if it is based on and is in response to the person's goals and to assist the family or carer to maintain their caring role. Respite should also be viewed as early intervention, particularly for younger people with disability and their families. Providing timely, regular and age-appropriate respite can assist a family to function more effectively and help to prevent it from slipping into crisis situations.

> … greater support for families is essential to ensuring people with disabilities have every opportunity to reach their full potential and participate meaningfully in the life of the community.

That is a quote from *Shut out: the experience of people with disabilities and their families*. The report identified a lack of appropriate and flexible respite as a particular concern. For example, one of the statements emphasised that teens with intellectual disability had a particular difficulty accessing sport and recreation activities because they sometimes need a support person. Increased access to community sport and recreational activities as part of respite care programs could and should make a real difference. People who have worked in respite care programs say that they need appropriate training for their role and for managing behaviour and complex health and lifestyle needs.

Other areas—and this is something we notice not only in respite care but in other areas—that training must emphasise are the value of the support worker role, because often you find them slipping into low morale, the human rights of people with disability, and effective communication with the person and the wider community about the person with disability.

They are the main points I would like to raise. I have some other comments I would like to make at the end, if that is possible.

THE CHAIR: You have obviously covered a whole range of issues there. On the matter of carers, do you recruit carers yourselves or—

Ms Verick: Focus ACT?

THE CHAIR: Yes.

Ms Verick: Yes, they do; very much so. In fact, the majority are casual, and they do have some highly qualified permanent staff in middle and senior management. I think we are proud of saying that the majority of the casual support workers have been with us for over 15 years.

THE CHAIR: Is there a set of guidelines or certification of carers—ACT guidelines that you follow?

Ms Verick: Focus ACT have certainly developed their own guidelines on this matter, based on the national disability service standards on the values and human rights of people with disability. I am not aware—I am not involved in day-to-day management; I am a director—that they use any other form of guidelines. But the people involved, as I said, at the senior management level have all been involved in disability for many years and they have come from other types of services. They understand, under the national disability service standards, that you have a certain approach to employing, orienting, training and upgrading training—absolutely critical. We know the history of some organisations, including Focus's, some years ago, under different management—that those things were not taken as seriously as the current management takes them. It is very important. The most critical aspect in delivering those services and making good use of that funding from the government is the calibre, ability and empathy of the carers. It is absolutely significant.

MS BRESNAN: On the issue of guidelines, you said that there have been some new guidelines developed internally in line with the national disability services standards. There seems to be a similar experience, as we heard, in a couple of other organisations. Do you think that there needs to be either a national or an ACT-based system of compliance or set of standards that services should to abide by?

Ms Verick: If you had such a thing, how it would be monitored would be a query that would come to mind. One thing that we know is pretty much across the board is that disability services would look for carers that have, as a minimum, certificate III, for instance, and preferably certificate IV. So there is already that sense that people are trying to conform to that.

If there was a system of saying, "You can only employ people under these guidelines," I wonder how much notice that would take of the in-depth values training that the service itself would do. You could bring in somebody with a certificate who still needs a significant understanding of the values of that organisation, such as how they relate to people and how they communicate to others about people. I am sure others would have the experience over the years of seeing support workers in the community with people with disability speaking to them reasonably roughly but, worst of all, communicating the attitude to someone else in the community, "Don't take any notice of him. He's just like that." Those things are values that you try to instil in support workers, particularly those who go out into the community.

MS BRESNAN: As you said, the values and the way people treat someone are crucial in this type of care. Do you think there needs to be, at the very least, a minimum set of standards?

Ms Verick: There is never any real harm in having a minimum set, which is what standards in themselves are. The national disability services standards, in a sense, are the minimum that you should be delivering. Enhanced standards would be up to the organisation. In New South Wales, the state government—I did some work years ago—gave the guidelines under each standard. They also gave a set of enhanced standards. If you give a minimum, don't let people believe that that is all they have to do. That could be worrying. "Minimum" realises that every service is different and hopefully takes into account the fact that the service is going to build on those minimum standards right across the board.

MS PORTER: Just to clarify, while we are still on the standards issue—is it your understanding that all of the organisations, whether they are ACT funded or federally funded, must come under the national standards? That is the adopted standard right across Australia and the states sign up to be part of that. So they do not have two layers of standards; they all adhere to the national standard? Is that your understanding?

Ms Verick: The national standards set the benchmark, if you like, because they were the first to bring in the Disability Services Act, and then subsequently the states and territories brought in their own at various stages. Under that agreement, which was the commonwealth, state and territory disability agreement, they had to develop their own standards for their services—

MS PORTER: For the services themselves.

Ms Verick: Yes, so the accommodation support standards really relate more to the ACT government standards. They grew out of the national disability services standards, which ultimately were changed slightly because they added two on for employment and so on. They were all based on the same beliefs and the same understanding of why we have a DSA in each state and territory and federally.

