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, 14 APRIL 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 9.37 am.

FRAZER, MRS FRANCES, Private capacity
O'DEA, MS KARNA, Parent/carer
VARDANEGA, MR MAX, Parent

THE CHAIR: Good morning everyone. Welcome to this public hearing of the Standing Committee on Health, Community and Social Services inquiry into respite care services in the ACT. There is a privilege statement; are you happy with it and have you had a chance to read it? If not, I will briefly read it out, as I think you should be aware of it.

Mr Vardanega: It was emailed to us, I think.

Ms O'Dea: Yes, we read it when we filled out the witness form.

THE CHAIR: Just to recap, all witnesses making submissions or giving evidence to an Assembly committee are protected by parliamentary privilege. "Parliamentary privilege" means the special rights and immunities which belong to the Assembly, its committees and its members. These rights and immunities enable committees to operate effectively, and enable those involved in committee processes to do so without obstruction, or fear of prosecution. Witnesses must tell the truth, and giving false or misleading evidence will be treated as a serious matter. It is fairly straightforward, and I hope you have read it.

Because there are three of you presenting individual cases, would you like a couple of minutes, each of you, to outline the reasons you are here, before we start asking questions?

Mr Vardanega: I am comfortable with however you want to do it.

THE CHAIR: Perhaps a very brief introduction would be useful.

Mr Vardanega: I am here because I am the parent of a 39-year-old intellectually disabled son. In that time we have been exposed to this system, as you could imagine, so I thought I would come along and put forward a couple of ideas. It seemed a damned sight easier to come here and speak to you than to write it out.

THE CHAIR: Thank you for taking the time to do so.

Mrs Frazer: I am the parent of a 21-year-old son who has autism spectrum disorder and an intellectual disability. I am here as part of a larger parent group who is concerned about service provision.

Ms O'Dea: I am like Frances. I have two on the spectrum. I have a 21-year-old and a nine-year-old. I am tired of writing endless submissions, so I thought I would come and see you. After talking to some people at Autism Asperger ACT, my story is pretty typical. It is quite common for families to have more than one, because I am beginning to think that, for a lot of people with ASD, it is genetic. I thought I would come and tell you about it, along with Frances and Max. Max has a longer corporate memory than I have, but I span what is happening now for the younger ones and what is happening with my older daughter.

THE CHAIR: Thank you for that. We will start by hearing from you, Ms O’Dea.

Ms O’Dea: I have come because I can remember a time when I think things were a bit better. My daughter is now 21. She has been in a group home for six years. She attended respite, mainly at Kese. It used to be at Birralee, which was at Holt. She then went to Kese, which is in Kaleen, and she went on to Teen respite. She went into a group home at 15 because she got beyond me, and I said I was not doing it anymore, so we got her in. It took a long fight, but she is in.

With respite, my daughter is at the very severe end of the spectrum. If you have not minded anyone or cared for anyone with autism, at her level you are looking at minding an 18-month-old, a toddler, 24/7. I am sure the other parents can understand where I am coming from. It is very hard work. The respite, when we got it, was adequate. The homes always looked daggy; I would say they looked clapped out. My little boy is starting to go to Kese; I have noticed that it looks run-down. It is rather sad because it is supposed to be a home away from home. Well, my house is kept in better order. So that is my main complaint. Currently, my little boy, Malcolm, who is nine, is at Cranleigh. He also has an intellectual disability but he is higher functioning than my little girl. We are gradually moving him into respite.

My complaint about the respite is that I inquired about respite at the start of last year. I got so desperate because we are starting to get the behavioural challenges, in his case, as adolescence kicks in. He is nine, but adolescence seems to come earlier and earlier in the generation. I think they are better nourished now—I am over-nourished—and the hormones seem to happen. I had to follow it up. I got so desperate. I spoke to Karin Wetselaar, who is the principal at Cranleigh. They run a social work facility as well as a special school. They have been very good. I got on to Steve Lowrie, who has—

THE CHAIR: Ms O’Dea, would you try and refrain from naming people specifically, if you do not mind.

Ms O’Dea: Okay. I got on to Disability ACT and got on to one of their brokerage managers, and he bumped my case up. We are gradually starting the integration process for him. But, as I said to you, Kese looks no better than it did when my daughter was there. I know they get a lot of damage from children, and the staff do their best, but it is pretty pathetic of the ACT government when they are providing it as a centre. It looks so run-down. I do not think the facilities have improved since my daughter was there, and she has not been there for 10 years. It does not look any better. It looks faded, it looks tatty. The staff seem good. The kids seem happy. But the place could be improved—the physical facility could be improved.

The other thing I have really got a beef with is that I was one of the carers who fought for after-school care for my daughter, and I understand that Gungahlin community services are cutting that out. It might surprise you: I go to work at Tax to get some respite. I also go to work to pay for all the therapy that no government pays for for my son. We never got the “helping children with autism”, any more than these parents did, but he is only two years over it. So it worked for me as respite. If they do not provide after-school care and holiday care for when my son turns 12, and he is no longer eligible to attend the normal after-school care, I am not going to be a very happy little Vegemite. I am going to join many parents who get so fed up that they consider putting their children into care, and I do not know what you lot are going to do. No-one is going to foster an autistic child. I know that I would not.

My feeling is: why did we have to fight so hard for that service and then it seems to be either worn down or taken away? The only ones who got after-school care for autistic children or for any mentally disabled children were Kerrie Tucker and Annette Ellis. They came to our meetings. We fought so long and hard for that 10 years ago, and to hear from other parents who have children who are going into high school that they might not have after-school care, with the exception of Noah's Ark, I think is pathetic. And to hear that it is really no longer required—you have to remember there are 11 official abandonments in the ACT. Do you know what "abandonment" means? It means they put them into respite and they do not take them out. I would love to know the figures for children that are abandoned. Anecdotally, I know of several parents who have dumped their children because they are desperate. I have had several parents contact me for advice on getting them into the group home.

The current mantra is "we offer no group homes". Well, I am saying to you that if you want parents to keep doing what basically is 24/7, you had better start making sure that there is after-school care and vacation care until they finish school, and there had better be respite for the parents who want to keep them after 20. They are also lowering the school age at Black Mountain school from 20 to 18. Where are the day programs? I am sure these parents will tell you exactly the same thing. Where are the day programs? Where are the meaningful work activities for the kids who are capable of work? Do you know that Koomarri has a five-year waiting list to get work for those who are capable of work?

My daughter is in a group home. We are paying for the one session she gets at Sharing Places. I have told Disability ACT they had better pay for the second session because she has gone so far backwards. She is in care but she is left to rot, and I am not very happy about that at all. My husband is ringing up the network coordinator basically to say that we are not happy and we want something done about it. She really should be going to Sharing Places four days a week.

My mother and I have discussed that. We often feel that they are so chronologically behind their peers. My daughter is mentally 18 months. I could say to you that, based on her cognitive age, maybe you should have kept her at school until she was 40. She learnt nothing at school but it was somewhere to go and something to do. And all these parents will tell you that every last service that seems to work, like Sharing Places, was set up by parents. Thirty years ago, they did not assume that mentally disabled children deserved an education. Parents set up Koomarri, which is now Black Mountain school. So I would say it was an indictment of you as a government.

MS PORTER: We are not the government.

Ms O'Dea: I know, but you all represent different people who have been in power, barring the Greens.

MS PORTER: We are not here representing the government.

THE CHAIR: Ms Porter, through the chair, please.

Ms O'Dea: I am saying to you that the services are lousy. The respite services seem to be stuck in the same state they were when my daughter attended them, and she is now 21. So that is what I have come to say. I am not happy—literally. I am sure the other parents would say pretty much the same thing but probably less emotively.

THE CHAIR: Ms O'Dea, thank you very much for your evidence.

Ms O'Dea: Well, I'm typical.

THE CHAIR: Any questions of Ms O'Dea?

MS PORTER: Chair, I was trying to get your attention before—and I apologise—but I just wanted to clarify for you, Ms O'Dea, what their role—

Ms O'Dea: I know you're a committee but all of your parties have been in government at different stages—the Liberal and the Labor parties.

MS PORTER: I can understand you are very angry and you are very stressed. I really empathise with you. That is why we—

THE CHAIR: Ms Porter.

MS PORTER: No, I just wanted to clarify our role, which is that we hear your evidence and then we are going to represent you. So we are not here representing the government—none of us. We are here as an independent committee and that is our role.

Ms O'Dea: Unless the government acts on your recommendations do you think the respite situation is going to improve?

MS PORTER: That is our job.

THE CHAIR: Ms Porter, we are here to listen to the witnesses and you can ask questions of the witnesses.

MS PORTER: Yes, I just wanted to clarify that.

THE CHAIR: This is not a time to make a positional statement. I think the witnesses are aware that we are a committee—

MS PORTER: I just wanted to make sure that she was clear on that.

THE CHAIR: Are there any questions that you would like to ask of Ms O'Dea, Ms Porter?

MS PORTER: Yes, I just wanted to talk a little bit more about the condition of the home that you were describing and the tattiness of it and I wanted to understand—

Ms O'Dea: Kese?

MS PORTER: Yes, thank you. I just wanted to understand—you referred to it as "tatty"—because—

Ms O'Dea: It just looks really really run-down. It is a big government house. I think they purpose built it. My daughter, as I said to you, is 21—the same as Frances's child. She went to it 10, 12 years ago. It used to be at Melba, called Birralee. The infrastructure had decayed so they sold it off. They moved them to Kese. It looks run-down. A lot of disabled children cause damage, but if it is supposed to be the kids' home away from home, it could be a lot fresher, a lot brighter and a lot more cheerful. I think the staff do their best. It is not as bad as a Romanian orphanage, but it is getting to look a bit like a Romanian orphanage. We are a first world country, not a Third World country.