MS PORTER: Thank you. My question was around the fact that the government is about to commence a feasibility study on the replacement of centre-based respite houses. If you had your druthers, could you say what you believe should be the key features of future respite both in terms of the physical environment—what it should look like physically—and the service model?

Ms Verick: The area of centre-based anything is always open for discussion, isn't it?

MS PORTER: That is right.

Ms Verick: Over the years I think I have changed a lot in the way I think about things. I have to be careful here that I am representing Focus. Focus believes very strongly that people should be in the community for all activities—that they are not separate and should not be treated as separate individual humans; they should be out there. So when you talk about centre-based respite care, sometimes you would say that it may not necessarily be a good developmental experience for the individual. It may give the family or the carer a break, which is absolutely critical anyway, but is it going to be a terrific experience for that person? That is the concern that I think I, speaking on behalf of Focus, would have—that if you have centre-based care, how does that support an individual? How many would be there at the one time? How much support would they get? How could they have a program for themselves that developed their skills or built on their skills?

It was very interesting to listen to the previous testimony and hear of some of the things that they are doing—life skills and so on—under different programs. It is exactly what you would want it to be, but that also cuts across day activity areas. Regarding centre-based care, I think some families would say, "At least we know the person is safe and so on." More broadly, I think we would say, "Community-based activity in home." There is no question—and I have heard that as well—that families would say they would like in home above all to help them do what they have to do daily. But I have heard from others over the years who say, "When the respite carer comes into the house to help it's more of a distraction and more of a problem."

So it is about individuals. You cannot say—and this is the dilemma about group homes and everything else—that just because one family or one individual did not want to use centre-based respite care it is bad. I do not think you should ever limit options. The caveat would be: how is it going to help that person grow in terms of their skills and development and help them interact socially and so on? That would be a very important thing for me.

THE CHAIR: Thank you. I understand that you are catering to the needs of about 70 people at the moment.

Ms Verick: Yes, that is right—71, actually.

THE CHAIR: Do you have more of an external demand for further services?

Ms Verick: Yes. We do not have a waiting list. There is no point. The funding has just been increased after two years of negotiations so that we can better meet the needs of the people that we have who have been involved with us for 17 or more years, who are ageing and developing complex medical needs and so on. We were never set up to do that. We do not have the staff trained to do that. We are working through those issues. We have been granted some extra recurrent funding, but that is only so that we can safely look after the people we currently have, so they do not have a risk of accident or death in our care and our care workers do not have a risk of something else happening.

We have not tried to take on new people. We have had a couple of people go into a nursing home because that was the only place they could get the kind of care that they needed because of dementia and other early developments, but that does not necessarily mean we have freed up enough space to allow new people to come in. Mind you, in terms of the people that we support, somebody may get one hour a week and some might get 24-hour care. It is right across that spectrum. One of the things we always wanted to do was provide more social activity by taking people out from where they live to activities in the community. Because we did not have enough money or enough support workers to do that we had to cut back on that. Any freedom that we get we try to bring more into the life of the person we support that lives in the community.

THE CHAIR: Could I have just a little bit of clarification, if you do not mind? The number of people you have had under your care, for want of a better word, has that been static over a number of years?

Ms Verick: Yes. It has not changed much.

THE CHAIR: Okay. And with people who are ageing and, for whatever reason, if they happen to leave—

Ms Verick: That has only been about three people in the last couple of years.

THE CHAIR: What I am trying to understand is this: you are looking into this group of people's needs, and, with the ageing—the natural ageing and illnesses and—

Ms Verick: Premature aging, actually, in many cases.

THE CHAIR: Yes. Does that open up other opportunities? Do you foresee much of a change in the way that you are operating with your current group of people, and does it offer any opportunities further down the track for other people to replace those people in time?

Ms Verick: I think Focus is open to the idea that new people will come in, as long as that does not mean that we cut short on what we do for other people—that it has been established by their individual plans what sort of support they should be getting. If we took on new people, we would need to be sure that that is not going to then take away benefits from those people. You just could not do that. That has already been cut, in a sense. As I said, about the social activity, that was cut back, not because we wanted to, but we just could not keep up with the pressures.

But, just to pre-empt something you may ask, Focus ACT has never thought about going into respite care. Focus ACT is always open to what is happening in the whole wider community, and the fact that families cannot get the respite care that they need as regularly as they would like does put pressure on some organisations like Focus ACT. Families would actually want their person, when they attain adulthood, like everybody else in the community, to go on to develop a life of their own, which would mean moving into community living or some other arrangement, if the family was not able to do it, or felt that the person would benefit from living outside of the family house and not being there until the parents died in their 80s and 90s.