THE CHAIR: Thank you very much for that. We might go on to each of the witnesses, get their statements and then ask questions at the conclusion.

Mrs Frazer: I have briefly written some of my recent experiences, so it is probably easier for me to read it. We first began to access respite services for our son when he was about 14 years old. We used a respite house for teens until he turned 18 and then moved to an adult respite house.

Recent experiences with the government respite house: in November 2009 I sent an email to the adult respite house manager raising three concerns. These were: failure to collect my son from a holiday program at the time requested in writing. I was informed about this a week later by holiday program staff who told me he was collected half an hour later than the closing time of the program.

There was a lack of communication about his activities during his week of respite. They had lost his communication book at the house. There was a lack of communication about money spent during his stay and the balance of his account at the house. We sent money with him each day to buy a takeaway meal as part of the usual routine in the house.

The response to my email was to send it up the line and treat it as a formal complaint. I was sent an email by a senior manager from Disability ACT and assured that all concerns would be investigated. The senior manager wrote, "We will be in further contact to let you know the outcome of the investigation." I have had no further contact and never received a report of the outcome of the investigation into the failure to collect my son on time from the holiday program. I received an email from the respite house manager informing me how much he had in credit at the house and that when the financial ledger was full I would receive a copy so I could have a record of his spending.

I was then asked to take part in a process to make changes to procedures when accessing respite services. I met with the coordinator from Disability ACT and the house manager. A new support plan was signed off and part of that plan included sending parents a summary of stay report to improve communication. I sent an email to the house manager on 20 February stating we had not received this report from his January stay. I received an email response apologising that the report had not been sent because of an office relocation happening. We still have not received the summary of stay report. We were offered a week stay at respite in March. We declined that offer and then received an invoice for that stay. It took me nearly a week of phone calls to resolve this error in paperwork.

The Auditor-General's report in May 2009 into the management of respite care services highlights problems with accountability lacking in records management, client information systems, risk management and quality performance management. According to the report, complaints and feedback processes need to be improved. In my experience, these problems are still there in abundance.

For many years we have been allocated three hours a week respite from a non-government provider of short-term respite. For a number of years we were fortunate to have a relatively easy time accessing respite through this service. Support workers liked working with our son and we had few changes to his program.

Late in 2009 changes began to happen. The service provider informed all users that weekend support hours were to be cut due to costs. We accessed three hours respite on a Sunday for many years. We agreed to change from weekend respite to weekday respite as it now fitted in with my son's post-school life. The coordinator found a new support worker in December. In January the support worker could not continue in this position as it clashed with his study timetable.

Since then I have made numerous phone calls to speak to the coordinator about finding a replacement support worker. The calls were not returned, until I made a call on 18 March and expressed annoyance when the receptionist suggested the coordinator could call me back. A new coordinator did call me back and promised to keep me informed as to the progress in getting a support worker. I have not had a call since then and we have had no respite since January with this provider. That is just a small glimpse of my experience.

THE CHAIR: Thank you, Mrs Frazer. Mr Vardenega?

Mr Vardenega: I would like to tell you a brief story and then I have some suggestions on what I think we may need to do. My son is 39 years of age. We are very fortunate that he is physically fine but he has an intellectual disability. He went to Woden special school and a special program at Daramalan and he went on to Chartwell Crafts. He has had employment on and off and is currently in part-time employment in the mail room at the Canberra Hospital. All of those sorts of things are really good.

We gave up a long time ago, and I mean a long time ago. When my son left school and left the Chartwell Crafts program we tried very hard—this was about 20 years ago—to get him involved in things and nothing worked. It was too complex. The reason I am here now is that nothing has changed. Unfortunately, my wife is quite ill. She suffers from chronic pain and has had about 30 days in hospital this year. That meant that in December I tried to reengage with the support system in the ACT because we needed some support.

The answer is that it has not changed. It was always too bureaucratic and it was always too complex. The staff were always undertrained and the properties were always run-down. The answer is that nothing has changed. We were quite surprised that, even with the help of the hospital social worker when my wife was in hospital, that the confusion between commonwealth carers' responsibility and ACT carers' responsibility and various support agencies is just rampant. I sympathise with the organisations trying to do it, but I guess my message is that it has not changed.

So I have a couple of ideas which I thought might be useful because they do not cost any money. One of the things I think we need to do, if we want to get the best result for people with disabilities in the ACT, is to focus on training all the existing community organisation employees in how to get a family through the process of getting the maximum from the existing community and state support. It is complicated and there are a whole range of programs out there. In my experience, digging through the piles of paperwork, there is money there if you can find it, but it is the game of finding it. If we trained all current employees in how to do that it would be very useful.

Then I think we should encourage all existing community organisations to take on the task of walking one family at a time through the processes to make sure that every family has got everything they are entitled to. I will give you an example. In the Centrelink process, which is funded by the commonwealth, there is a carer payment and there is a carer allowance. I get the two of them confused. When you get to about page 30 of the application for the higher payment, it tells you that you are unlikely to be eligible for this payment but you should perhaps apply for, I think, the allowance. But that means you have got to start all over again. For families that are stressed and already operating on the edge of their capacity, that is a disaster.

My feeling is that if every agency took on the job of walking one family through this process—and for one family it might take eight to 10 weeks to walk them through the process—and it was a job to do, at the end of the year we might get 25 or 30 families through. At the end of two years we might have 60 families through. It is that complicated. That is my second suggestion.

The other suggestion is that the government—in fact, I should not say "the government" because the government changes; it is the senior public servants who run the place. You will have a view about whether they run it efficiently or inefficiently, but they actually run it. It is a very small pool and it seems that we recycle the same failures around and around. We just move them around, hoping they will do better in the next job. I think we should be supporting organisations like community living. Community living is a program which is struggling to get off the ground, but it looks like it will do well. It is really interesting because what it is saying is that if you give support to a person with a disability—excuse me, this upsets me; it has been a long struggle and I get a bit worn out.

MS PORTER: Would you like this, Max?

Mr Vardanega: No. That is fine. It is probably not in the budget so I had better use my own.

MS PORTER: Max, they are in the budget. That is why I am using them.

Mr Vardanega: Thank you. With a young person who has a disability, you support them in one process while they are at school and then you take them out of school and you support them in another process and then maybe you support them in the medical system for a while, or mental health. Then, when their parents get too old to look after them, you try to put them into a retirement village or disability support. It is a disaster for them.

The idea with community living is that they are starting the equivalent of a retirement village but for young persons, so you get supported in this community all the way through. So at the age of 55 or 60 you do not get moved into inappropriate accommodation away from the people you know. You get this really simple concept of a retirement village, supported accommodation, which starts basically when you leave school. And that means that those people who can live independently do, but they stay with their friends and all that sort of stuff.

So, if we looked at the community living plan and supported that, that would be fantastic.

Ms O'Dea: Sorry to butt in, Max, but you must have heard from Esther Woodbury and Alison McGregor about it. For the people who have got their kids at home they were talking about providing day programs.

Mr Vardanega: Yes, it is a really good one.

Ms O'Dea: It is the best idea around.

Mr Vardanega: Yes, and the last thing I would say is that if someone would come up with—they might need an A3 plan printer or something—a flow chart of all the organisations, support programs and phone numbers, I have a wall big enough to put it on, but it is just huge. It would be simple. Even if all we got was a bloody great flow chart once a year for each family which said who you ring for what, that would be good.

THE CHAIR: Thank you. The reason that this committee has been formed is to look into some of the issues that have been brought up through the Auditor-General's report. We are very much aware of some of the issues from a corporate point of view, for want of a better word, and what we are trying to do is get the feedback directly from you. That is why we have called this series of hearings and inquiry into it.

My first question relates to the concerns and the complaints that each of you have raised. Have these been taken anywhere beyond the actual service delivery organisation? Have you taken any of the complaints to the disability and community services commissioner?

Mrs Frazer: Can I answer that? I was going through my records about my probably relatively minor complaints, I suppose. It takes an enormous amount of time to telephone your way through these people. I simply do not have time. I could have rung the senior manager in Disability ACT and said, “Where’s my report?” I go to work too. I just do not have time to spend the hours writing to and telephoning people with my complaints. Because the system is so fragmented, we are dealing with a huge array of services. You would need to do it full time. And does it get you anywhere? Does it improve the quality of service in the end? No. I am at the—

Ms O’Dea: You get it off your chest, though, Frances.

Mrs Frazer: You do give up. If I could, I would have my son right out of respite care services. I would want him working five days a week and living in appropriate accommodation, so that he has a life. At the moment, what I have got for him in respite services is not.

Ms O’Dea: The worst case I found was before we got my daughter into a group home. She was going to respite, week on, week off, and the trouble was that it was very hard to take up the caring if you had not had her for a week, because all these people represent different challenges; they are all hard work and it takes so much out of families. I am still living in an intact marriage; in a lot of families I know the husband nicks off. I have met so many young girls at Cranleigh who are left as a single parent. I am surprised that more of those kids are not dumped. I do not know how they carry on with the physically and mentally disabled, because you are basically shackled to somebody. If somebody has got cerebral palsy and is mentally all there, you get a lot back. But if you have got the severe end of the scale with Rett syndrome—I found it with my daughter; I love her but she is too hard.

If my husband had nicked off, I would have put her into care. We were thinking at age five of putting her into care because we had endless issues. The only way I managed was because I had my mother. My mother, Margaret Mary Goyne, was a blinking godsend; she meant that I could work. They were very pathetic about childcare. They still are about kids with disabilities. I think that basically all governments have dumped families and expect families to keep carrying the can for them. I think disabled children and adults are the last human rights cases. If we all got together, we could sue all you governments—and I do not care who is in power—for basically abrogating your responsibility to probably the most vulnerable section of the community, along with the frail and mentally aged.