So the lack of respite has limited the options for individuals to keep their families operating. We know that there are families out there who want something like what Focus is delivering to 71 people, but we cannot help them. And we are not the only ones.

THE CHAIR: I have just one final question. I am trying to come to grips with this whole area of your activity. Are you aware of any unmet need that is in the community that surrounds you? Are you aware of how many other people require the same sort of service?

Ms Verick: Yes, we are starting to get to grips with more details of that. I do not actually have them with me today, but, yes, we are aware that it is significant. In the *Shut out* report, which you have probably all seen, the clear message was that families desperately need respite, but then, as their person ages, grows up and so on, the unmet need in accommodation support is one of the greatest around Australia and has been for the last 20 or 30 years, ever since people moved from institutional care and families no longer sought to put people into institutional care—because it was not viable, it was not going to happen and, in Victoria, for instance, you cannot do it anyway. So, yes, there is huge unmet need. I do not have the detail with me. I did not think of that.

THE CHAIR: Thank you, Ms Verick.

MS BRESNAN: I just have a question around the support worker roles. You raised the issue of morale—I do not think that was the exact word you used—

Ms Verick: Yes, it was.

MS BRESNAN: Yes, regarding the morale of support workers, how do you think that can be addressed? Is it through providing a clear path or qualifications or through pay? Are there any particular ways in which the value of that role can be better recognised?

Ms Verick: I think you are right on all three, actually. Of course, the salary one is the hardest one, and you can only pay what is the going rate or slightly above, or work it into your agreement with people that they get some benefits of flexibility or they get an extra week of holiday pay.

You do what you can to make working with you attractive. You do indeed try to look at the opportunity for career paths, and I know Focus over the years has invited some of the casual workers, saying, “If you want to upgrade the way you work with us, we are very open to that.” Because there is turnover. It is not huge for us. We do not lose a lot of people. But we say, “You are always welcome to come to us and we can talk through that.” I have seen people go through some stages since I have been involved with Focus—I have been on the board for just over four years, I think. Yes, I think that is very important.

A couple of the things that we have noticed in valuing our support workers is giving them opportunities for broadening their training, understanding more about what goes on in the whole sector, individual training, inviting people to come in and talk to them about a whole range of things, including safe working with people and how you do certain things. They are really important, and I think we noticed a difference.

The feedback we get from staff is that they value the opportunities to team build, because at one stage they actually worked out in the community alone, without any coordination. So you have to build a team, you have to give them values, you have to give them opportunities to learn more, to open their minds, to give them a little tiny bit extra. But you are limited on how much extra you can give them. You really are. That is tricky. People do not poach exactly from each other, but there is a little bit of movement.

Could I just make a couple of quick comments?

THE CHAIR: Certainly. I was going to say that we are running out of time, but yes, please do make them.

Ms Verick: I just wanted to say that Focus ACT strongly supports the comments made by National Disability Services ACT in its submission, which you have already read. In particular, respite care is a service that cannot be viewed in isolation from other disability services, which I have just been talking about. It is important that the need to increase access to respite services is considered in the context of increasing demand for supportive accommodation, as I said.

The linkages between respite services and community access services should be given better recognition. Very often they cross over. Respite must offer preventative solutions to families and individuals—in other words, we are not waiting for crisis. The higher cost per respite user provided by government service warrants further consideration of wider outsourcing of services to or increased funding to non-government services.

Some of the other submissions raised just a couple of points that I would like to make. Eligibility criteria for specialist disability services should be defined in the ACT's disability services legislation. Disability ACT should formalise procedures and guidelines used in assessing an individual's eligibility for services. It was striking that there was no uniformity in how many of these things were done.

The critical safety issue for individuals receiving respite identified in the audit must be urgently addressed. That means updating and maintaining risk management processes. Enhanced review processes and record keeping must be implemented as a matter of urgency. I know from Focus that they are absolute sticklers for how you record every single incident, how you maintain a watch on the individual plans and so on. And, basically, respite care has to be based on some individual choice and flexibility.

There was one comment I wanted to make about the national disability insurance scheme, which is hopefully in the offing. Governments cannot wait to see what happens there. It could be some years down the track. There is a lot of support for it. But we do not know exactly which year it is going to come in, so we cannot wait to see what will happen there. Hopefully, it will happen.

THE CHAIR: That is a little bit outside the scope of our inquiry, but thank you for your comment.

Ms Verick: Yes, I suppose it is.

THE CHAIR: Thank you very much for coming in and sharing your point of view with us. If anything else crops up that you think would be relevant to our inquiry, we would certainly like to hear from you.

Ms Verick: Is there a deadline for that?

THE CHAIR: The deadline is over the next two or three weeks. Thank you very much.

Public hearing concluded at 12.14 pm.