To be honest, love has its limits. I think people have got to understand this. I look at these young girls at Cranleigh who have got littlies, preschoolers. I think they think that God is going to miraculously come down and fix them. If Jesus came back, there would be queues at Cranleigh to get them fixed. I am sure you would all be lining up too. He is the only politician I would like to see—Jesus. You wouldn’t even have to worry about the funding thereafter.

If you make it harder for families to keep looking after people, people just cannot keep going. You have to understand about caring. You have a boy, don’t you?

Mrs Frazer: Yes. I do not want to change him for anything. I want him to have a reasonable life that every other 21-year-old has.

Ms O’Dea: You want him to be happy.

Mrs Frazer: He is happy but he does not have a sustainable work life and he does not want to live with his parents forever.

Ms O’Dea: He would like to be independent.

Mrs Frazer: We are boring. He is 21. He needs to have a life.

Ms O’Dea: And does his social life come from you?

Mrs Frazer: Yes.

THE CHAIR: Thank you very much for that.

Mr Vardanega: This issue on the complaints: I would say that we have some of the most beautifully crafted complaints processes in the world in the ACT. The simple problem is that they do not work. It is nothing to do with the process, because they are beautifully crafted and we have some wonderful brochures; they are delightful. It is an attitudinal problem.

There is a major problem in the ACT in that our bureaucracy will not admit an error. At all levels they are taught never to admit an error. All you have to do is look at the number of unsuccessful cases that the ACT Government Solicitor defends in the courts about administrative errors et cetera. There is this attitude that, if there is an error, we will defend it to the death and we will never admit it. So, instead of getting a simple problem resolved at a low level, on it goes up the line. And you can even get situations in the ACT where you will have the Community Advocate, the ACT Ombudsman and an internal organisation’s complaints process all engaged in circular letter writing; they write to each other. My view, from over quite a few years of dealing with this sort of stuff, is that the processes are there but the problem is the attitude. Someone needs to be prepared to admit error.

THE CHAIR: That is the reason I asked the question. Thank you for answering it.

MS BRESNAN: You have been talking, and it is in the submissions we have received, about the options available for respite care for younger kids and that as they get older there are fewer opportunities. Do you feel the services you have been provided with in the past and now are doing anything to enhance the lives of your children, whether through educational or recreational opportunities, and if that is something that is more of a focus when they are younger than when they are older?

Mrs Frazer: I was asked to come in in January and go through a new process with the government respite people. They say that they are there to give that person a quality week. But the reality, when you have half a dozen people staying in that house, with the variety of disabilities that they have, is that, if I did not organise activities for my son to do during his respite stay, he would be watching television in the house for the whole week.

MS BRESNAN: When you say that you are the one organising those respite opportunities, is that through other services coming in or getting people at the actual service where your son is staying?

Mrs Frazer: That is at the government respite house, the adult respite house.

MS BRESNAN: I was wondering what sort of services they are providing. You say that you have to organise that yourself, because of the staffing and all of the other issues there. I was wondering what that process is and what sort of services would provide that enhancement or do provide that enhancement.

Mrs Frazer: I organise his week so that he is out of the house as much as possible while he is staying at respite; otherwise, I know he would be sitting watching television and doing nothing else. So it is up to me to make sure that his week at respite has varied activities for him to do.

MS BRESNAN: I was wondering what sort of activities provide that sort of enhancement.

Mrs Frazer: One is through his supported employment program, which he has for two days, and one is through a community service holiday program provision, which I guess is funded as a respite service somewhere down the track. I do not know how it is funded. I like him out of the house as much as possible. His experience is to stay away from home, be away from his parents, be in a group situation. That is all that is provided really.

MS BRESNAN: But beyond that it is something you have to organise yourself.

Mrs Frazer: Yes.

MS BRESNAN: You said, Ms O’Dea, that with the behavioural problems in adolescence and all those things the difficulty level increases.

Ms O’Dea: It depends. Max has got a son. Max’s son sounds to me like he is very mildly handicapped. Is that a fair assessment?

Mr Vardanega: Yes. He is in that category where his intellectual disability is not a limitation until you underestimate it. I will give you an example of the sort of thing that Scott will do. He works part time at the hospital. They have put up signs about washing of the hands to combat the flu. It took us about a week and a half to realise that every time he saw the sign he washed his hands. He was losing skin on his knuckles and that sort of stuff. We were trying to work out what was going on.

So there is a whole lot of stuff going on with him which you have got to keep a really close eye on. But we are very fortunate that he is substantially along the lines of some of the problems that other people have to deal with.

MS BRESNAN: Do you think that almost blanket-type approach applies to particular ages because it is seen as being too difficult and, rather than looking at individual cases, that is—

Ms O'Dea: It depends. From what I have seen of Kese, they seem pretty good. As I said to you, the place is a dump. I think a Romanian orphanage might even look better, for all I know.

With my daughter, I would be the same as Frances and Max. It depends on the degree. As I said to you, my eldest is severe. She is not profound which I think means you are almost catatonic. She is severe; whereas my son is moderate. He is learning to read and write. So it depends on the level. He would not be as good as Max's son. He has got autism and he has got the behavioural issues.

I do think the services peter out. I really think that is very cruel because nowadays it costs ACT Disability, according to them, $400,000 to put one person in a group home. My attitude is: isn't that tough luck? They expect families to carry the load. Nowadays they will tell you bluntly, "We don't provide any group homes." I said, "That's very nice. If you haven't got the community living concept, I don't know what you are going to do because he will be moving in with one of you, won't he?"

Look at Max. His wife is sick. Parents die.

Mr Vardanega: I think what has happened is that, because the ACT has such an appalling record of managing those sorts of homes, some genius has come up with the idea, "If we can't do it well, let's not do it at all." That is bizarre. If you can't do it well, learn how to do it well.

Ms O'Dea: My daughter's home is quite good but there are only two of them. The lass who runs the home is a very nice girl. On the whole, they have had good people at the DSO2 level who care about the two girls. She said to me, "I don't know how you did it 24/7." I said, "I never knew." I was going to murder her; that is how fed up I was getting.

Mr Vardanega: One of the experiences I have had with staff is that we don't pay them enough and we don't recognise extra payment for training. Let us say we have got staff member A. They go off to CIT and do a certificate IV in disability or whatever the course happens to be. They go back to their job. That may not get them any more money. They have worked at night; they have done their study and all that sort of thing. We really need to pay people who are prepared to be trained and give them extra money for having got those qualifications, because one well-trained person in a group makes a big difference.

MS PORTER: Frances, I want to go back to your original discussion with us when you read out from that piece of paper. You talked about the various incidents with the record keeping and your son not being picked up from after-school care.

Mrs Frazer: It was during the holiday program.

MS PORTER: You said the email was treated as a formal complaint. You said he was 14 at that time.

Mrs Frazer: He started using the service when he was 14.

MS PORTER: When was this incident?

Mrs Frazer: Last year. He was 20.

MS PORTER: About what time of the year?

Mrs Frazer: October.

MS PORTER: To this point, which is now April, you have not had a response other than they said they were going to investigate it. So you have not had a response. Going back to the chair's question about the commissioner, you did not mention this but it was probably in the group that you were talking about that talked to one another. At the time you thought it was being handled. I am not trying to put words into your mouth but you did not send that same email to the commissioner at that time?

Mrs Frazer: No. I just expected that I would get an outcome, that somebody would let me know the outcome of that investigation.

MS PORTER: You are still waiting?

Mrs Frazer: Yes. I have given up. I have not received any feedback whatsoever.

MS PORTER: I want to clarify from the three of you, because I did not hear the direct answer, notwithstanding that you do not necessarily have time to do it, whether any of you has put in a formal complaint to the commissioner.

Mrs Frazer: No.

THE CHAIR: Unfortunately, time is coming to a rapid conclusion. Are there any other questions? On the initial question, which Ms Porter has just followed up on, I do understand your concerns and scepticism which goes with putting these complaints before other areas that may be overseeing what you are talking about. I do not think we can afford to say, "Nothing will be done about it; so we can't complain."

It is very difficult for us to put ourselves in your position. We understand what you are going through. We understand the constraints on your time. We are not trying to be apologetic in any way. We are saying, "Let's address the issues." The ideas that you have come up with, I think, are very logical. This is what we are trying to get to the bottom of.

Are there any other points that you would see as the most important from each of your points of view? What is the one issue, if you like, on which we could start addressing the problems that you face?

Ms O'Dea: I want the community living concept in place for my son, and I am tired of Disability ACT's mantra that it is an institution. I work in the tax office. It is an institution. I worship at the Catholic Church. It is an institution. My daughter goes to Daramalan. It is an institution. I think a lot of parents are tired of it just being assumed that they ought to do caring until they die. I think it is time that they realised that government is going to have to shoulder the burden.

We got on to Bill Shorten and he got harangued by me and another parent, Bob Buckley, who was also fed up. We have said, “You are really going to have to carry the can.” I do not think the states have got the money. I think they are going to have to become the department of health and care, rather than health and ageing, because there are a whole lot of people who are ageing, who are going to need care themselves and who will not be able to provide care for their adult children. There is a limit. I think you all need to understand that love and care for most families has a limit, particularly when you are looking after a severely disabled person.

Mrs Frazer: I would like my son to be done with respite completely. I want him to go to work five days a week and to be able to live in a supported accommodation environment which suits his needs. I wouldn’t have him any other way.

Mr Vardanega: I think the community living model is something that should be strongly supported. I think the other thing I would like to say is that the people who have the task of running these agencies should not assume that parents know nothing. I am sick of talking to so-called experts. Parents actually do know something, particularly about their own kids.

Ms O’Dea: I think you get to be an expert on the condition. I know more about autism than a lot of the professors I have met. I am an ex-librarian. Of course I know how to research. Some of them, you look at them and think, “Where did you get that nut of an idea from?” I agree that parents know what is best for their children but I think parents want the options.

I want my son to have work five days a week, whether it is a hobby or paid work. People with disabilities need to be occupied, like the rest of us. I like work. I go to work and I forget about all the problems at home. I like the routine. I am on holiday now. I still think, “I had better get up and go to work.” I might do nothing at work but it is the routine. Most of us like routine.

Frances is working. I am working. I am not going to give up work. I have no desire to give up work. Work has kept me sane. I am dealing with adults and I am working in a different environment. I don’t think about autism at work.

THE CHAIR: Thank you, all three of you, for taking the time to present your information to us. The transcript will be available to you. This committee will be hearing submissions way past September and will be looking at putting out a report towards the end of the year. It will have recommendations. We look forward to further feedback that you may come across and that you feel would be of benefit for us to consider. Thank you very much for coming.

TREWHELLA, MR IAN ANTHONY AM, Private capacity

THE CHAIR: Good morning, Mr Trewhella, and Mrs Trewhella. You probably heard the preamble that I gave before about reading the privilege card.

Mr Trewhella: Yes, I read that.

THE CHAIR: Unless you want me to touch on that?

Mr Trewhella: No, I accept all of that.

THE CHAIR: I do not think I need to introduce the committee members; you probably know Ms Bresnan, Ms Porter and me. Thank you very much for coming in, and we look forward to hearing what you want to say to us this morning.

Mr Trewhella: Thank you, committee, for the opportunity to address you today. I would like to make an opening statement which I believe encompasses what I will later address. My statement simply is that, whilst I accept that the terms of reference for the inquiry are simply about respite, it is my strong belief that over the term of the inquiry the committee, I suggest, will find that respite means different things to different people and that the causes for demand for respite will come from fragmented services and lack of support for services for people with disabilities, families and carers.

Having said that, I come here and, may I say, it is timely, in my view, especially as I base my address to the committee on my own experience, having lived with a significant disability for over 49 years and having regard to my attempts to access all types of disability services, including respite. To say it is not difficult to live with and try to survive with a disability is a gross understatement as one tries to use, in one’s best interests, a fragmented disability support services system.

As funding is often the key component to service delivery, it is further compounded by where that funding depicts or determines where, or with whom, the responsibility for service delivery lies. What I am identifying here is the delineation of responsibility for service delivery. The committee would be aware that funding for disability and aged-care services comes from both commonwealth and state, and it is this funding aspect that further adds to, I contend, the fragmented services system.

This funding approach also sees duplication in many areas, and that adds to confusion with identifying what is out there, who is responsible for what and the lack of uniformity. It also identifies the fact that there is not a whole-of-life approach and people, as they age through the system—and our predecessors identified many of the aspects and problems—have to work in lots of different areas to try and get a reasonable outcome. And it is certainly not easy.

In addressing the hearing, I do so from the perspective of a care recipient who is a quadriplegic and now has a 24/7 high-care need. The committee will appreciate that such a need as mine puts tremendous physical and mental demand on my primary carer, my wife. My need for increased care follows on from a significant decline in my physical wellbeing since 2002. Until 2002, I was reasonably independent, although a quadriplegic, and I only ever needed low to medium-care assistance. And that I was able to cope with.

This all changed then, to a point in 2005 when I had to access in-home care to survive and allow my wife to continue working. Unfortunately, and as a result of this significant demand for extra care, the inappropriate in-home care did not suit our lifestyle. As a result my wife, being my primary carer, had to give up her employment. Her forced retirement comes after three years of aged-care in-home support experiences that fashioned my care more around the care provider needs than our need for a lifestyle of our choice.

In an attempt to access respite in an aged-care facility, I was prevented at the time from accessing this respite as my ACAT assessment was not current. So once an ACAT assessment initially was put in place, it had a life term of about three years, and if you dropped out of the system and tried to get back into it, you had to go through another aged-care assessment. To get an aged-care assessment, it took us about three months to get an appointment. So you have to live with the opportunity of trying to get an ACAT assessment while you are still trying to get respite. It was not something that was easy, because the aged-care system would not touch you unless you had the ACAT assessment, which is a major difficulty.

As a result, I eventually got an updated aged-care assessment, and the commonwealth has now made that a permanent situation. Therefore, it ensures that I can access aged-care services, and this includes respite, should that be a requirement. However, I did not believe that respite in an aged-care facility was of my liking because I am a pretty outgoing bloke and my lifestyle does not fit within a nursing home environment, and you will appreciate that.

My address to the inquiry is about the difficulties we have experienced trying to access respite services, other than aged-care respite, that provide choices and options in a timely manner. It is extremely difficult trying to find out who provides respite that would suit my needs in the short term or the long term. There is no “one-stop shop” approach that I could go to and get directed to respite providers.

It is difficult determining from services the difference between respite and other care for disability services. There appears to be significant fragmentation, and predecessors also identified that. Just trying to find out what is out there is a major problem. Easy and clear information about who offers what services would assist planning needs.

We do not have a single service that provides all things to all people with disabilities, and you would appreciate that from what I mentioned earlier. We get bits and pieces of support from multiple providers, and that type of approach makes it very difficult to manage your requirements on a daily or ongoing basis. There are no easily accessible information services in Canberra that provide appropriate information in one location that can inform your decisions on where you might access respite if you need it. There is a need to justify one’s disability every time you want to access a service—not just respite but just about every disability service.

When you have got a permanent disability and you approach these people, they give you a form and they say, “Go to a doctor. Get a doctor to assess that you have got a permanent disability." I have lived with it for 49 years. If it ain't permanent now it never will be. Yet you have to keep justifying that. That is a major difficulty.

I have tried to access aged care for my current need and I am eligible, under the aged-care system, for an EACH package. We know that there are caps and that there are EACH dementia packages. But in my case, being in EACH, this package is only worth 10 hours a week. When you try and fit 24/7 into 10 hours—Einstein could never do it and I am bloody sure a service provider can't. I think also the aged-care services are built around significant standards. We have national disability service standards but we do not seem to have a service standard that fits respite.

In addition to accessing respite in an aged-care service facility, the aged-care service provider is allocated some funding from the commonwealth to look after your EACH package. That system also provides the opportunity for the provider to assess your means to pay something or everything. In my case, with my 10 hours a week on an EACH package, I also had to pay, they assessed, an additional $205 a month on top of the money that they were getting from the commonwealth, which, had I not been in the position to pay, would have more than addressed my EACH package need.

They also have in that EACH package an equipment component, but their costing, because I had to pay, could not cover the same funding and equipment as you can get from the CAAS scheme—the same things that I was getting from the CAAS scheme on the $460-odd a year for CAAS. When my service provider tried to offset that, they were buying things far in excess of what the CAAS people could provide. In other words, they were selling catheters to me for $20 a catheter and the CAAS scheme was providing me with catheters for $6.50. Where is the justification? The buying facility in the aged-care provider network was not strong enough and, consequently, the prices were such—whether they set them or their supplier set them I am not sure; I did not go into it.

The EACH package was such that it did not provide adequately and we had multiple carers running through the house. You could not have a sleep-in because the carer had to turn up at 8 o'clock. You could not get things. If you require bowel care, they are not allowed to do it; that is a nursing facility. You have to wait for a community nurse. Community nurses are overloaded. They will turn up when the system allows them to turn up.

You might have a routine that you would normally get over and done with in 45 minutes from, say, when you get out of bed in the morning, but if you are waiting on a community nurse they will turn up whenever they can turn up because the demand is such that they turn up at your door only when they are ready. You have to sit around and wait—and I mean wait. You might have an early start, but they turn up mid-morning, so you are left in bed. That is a major difficulty.

One of the things that are often misunderstood is the cost of disability. This is a major problem for people with disabilities. Yes, I get CAAS. I am a self-funded retiree. I get some assistance elsewhere, but on top of that there is not a financial year goes by when I do not spend money out of my own pocket just to survive my disability. It is usually in excess of $5,000 a year. Yes I can claim that back on tax because I am a self-funded retiree and I still pay tax. But you have got to find $5,000. When you are a self-funded retiree, it is not a big pension, but I still have to find that $5,000 irrespectively.

Those are things that you have to take account of before you put food in your mouth and pay your rates, water and telephone bills. I am very frugal. I know how to work the system. I know where the cheaper goods are and I use the system to try and get $1.50 or $2 out of every dollar I put in. That is a significant thing.

One of the things that are required over the life of the Commonwealth State Territory Disability Agreement, now known as the national disability agreement, is that the states and territories collect statistical information on funded services. That statistical information is known as the national dataset. We were led to believe that the national dataset was to be used for planning services, but I am yet to see or hear whether it is used for that purpose, whether it is used or whether somewhere along the line there is a massive growing database system that no-one can access or interrogate or it is not used for planning services. The Commonwealth State Territory Disability Agreement goes back a decade, I think, now. So if you have got a decade of data, someone needs to be looking at it to plan services.

It is not, I believe, difficult to establish that there is insufficient respite. It is blatantly obvious, but respite needs to be affordable. We cannot just put respite in place and say, “We will give you respite, but you need to provide a co-contribution.” That co-contribution, while it may be small, adds to the cost of disability. It is having lots of these co-contributions collectively that adds up to my $5,000 or better every year.

I have looked at researching over the last two years where I might get something in the order of four to eight weeks of respite. The need is becoming more urgent as my carer needs some medical intervention that is going to put her away from my care for about eight weeks. I cannot find respite to cover that loss of care, other than to say that maybe, like I said at a forum the other day, I will rob a bank. If I do so, they will put me in the Alexander Maconochie Centre. As soon as I go through the gates of the Alexander Maconochie Centre, the duty of care of that organisation would require them to provide me 7/24 care—very bloody cheap for me, hey?

In closing, may I say that my own attempts to find respite have been difficult. I have had a look at several organisations. One down at Rivett has Monday to Friday respite but it is not high care. What do you do on the weekends, even if you were able to accept that it is not high care? My only option still looks to be a nursing home, because I cannot find anything out there.

I have put the problem to Carers ACT, an excellent organisation, an organisation that is very globally thinking about what they might be able to put in place. I have squirrelled away a few bucks, and I might have to use that to try and buy a nurse 7/24 for a period of about eight weeks to cover my care. Carers in the aged-care system, if I were to use them, cannot do certain aspects of my care because it is classed as nursing duty, and that precludes them from doing certain things.

So my only real option is to look at funding, out of my own pocket, a full nurse, 7/24, for up to the eight weeks. That, I might add, is going to be quite expensive, but I am probably lucky because I have worked on this problem for two years and it has given me the ability to squirrel a few bucks away. But I will be penalised because there is no respite out there that can offset that. So it is a major difficulty.

I know governments have responsibilities for all things for all people, but it is difficult to see, having regard to the current system. We have got *Future directions: towards* c*hallenge 2014*, which Disability ACT have used as their policy framework to develop disability services, including respite. But it does not appear to be working. It may well be an ideal, beautiful document and it may look good, but at the coalface it is not achieving change.

We went through the Gallop inquiry. A lot of people came out of the woodwork and said they would be more than happy to accept the status quo that Mr Gallop found and that they would work closely with government to fix it, and help fix it—without pointing blame, but to fix it. But it has not been fixed. It may only be anecdotal evidence, but there are many people that I move amongst, because of my disability, that continually ask, “Why haven’t we got effective change?” I think it is incumbent on the inquiry to develop a series of recommendations that may well address this but it is also even more incumbent on the government of the day to take those recommendations on board, put them into practice and effectively make change. Thank you.

THE CHAIR: Thank you, Mr Trewhella. That was a very extensive explanation of your situation, and I have heard that a lot of other people are in a similar situation. You touched on issues regarding funding from commonwealth and state and also said that there are some inadequacies or a shortfall in the way that funding is carried out—the waste, I guess, that occurs, and so forth. You gave an example of buying certain items but they are supplied to you at a different price.

Mr Trewhella: Yes.

THE CHAIR: Is there an administration fee that applies to any of the funding that comes to you?

Mr Trewhella: Not to me personally, but when the funding goes to the organisation that is going to supply the service, there is in that service an administration component added to the overall bucket of money. In other words, an organisation that is going to provide a service is given a bucket of money and in that bucket of money there is also an administration cost. That administration cost does not get passed on to me. Well, I hope it does not; it may well be, but we do not know that it does. So it is a problem.

Another thing that I have found to be a problem over the years is that the evolution of disability services has grown out of the need, and governments do not take on real direction. Governments of the day—and this is my assumption—put a bucket of money out to an organisation and they go away and develop that service. It is that organisation that controls the direction of the evolution of that service. But that is not a service that fits all people. Consequently, you get this narrow approach to services, and that is similar across all of the services. And that is where you get your fragmentation. It is something that needs to be addressed.

THE CHAIR: Obviously, if there are areas of concern within the funding process, that would be useful for us to know about as well, so you may want to think about that. I do not necessarily want it now, but at some point—

Mr Trewhella: I will do some research into that.

THE CHAIR: Obviously, funding is an issue, and the more we can streamline it to ensure that there is no leakage from the amount that is going to you, that would be useful.

MS PORTER: I was going to ask for some clarification of the issue around the aged-care facility and your lifestyle, but I think you answered that in a later part of your presentation.

Mr Trewhella: Yes.

MS PORTER: Would you be willing to give us your written notes, to help us?

Mr Trewhella: Yes, certainly.

MS PORTER: Would you be happy for a copy of those to be tabled?

Mr Trewhella: I will hand them over; you can have those.

MS BRESNAN: I have a question about unmet need. You mentioned that we know there is a need for respite; it is not hard to work out. In terms of the methods that are used by government to calculate unmet need so that you have that information there, do you have any ideas on what would be better ways to calculate unmet need and whether or not, as you mentioned, it is about actually getting access to that data under the disability agreement? In terms of the ACT, are there better ways that we can calculate unmet need so that we have that evidence in front of us?

Mr Trewhella: If we really want to be radical—and it has only been picked up in recent years—there is the evolution of ISP funding; that is, buckets of money going to the individual to buy the service. That sort of approach would see the development of services based on need, because you would only buy the services that you need, and that is one way that you are going to get proper growth and service delivery meeting unmet need.

Not everybody would want to manage ISPs themselves, because it is tough enough living with a disability without having to be a manager of a large bucket of money, hiring and firing staff and all of those things. Not everybody wants to do that, but there are brokerage services that could do that chore for you. So the greater development of ISPs would be something that I believe would guide a system to better meet unmet need. If you have got the money to do something, you will do it. Consequently, you will buy the services that suit your lifestyle and need. At the moment we seem to constantly have this top-down approach. We have the triangle and we are trying to stand it on its point. History has shown that that is not the way to go.

THE CHAIR: Mr Trewhella, thank you very much. Time has beaten us. A copy of the transcript will be available to you, and we will notify you of that. As you may have heard me say before, if there is anything else that comes to mind that will add value to what we are trying to consider at the moment, could we keep that open as an option to communicate with us on that.

Mr Trewhella: Yes, I certainly will do.

Meeting adjourned from 10.55 to 11.08 am.

POLLARD, MS CHERYL, Chief Executive Officer, Tandem Respite Inc

THE CHAIR: Good morning, Ms Pollard, and thank you for being so patient in waiting with the slight delay that we have had. You are familiar with the privilege information so I do not need to repeat that for your benefit, do I?

Ms Pollard: No.

THE CHAIR: Welcome to the hearing and thank you for taking part. Would you like to give a bit of a preamble about your organisation's background before we start asking questions?

Ms Pollard: Yes, I can do that. Tandem is a non-government community organisation with charitable status that is funded by the ACT government and the federal governments, through the HACC, Disability ACT and mental health agencies, to provide respite, social support, case management and personal care to 600 individuals and families living in the ACT who might have a child or a young person with a moderate to profound disability, an adult with a disability, a person living with mental illness, the frail elderly and their families and carers. We support 600 families across the ACT and we do this by providing in-house or community-based access with staffing of about 250 support workers and we provide over 100,000 hours a year.

Added to that background, Tandem was created in 2008 following an amalgamation of FaBRiC and Respite Care ACT. Both of those agencies had been operating, I suppose, since deinstitutionalisation in the late 80s and early 90s. We are probably the largest respite provider in the ACT outside of the government. I am not really sure what the government provides.

Probably the easiest way to go is if I just speak to my report, but I might just start by saying that what we have heard this morning I have heard since I have been at FaBRiC and then Tandem since 2000. They all painted typical individual pictures of what it is like living with disability. I cannot stress enough the challenges that they face and that respite is only one part of the puzzle. The challenges they have with education and with just providing their young people or adults with a meaningful life and somewhere appropriate to live are critically important. I am not quite sure how that fits into your purpose but I think it really needs to be addressed.

Tandem's services are underpinned by a strategic vision and future goals that focus on delivering quality services aimed at enabling and enriching the lives of individuals and their families while operating in full recognition of and compliance with our statutory obligations. We do this at a strategic and operational level and we use the frameworks of strength-based practice and social role valorisation which underpin all our policies, procedures and processes.

To put it into a nutshell, we work towards enabling clients to do for themselves rather than having things done for them. We have a number of programs. The largest is the children's and young people's program providing respite and social support to probably about 300 families. The adults program includes a living skills program which is very specifically about developing and supporting ongoing living skills. There is a leisure link volunteer program; all the other programs are paid positions.

That is about working with predominantly adults to reduce social isolation. Our affirm program provides intensive case management support to strengthen families who are caring for a young person with a disability. I have to say that with Karna's situation with a nine-year-old and what she has to go through with her adult daughter, the affirm program might be able to assist. But it only works with half a dozen families at any one time. It is very intensive but much needed—the need for case management in general to be able to help families work through the system to find a better life.

Some of the strengths of Tandem's current model of practice are that we work towards matching support workers' skills, experience, personality and interests with the needs and interests of the person to be supported. We use an active respite model where support is responsive to the client needs so enabling the doing with rather than doing for. It is an outreach program, so we are either within the family home or in the community and it is about meeting their needs during that period of time. We are very much age appropriate so whether we have a five-year-old child or a teenager or adult we try to work to what that age group would be looking for. Having said that, there is also that babysitting concept because parents cannot leave their children at home on their own and adults do need to be supported maybe to be put to bed, to get up and get dressed, be fed and so on.

We provide respite "at any time" so it could be after school or during school holidays. Weekends we have had to reduce, and I can go into that in a bit more detail later on. But we do try, as best we can with the support staff we have got and the dollars we have got, to provide the support as and when the families and the person being cared for require it. We also, because we are ACT funded as opposed to federal, provide support for the siblings if that fits in well for the support session. That is an added benefit for the family member. And at times we have looked after the siblings so that the parent can go with their child with the disability.

What we do with our model, based on an assessment, is provide what could be four hours a week, a couple of times a week, based on the individual need. It could be one or two sessions a week and it is ongoing and sustained. That can sustain the family to have a reasonable quality of life and you do not actually need the additional other services. On the other hand, it is not a panacea. With other families, particularly with changes in school and challenging behaviours and so on, there is a need for other services.

Some of the challenges experienced by Tandem in providing our service are the complexity of complying with all business requirements while working within a charitable model. The rhetoric has changed very much from when I first started in the sector—that we are a charity and should be treated as such. The reality is that we are a business and we have to operate in that way and sometimes that can conflict with the way we might want to provide the service. One of the family members said today that they might be looking for something but our funding model will not allow us to do that within the parameters of what we have got from HACC or Disability ACT, for instance.

There is an enormous financial and personnel resource impact of compliance towards standards, service consistency, legislation and funding, all of which are essential to ensure best practice and professionalisation of the community sector but come with significant challenges. I suppose just in the example of funding, Disability ACT, HACC and mental health all have their own standards and that requires a significant administrative workload to meet those requirements.

We have difficulty in providing a quality service with meaningful outcomes within the constraints of legislation, contractual and statutory requirements, including industrial relations and OH&S. They are both really big ones; OH&S has been for some time. If we do not get that right, we have huge insurance issues. I have to say that in the end if our insurance broker says, “No, we’re not going to cover you for that,” we cannot do anything anyway. So that is probably right at the top of the tree.

Industrial relations: there is a huge review going on at the moment. We have got to review a new award, which is part of award certification, and see the impact of that. An example in the new award for us is that we currently provide one hour of support and they have said that the minimum is a three-hour shift. How do we cover that? Do we pay the support worker three hours but only one hour is required? Providing the individual response that we do, they might not be able to get three consecutive hours. So that is a significant challenge, let alone that it is going to the Industrial Relations Commission and we might be required to increase wages. I believe everyone in the sector should have an increased wage, but how is it going to be funded?

And, of course, there is the true cost of compliance with industry directives such as a portable long service leave scheme. I mentioned the other day that I believe in principle it is the right thing to do, but it needs to be funded and we need to look at how much it is really going to cost. Putting it back on the government, HACC and so on, to negotiate with the agencies will not be the right answer because I think it needs to be a whole of government response anyway.

One of the challenges is the financial need to apply a ceiling to weekend service provision due to a combination of funding being provided on a weekday unit cost basis and the imperative to meet funded hour allocations. So with our funding from HACC, Disability ACT and mental health we have to provide a certain number of outputs, we have a certain number of dollars to do that with and we have to then put the hours out. The reality is that we identified last year that we were not able to sustain the level of weekend support that we were providing, mainly in the children’s program. We need to have a discussion and negotiation, particularly with HACC, to see if we can come up with a better response because we know that it has a significant impact on families. But the agency would fall over if we continued the level we are currently providing. That is a real concern, because there is not much negotiation power with an NGO and the government. Pretty much we would end up having to reduce our hours. They might keep the same dollars but fewer hours and that is not a good outcome either.

We have significant financial availability issues in providing relevant and needed training to all our staff, particularly in the areas of managing challenging behaviours and complex health and lifestyle needs. We certainly are very focused on training our staff and we do provide very good training, particularly around the complex health and lifestyle needs. We would not send any support worker into a situation that they were not trained for. They are non-professional people, support workers; they are not nursing qualified and they do go into some very difficult situations. Having said that, it is a transient population—we have to accept that—so we are constantly recruiting and training and that is a huge financial burden for our agency. The good side of that is: let us hope these people go somewhere worth while where they can share their knowledge of disability particularly.

The lack of opportunity to negotiate contracts effectively and meaningfully I think does need to be addressed. NDS is doing some work around that but we do not carry much weight, particularly on an individual basis. Last week Andrea Simmons mentioned reviewing the compact and I think that is probably very timely.

THE CHAIR: You could elaborate on that lack of opportunity to negotiate contracts. Is it with the government?

Ms Pollard: Yes, and the opportunity to negotiate a contract but also to assist in the planning for the future. Ian talked about the minimum data set. We have all been collecting that information for the government. I have never seen anything come out of it. It is only collecting information about what is being provided; it is not collecting information on unmet need. I am sure there must be some data somewhere that could be started to be used to plan for the future—the schools, for instance—gather that information and start planning for the future. Talk to the agencies about what we are seeing. It might be anecdotal evidence but it is still evidence, just the same, about the unmet need.

A fantastic example is the school leavers at 18 and even 20. It is horrific. I would hate to be a family member in that situation, knowing that I am not going to have that life retirement plan that I thought I would but in fact I am going to have to give up work, become a full-time carer, because there is not the opportunity, there are not any houses or accommodation for the young people. There is a lot of rhetoric around natural supports. That is there a little bit. I am getting a bit edgy sitting here, watching Ian and his wife. They are not a couple as such. She is his carer. That, to me, was very sad.

I think there is also a lot of rhetoric about achieving outcomes. We talk about it ourselves. Tandem is very bureaucratic at times as well. But the reality is that we have to meet budgets and we have to meet outputs. Talking about outcomes, let us really put some effort into providing that and supporting agencies to be able to do that. I suppose, within the budgets we have got and the outputs we have to achieve, it is nearly impossible to do so.

There needs to be more case management for people of all ages who require access to negotiate the complexity of the system. That came up again earlier this morning. I can remember the spider’s web. There was a report on it a few years ago. Nothing has been done to make that any easier for families. My understanding is that what the local area coordination was meant to do was help families to work through the system, not when it is too late but at the beginning. We could work through the system of what is out there to be able to fully support their needs.

I think there is a real issue about the ageing population and providing respite to this group of people. I suppose also we have got an issue within Tandem on the allocation of hours. There is a strong sense of entitlement for a lot of our service users. This is in part because there is so little out there. We allocate a certain number of hours. They are not going to give them up because they might need them in the future and we might not be able to give it to them at that time.

There are service practicalities, for example, the challenge of providing consistency in contact and service for clients with familiar office and field staff within a transient employee population. We hear this time and time again. We can't come up with the right answer for it but we do understand that it is truly challenging, particularly when you have got people coming in and out of your house all the time—and we might be just one agency of many—and particularly if it is a person with autism who needs that regular phase and regular time. We do work very hard with our support workers to try to address that but it is an issue.

There are other support worker constraints. We talk about indivualised support services and matching them to meet the client need but sometimes the reality is that we do not have a support worker at the time that is needed and we do have to try to come up with the best response.

There is the desirability and the usefulness of providing the therapeutic response within a session plan against the practicality and the reality of funding limitations and support workers' skills and experience levels. There is the availability, willingness and ability of the support workers to work across the ACT community at any time, day or night, and at different times to meet the needs of individuals and their families.

We do not have a system where an adult, for instance, might want to go out for the night and just be able to respond by saying, "I'll be home at 11." Our support worker might not want to stay up till 11 o'clock. It has to be negotiated. Their lifestyle is severely hampered.

I think another challenge is the lack of alternative respite options such as respite houses that are age appropriate, therapeutic in response and nice to go to. You heard that again this morning. We hear all the time that there is a desperate need for an alternative respite within the ACT, because what is there is just not meeting their needs. Our respite model does not meet everybody's need either.

Families, for instance, are wanting their young person out of the house but in the middle of winter there are limited opportunities to do that. It needs to have some dollars attached if you are going to do a worthwhile activity. If you are out for three or four hours in the middle of a winter day, what do you do? I think there needs to be considerable thought and probably dollars attached to come up with alternative respite models.

I have listed a few solutions to some of these challenges. I think we need additional case management that will work closely with the family and maybe just drop in and out of their lives across a period of time. We certainly need to support other in-house respite models that offer a range of activities within the community, not typically that you go there for 24 hours or seven days a week. It could be like a drop-in centre, just providing other respite that is very age appropriate, that is activity based. It could be for the siblings even but just some different opportunities for families.

Increasing options in terms of enhancing staff retention and satisfaction and career pathways might do that in part. Tandem is a little different from many other agencies because we have that large support worker cohort but in terms of the office administration and coordination I think we could do a lot more. In fact, Tandem has been at the forefront since our amalgamation, so people are able to progress either to a different position or a more senior position.

I have listed the increased use of natural supports if they are there, in addition to paid respite. This is both a challenge and part of the solution. Natural support does not necessarily have to be family members but if we can put some time and effort into non-disability specific programs, whether it is after-school care, the local scouts or something like that, there might be some natural connections happening to reduce the need for paid respite.

Increased partnerships with other agencies, particularly when supporting people with more complex and challenging needs, are another example. There are the mental health agencies. Our mental health program, for instance, has managers. We work very closely with the clinical managers to provide the best outcomes possible for the people we support in those programs. We also do that in disability, working with brokerage agencies like Community Connections and Community Options, so that we work collectively.

I suppose appropriate government funding is required to meet the compliance needs to ensure agencies have the financial and human resources to provide a quality service because I certainly know, from my time, there is more and more expectation on the agency, that dollars are attached to everything we do and nothing is forthcoming. It is generally a hard slog to get there.

THE CHAIR: You mentioned at the outset some of the other areas that we are looking at. Obviously we are having input on the needs of carer siblings themselves. We are also very interested in interaction between government and non-government providers of respite care. That is part of our terms of reference. We have been hearing the experience of quite a few service users who utilise government and non-government providers of respite care.

We have had some submissions, of which you may be aware and which are on our website, that in some way do comment on your organisation. Would you like to address any of those comments that have been made?

Ms Pollard: I have only read a couple of submissions but I would suggest most of them are around the weekend hours. Certainly at a board level, we put considerable time and energy into looking at our budget for this financial year. We are starting to plan for it. We recognise that the weekend usage was just not sustainable as we have been providing it and that we need to take action to avoid the agency using up its surplus, when most NGOs do not have a significant surplus, so that the agency could continue to provide services.

The result was that, at a board level, we were directed to reduce hours as much as we possibly could. We first went in, I suppose, more softly and asked families whether they could move their weekend usage across. That would be preferable. We were not getting a big enough impact. So we had to then go in and say, "This is what we can offer, four hours a fortnight." It is not the outcome that I would want but it is the reality of making the dollars that we get go as far as they possibly can to meet our outputs.

In discussion with quite a number of family members, we did come up with some alternative options. They certainly will not meet the needs of all of our families because we do have a significant number who are on lower incomes. One was to pay the gap. We have got quite a number. The gap is in providing the weekday rate as opposed to the penalty rate: Saturday, time and a half; Sunday, double time. Some families have picked up that option.

Another, which has not been explored greatly, is the capacity to have one support worker providing support to two young people, more as a friendship-type program. Of course, that is not going to work for every young person either but that is at least another option.

Another option is 24-hour support because we can do that under the award by paying a lesser amount of money to the support worker. They would still get a reasonable amount. The client gets a 24-hour break. We use up a good number of hours. It is just trying to balance the three areas. Coordinators have spoken with all their families and worked toward negotiating an outcome that might not be the best outcome but at least an outcome that can sustain Tandem and give them something.

MS BRESNAN: My question is in relation to that and is about the discrepancy in cost between what you and other providers are providing in terms of the respite services and the actual cost in terms of what you are being funded for. Is there a discrepancy in terms of what the government and departments are saying you should provide for each dollar and the actual cost? Has that had an impact on those weekend hours?

Ms Pollard: Both agencies, FaBRiC and Respite Care, which amalgamated to form Tandem, used the same model. Our model was always to provide individualised, one-on-one support at any time of the week. That is where our model is different to, say, the government or group home where you have one worker and a handful of people. The unit costing is different. I think we have got to be careful. You cannot compare it because it is apples and pears.

MS BRESNAN: I understand. In terms of the funding that you have been given each year to provide certain outputs, are we keeping up with the real costs of providing these services?

Ms Pollard: No. I think every agency would say that. The funding that we receive is historic. Whenever FaBRiC or Respite Care started, the unit costing was such and such. Each year you get indexation on top of that.

In a way, it is a little crazy because we are currently going into planning for our budget for next financial year. We know the impact the ACT budget will set. We have to wait until the federal government present their budget. Then they negotiate with HACC ACT, because there has to be a matching amount. So we might not hear until October. Sometimes it is in March that we hear what we are getting and actually get it.

We have to manage. We have to try to guess what we put into our budget. It is a crazy way of doing business.

It has a significant impact. We get a lot of money from the government but the majority of is for wages. We have to pay our people. They deserve to be paid.

MS PORTER: I have a couple of questions. One is seeking clarification. When you talked about the minimum hours, I thought I heard you say three. Your submission says two. Was there a typo? Could you clarify that?

Ms Pollard: With the hours currently, particularly in the adult program, we might go in and do one hour of support. That could be to get a person out of bed, dressed and ready for work. The new award that was implemented on 1 January, with the terms and conditions coming into effect on 1 July, said that, as is pretty standard, you have to do a minimum of three hours. I think there has been negotiation to bring it back to two hours. I am hoping that they will go back to one, because that is going to have a significant impact on our adult programs.

MS PORTER: That clarifies that. The other was around staff training. You talked about the fact that they are a mobile workforce and that they come and go. You did say it was important that you did train the staff. To what level are they trained?

Ms Pollard: We do not have a mandatory requirement, although I suspect that will come in within the next 12 months or so. In a slow process, that is happening at a national level. We require senior first aid. We do a two-day induction course. At that, we try to cover as many areas as possible—disability, mental illness, frail elderly, autism and so on. Manual handling is a big one. Then, if support workers are required to do PEG feeding, they would certainly need to have that training. We organise that. We have a rolling training program over the 12-month period. We redo that every year.

In addition, we also work with training providers to put forward cert IIIs and IVs in disability and community care. We do have a highly educated support workforce, having those sorts of qualifications. We certainly encourage it actively.

MS PORTER: I have one other matter of clarification. When you were talking about negotiating your contract, it is with the contract managers of both the commonwealth and the ACT governments?

Ms Pollard: No. We have only got ACT funding.

MS PORTER: Entirely?

Ms Pollard: Yes.

MS PORTER: So you are only dealing with one contract manager?

Ms Pollard: No. We deal with HACC, Disability ACT and mental health.

MS PORTER: So you have three contract managers that you have to negotiate with?

Ms Pollard: That is right.

THE CHAIR: We are running out of time. I have one question. Do you provide respite care for children with ADD and ADHD?

Ms Pollard: We do. We should not tell anyone that because I am not quite sure whether it fits within the parameters. Yes, we do.

THE CHAIR: Thank you so much for coming in. Unfortunately, time has beaten us again. A transcript of everything that has been said here today will be provided to you.

BROWN, MS ROSLYN, Elected member, ACT Indigenous Elected Body
SHEA, MRS AGNES, senior Ngunnawal elder, United Ngunnawal Elders Council

THE CHAIR: Good morning, Ms Roslyn Brown and Mrs Agnes Shea. You are from the Aboriginal and Torres Strait Islander Elected Body; is that correct? That is who you represent?

Ms Brown: Yes.

THE CHAIR: Thank you for joining us here this morning. There is a privilege statement that is available. I might read this out to you so that you are fully aware:

> The committee has authorised the recording, broadcasting and rebroadcasting of these proceedings.
>
> All witnesses making submissions or giving evidence to an Assembly committee are protected by parliamentary privilege.
>
> "Parliamentary privilege" means the special rights and immunities which belong to the Assembly, its committees and its members. These rights and immunities enable committees to operate effectively, and enable those involved in committee processes to do so without obstruction, or fear of prosecution. Witnesses must tell the truth, and giving false or misleading evidence will be treated as a serious matter.
>
> While the committee prefers to hear all evidence in public, it may take evidence in-camera if requested. Confidential evidence will be recorded and kept securely. It is within the power of the committee at a later date to publish or present all or part of that evidence to the Assembly; but any decision to publish or present in-camera evidence will not be taken without consulting with the person who gave the evidence.

Is that clear?

Ms Brown: Yes.

THE CHAIR: Thank you for joining us here today. Would you like to give us a brief overview about your issues?

Ms Brown: Yes, I would. I am a member of the ACT Indigenous Elected Body. I have four portfolios. One of those is a primary portfolio of community services. I have worked a long time in the aged-care sector. Since 2008, since the elected body has been established, we have had two Indigenous community forums in the ACT. There was widespread support for an aged-care village specific to Aboriginal and Torres Strait Islander people being set up in the ACT.

The need is increasing. As most people will be aware, our illness increases from the age of 45-plus. This is just getting worse. It is a big burden on the families because of overcrowding issues and extended family and kin visiting. There is a shortage of accommodation for our old people too. I have brought Agnes Shea, our senior Ngunnawal elder, along with me because she has a lot of knowledge about the need for this too.

THE CHAIR: Would you like to make a statement at all, Mrs Shea?

Mrs Shea: Yes. I go around from time to time visiting some of the aged people and their families. There is definitely a real and urgent need for an aged-care village. As you know, Aboriginal people have a lot of extended families and a lot of them are middle aged or young ones with families and children. I see some of the old people there not actually getting upset but feeling that maybe they are a bit in the way at times because of their immediate families.

We have talked about trying to get something up for them where they can go. It also gives them back their pride, their dignity and their self-esteem. They said, “It would be wonderful if something like that could happen here for us.” They are still being cared for in a place where families can go and visit but they are not a hindrance. Sometimes they feel they might be a hindrance to the other families.

THE CHAIR: How many families are taking up respite care services at the moment from your community?

Ms Brown: Respite in the home, like HACC and aged-care packages?

THE CHAIR: Yes, any.

Ms Brown: I worked for Carers ACT. I was a coordinator of the Indigenous program with Carers ACT from 2007 to 2009. During my time there there was an increase. I think they have about 70 families now because we have them coming on all the time once word of mouth gets out. This is a mainstream organisation, as you know. That was a big thing in itself for Aboriginal and Torres Strait Islander people to access. I think a plus to that was that Indigenous staff were coordinating the program.

What is happening is that in our community, because of the high morbidity and mortality rates, the carers are caring for each other. It is not just the normal case of what we expect of a carer when we are the recipient. Both are recipients now. The need for some type of residential and respite centre, like a one-stop shop, which is Indigenous-specific and run by Indigenous people is a must in the ACT. We are in the capital and we do not have anything for them. They will not access mainstream. Research has shown that you will find that only about one or two access mainstream.

This is not because of resentment towards mainstream services. It is just that they need to be in their community setting with their own people caring for them. I really feel that it is a community service initiative to have our own people looking after our frail and disabled.

THE CHAIR: In terms of the 70 families you mentioned, are they getting adequate care at the moment?

Ms Brown: That is just Carers ACT. There are other organisations too. We had about 70 carers. We looked after the carers when I was coordinating the program. Sometimes it was a bit difficult for mainstream to understand that it is not just a carer and a recipient. Both are recipients and both are co-caring. I am sorry, your question?

THE CHAIR: I was just wondering whether there is a requirement for more assistance in this regard or do you have access—

Ms Brown: There is much requirement. We have not brought any statistics or anything. I am having an Indigenous Elected Body meeting on Friday to discuss these issues and to see how we are progressing from the community forums that called for an aged residential service village.

MS BRESNAN: That forum you mentioned that the elected body held, was that specifically about the need for an Indigenous-specific aged-care facility or service?

Ms Brown: I think it was a bit broader. It was about just meeting with the people, because we were a newly elected body, to ascertain—which we already know because we are Indigenous but, as you know, we have to have community forums. Most of the people spoke about the need for more support for carers, more Indigenous-specific services and a retirement village. There is a place down at Nowra called Rose Mumbler village. That is an Aboriginal aged retirement village. It is doing wonders down there. As I said, they have long-term residents as well as overnight or weekend stays for respite.

MS BRESNAN: The Indigenous-specific services, obviously you saw carers and they were raising issues. Did respite or any specific respite come out as an issue also in that forum?

Ms Brown: Yes. I can get the information for you. I do not have it off the top of my head at the moment, I am sorry. If you would like it, I can forward some information to you.

MS BRESNAN: That would be really good.

THE CHAIR: Ms Porter?

MS PORTER: Thank you, Chair. I just wanted to explore these concepts a little bit more with you. The village that you mentioned that is in Nowra, does it have a nursing home facility or a hostel attached to it for higher needs care or is it just a self-care unit arrangement?

Ms Brown: That is why I have brought Agnes with me.

MS PORTER: Auntie Agnes, do you know?

Mrs Shea: They do have a healthcare service in the village itself. I was really amazed at the way it has been set up and the way it is run. I spoke to quite a lot of elderly people down there and they said they thought all of their Christmases had come at once on the day they went there. They have been there ever since. They do not want to leave because they are there with people their own age and they relate more to Aboriginal people. It is not that we have anything against non-Indigenous people. And it is in their time. They talk with people from when they were young and from where they lived and the battles that they went through, whereas now, in this day and age, when they are in the homes, it is the young people that come and stay with the extended families. It was wonderful to see how that service was set up and the way it is run. It is fantastic.

MS PORTER: Auntie Agnes, is it self-care or is it a combination of self-care and nursing home care—the combination?

Mrs Shea: Yes, the combination.

MS PORTER: And people can access it for respite as well as for permanent residence?

Mrs Shea: Yes.

Ms Brown: I am asking the IEB on Friday whether I can have support to go down to Rose Mumbler to have a look at it myself. Because we are Indigenous and we are connected to a lot of people in the region, and down the coast, word-of-mouth says it all to you. So you hear really great reports back on it. There is a lady who is living in an aged-care village here in the ACT and she is the only Indigenous woman there. She is darker-skinned than me, and she is just living a nightmare. She has told us that non-Indigenous people seem to have a real fear of her. She is the only Indigenous person there, as I said. So people are knocking on her door and wondering why she is getting so many visitors. There is a real difference between the Aboriginal community and the mainstream community.

I respect both communities having regard to the way people live, but a lot of non-Indigenous people, especially at an advanced age, are not really used to big families coming along all at once. This caused a lot of trauma for this lady. We often say to her: “Don’t worry, we’re going to try somehow to get our own specific aged-care residential service where you can feel more comfortable. You don’t have to explain yourself at your age and you don’t have to feel that you’re just a target for everybody in the centre.” People are knocking on her door and leaving notes under her door about visiting and different things. She has asked me to speak today about that.

THE CHAIR: We are obviously very keen to find out more about the needs that the Indigenous population has within our jurisdiction in the ACT. We might send you a copy of our terms of reference. When you are meeting with your board, you can have a look at the terms of reference that we are looking into and see how some of the issues that you may have within the community could apply to some of the things we are looking into. Obviously, we are also looking into how some of the younger people who may have disabilities are coping with life in general and how we can assist in looking to their needs as well.

While we understand you are talking about aged care, we are talking about across the whole spectrum of young, middle aged and elderly. Especially for people with disabilities, we are looking into how we can assist, including with respite care services. So if you do not have any current information on that, we would certainly appreciate you providing this committee with any statistics or whatever figures you have available. It would be very useful for us to have them.

Ms Brown: I think there would need to be a whole different service rather than having them with the aged-care respite. The need there is phenomenal, too. I just do not have the stats with me today. Having worked for Carers ACT, I am aware of the aged and the disabled in our community.

THE CHAIR: Even working within the ACT, you may be aware of some of the specific issues that they may have that could be addressed differently or better than is currently the case.

Ms Brown: Yes.

Mrs Shea: A lot of our elders live out of Canberra. We are the United Ngunnawal Elders Council, and we spoke with them several times about trying to get a village. They are very keen to see that because they live out of Canberra but they have families here. They said it would be wonderful because when they have to go into, say, a nursing home or a caring place, they would love to come back to their own country.

Ms Brown: Are you aware that when Indigenous people get to a certain age they go home to die? They want to be buried on their own country. That is still strong amongst us. Living outside of Canberra, it is people in the region, mainly, because that is where the missions were—the mission in Yass, the Hollywood mission, and Brungle mission at Tumut. So we have a lot of Ngunnawal people in the area that we bring back.

MS BRESNAN: This may be a question that you need to get back to us on. You mentioned the program that you coordinated for Carers ACT. Anecdotally, were the families you came in touch with accessing mainstream services at all? Were their kids going to some of the schools such as Cranleigh or the Woden school? Were they accessing those sorts of programs and services?

Ms Brown: Accessing the schools?

MS BRESNAN: I was just using that as an example. Was there a good take-up of mainstream services amongst those families?

Ms Brown: When I first started there in 2007, there were not many clients. There was not an Indigenous presence in the program. It is a bit hard because you really have to convince Indigenous people, especially aged and disabled, to access mainstream. Racism comes in many forms, and not everybody can monitor it. Certain people get spoken down to in a certain way. But if there is an Indigenous presence there, they feel much more comfortable. It grew from about 37 or something clients—I am not quite sure but it was in the 30s—from the time I was there from 2007 to 2009, and two other Indigenous staff came into the program and are still there now, to up to 70-something. So they knew Kooris were in there and that we were brokering for them.

With a few of the services, we contact Winnunga Aboriginal medical service, we contact Ngunnawal aged care. We would also contact non-Indigenous services but people were reluctant to go to them at times. That is not to say that they are not reluctant sometimes to access Indigenous services either. So it goes both ways, but it is more in the mainstream that they do not feel they are welcome or they feel they are being treated as a nuisance. Many times we have heard, over our time working for the Aboriginal and Torres Strait Islander community, that it is not just Aboriginal, but in this context and in this country it is just Aboriginal. So when Indigenous people hear of anybody in the mainstream saying that, they will back right off. It is a matter of saying, "They don't know us, they don't understand us and they don't really care." Literally, they just sit at home and die.

Mrs Shea: I had to put my mother in a nursing home for respite care and if I had told her she was going into a nursing home she would never have gone there. I told her that she was going to a special hospital. The people there were fantastic with her, I must say, but she always felt that she was the odd one out because she was the only Aborigine there. She said to us one day, "Why are these white people looking after me?" She was a stolen generation child. I think it was because of the shame that they still carry that they are not good enough to go into other places. I said, "You're in the hospital, Mum." If I had said she was in a nursing home, we would never have got her in there.

That is happening with a lot of our elderly Aborigine people now. They still carry that shame with them. Once they know that there is an Indigenous worker there, they start to relax a little bit, but they do not fully understand why they end up in a non-Indigenous place. Why haven't we got our own facilities, with our own coloured staff? That is the understanding of Aborigine culture, the caring and sharing.

Ms Brown: It is also about the fact too that we are getting an Aboriginal and Torres Strait Islander healing farm. Government have recognised and acknowledged the problem and are actually supporting the healing farm, mainly for our youth with substance abuse problems. That has caused such momentum and excitement in the community. It has given us a lift. We feel that we are cared about by the mainstream. So it has brought a lot of excitement in the community. But the other thing that would be great would be a residential village and respite centre specifically for Aboriginal and Torres Strait Islander people. That would be just fantastic. It would be seen that government had acknowledged and were helping to address the problems with our youth and were now acknowledging the problems for our disabled and our aged.

THE CHAIR: You may not be aware of what I am about to ask but perhaps you could take this on board. Are you aware of how many Aboriginal and Torres Strait Islander people with disability—so apart from frail and the aged—are in the community? If they are not being cared for within the mainstream areas, are they being looked after at the moment? How many people are there?

Ms Brown: I do not have that information on me at the moment but I could find it for you.

THE CHAIR: Sure. What we are trying to do is see whether there are services in place that are adequate to cater for people. We take on board what you are saying too, that sometimes they are unlikely to go into mainstream. So are they being neglected? Is there any way that we can help to make sure that we do cater for their requirements?

Ms Brown: Disability: do you define that as a physical disability or mental?

THE CHAIR: Physical or mental.

Ms Brown: Because of drugs and alcohol, there is a huge increase in mental disability in our community. There is a high need for that. I think the Indigenous service providers are pretty strapped and stretched and always looking for funding. They do their best, and I am sure mainstream does too. But it is going back to that invisible line between Aboriginal and mainstream Australia and them crossing it, going over it, or mainstream crossing it and coming to us. I would have to find that information for you but I know there is a huge demand with mental health.

Because of accidents and what drugs and alcohol can physically do to people, there is a lot of disability. We have quite a few young people who are paraplegics. I know of one quadriplegic badly in need of help who also has some problems mentally. There is a high need for everything in our community. You put a name on it, say it is Aboriginal and Torres Strait Islander and there is a high need for it. But we understand that the high need at the moment is for an aged care residential village for our older people.

Mrs Shea: I have a disabled son who lives with me. He is a double amputee and he is restricted to a wheelchair all the time now. Also, my youngest brother was born partly crippled and his main residence is with me. But when he wants to give me a break from looking after him he travels into New South Wales to go and live with nieces and nephews. He is coming back this weekend, but he said the last time he went away, about a month ago: “I’m getting too old to travel. What are we going to do if something happens to you? Who’s going to look after us?”

Ms Brown: She is nearly 80 and they are asking her who is going to look after them if she goes.

Mrs Shea: I am going blind in one eye and the other eye is just coping. So this is another concern eventually for me: who is going to look after my son, who is in his early fifties, and my brother? Also, my youngest daughter is an epileptic, and she and I between us look after my brother and my son. There are a lot of families in the ACT in the same situation.

Ms Brown: Also, because Agnes is losing her sight, her licence has been taken from her.

Mrs Shea: So that has left me with another sort of disadvantage.

Ms Brown: This is the co-caring that I am speaking about.

THE CHAIR: This is what we are trying to get across, that there is an opportunity to present these issues to this committee that is looking into these very issues. We need a little bit more information from you in whatever way that can be provided. That would be very much appreciated. The committee will be operating until at least

September in taking submissions; you do not have to rush into anything over the next couple of days or whatever. Take time to get the information together and present it to us so that we can then make appropriate recommendations to the government. Thank you very much for coming in.

Ms Brown: Thank you for listening to us.

Mrs Shea: Thank you very much.

THE CHAIR: Our secretary, Grace Concannon, will also contact you to give you an idea of the sort of information that we are after.

The committee adjourned at 12.11 pm.