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

FRIDAY, 3 SEPTEMBER 2010

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

By authority of the Legislative Assembly for the Australian Capital Territory

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

WITNESSES

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Amended 21 January 2009

The committee met at 9.32 am.

BUCKLEY, MR BOB, Community member

THE CHAIR: Good morning, Mr Buckley. Welcome to the fifth public hearing of the Standing Committee on Health, Community and Social Services inquiry into respite care services in the ACT. Have you read the privilege card that is in front of you?

Mr Buckley: Not on this occasion but on plenty of others.

THE CHAIR: So you are comfortable with it?

Mr Buckley: Absolutely.

THE CHAIR: We have received a couple of submissions from you. Obviously, there are some things that we would like to discuss with you. Would you like to make an opening statement and talk about your submissions?

Mr Buckley: Yes, I certainly would. I am a carer of a 19-year-old son with quite severe autism. I am on a number of autism groups, having senior positions on two national autism bodies and the autism body in the ACT.

I would like to point out a couple of things at the start. One is that autism is a very rapidly growing disability. The number of people diagnosed with autism has more than doubled every five years for at least the past 20 years. So the number of cases is significantly on the increase. We really do not know why that is. Autism, by definition, is a severe and profound disability, and the evidence backs up that that is what it is in the population. I point that out because there are some disability groups who do not regard autism as severe disability, and there are a lot of people who believe that children with autism do not have severe disability or that the increase in numbers is not an increase in numbers of people with severe disability. The evidence does not support that.

Going on to the issues of the respite inquiry, I would like to say at the outset that, in my view, the need for respite exists primarily because of systemic failure in the disability sector. If the disability sector was actually working, there would be no need for respite. Respite is a sort of bandaid measure that we need because the other services do not provide an equitable life. They do not provide the services that people need to live in the same manner as the rest of the community. It is not a service that is available generally to the community. It is specific to disability.

The fact that we are having an inquiry and the fact that we have issues in respite really shows how fundamentally failed our disability services are. And I think some of this is coming out in the material that has been put before the Productivity Commission in their care and support inquiry. I think care and support is such a small part of the disability sector that is being looked at at the commonwealth level, and I am disappointed that the issue is not being looked at more broadly. But there are bigger issues that need to be addressed as well.

The Productivity Commission's initial report put down a figure of $100,000 to look after a person with severe disability, but that was only for 64 hours a week. If you do the sums, to actually extend it to a full week means that the bit that is not covered by that, the bit that is actually covered by family carers and other services, equates to $180,000 a year. So, in effect, what is happening is that family carers are meeting the needs, if we think about it in those kinds of economic terms, of anybody with severe disability to the extent of at least $180,000. I do not think those Productivity Commission figures actually catered for holiday periods and leave periods, so I think the figure is actually higher than that.

We are really talking big issues here. The interesting thing is that these people do not have the same life expectancy as the rest of us. The data that I have seems to suggest that life expectancy for people with a disability is at least 20 years less than the average for the population.

In terms of health, they are expected to have, on average, 2.2 undiagnosed chronic health conditions. What this means is that people with a disability are actually experiencing worse health outcomes and worse lifestyle outcomes than the Indigenous population. But we do not hear any politicians talking about this or any of those kinds of issues in election campaigns.

We need to be really understanding of what is the nature of the situation we are dealing with. Those are some introductory comments on respite and some of the general disability stuff.

I am very concerned by the auditor's report that I think was before this committee. It really did not have the information that it needed to have in front of it. The statement that there were no level 8 incidents is a major concern to me because I know that Jack Sullivan died in respite that was funded by the ACT government. That, to me, constitutes a level 8 incident. I am very concerned that it did not appear in the report.

Basically, as far as I am concerned, that means that the auditor's report actually failed to address what an auditor's report in those circumstances should cover. I do not think it is the auditor's fault. I think it is just that the information is not made available in the circumstances. And that is extremely concerning to me.

I am disappointed that I put in two submissions, one of which related to that matter and, as far as I know, has not appeared on the website yet. Perhaps we will talk about that later.

My personal experience with respite is that we have stopped using centre-based respite, for a range of reasons. It is simply not a service that really works for us. I do not think the standard is good enough.

I want to talk a little about the role of carers. People with autism need, in most cases, 24-hour care. It is full on, around the clock. If my son is awake in the night, one of us has to get up and be with him. The impact that has on my working life and on my health generally is significant. It is not an easy thing to be available and caring for somebody at that level and that intensity.

He is 19. I do not have to think about getting up if my 16-year-old daughter gets up. The level of care and support that my son needs is massive compared to that needed by normal children. I guess the challenge is how we, as a community, figure out how we are going to deal with these kinds of issues, especially if, as I say, they keep doubling every five years. This is a serious concern.

One of my big concerns at the moment is the lack of behaviour support in the ACT. We know that at the budget estimates committee—I think some of you, if not all of you, sat on the budget estimates committee—the department said they just don't do applied behavioural analysis, the method that really deals with any kind of challenging behaviour or dysfunctional behaviour. They said they don't do it. I have had some discussions where they seem to have changed their mind, but I have not seen in writing what they actually think they are doing or what is actually going on. I am very concerned about this. I am very concerned that those kinds of services are not available and they are especially not available for people on the autism spectrum.

I have had a growing number of families approach me in my official capacities because they have had to give up children as young as nine years of age because they cannot manage their behaviour. There are families who have come to me because they are being threatened with having children taken away from them because they cannot manage them. The main reason they cannot manage them is that they cannot get the behavioural support that they need to help them look after those children.

This has been, and remains, a massive hole in our services. It is not just due to the ACT government. It is a national phenomenon. It is particularly poor in the ACT and I really think something needs to be done urgently. Whether you think that behavioural support is under the terms of reference of the respite inquiry, I do not know, but certainly the demand for respite is massively increased by the lack of services in other areas. Those are the things I would like to open with.

THE CHAIR: Thank you, Mr Buckley. You made a fairly strong statement at the outset about a failure of systemic services, if I am quoting you correctly. Have you had opportunities to make any formal complaints? Are there areas where these complaints can be made? That is the first part of my question: have you had the opportunity to do that?

Mr Buckley: I certainly have. You may not be aware, but we made a formal complaint to the discrimination tribunal that my son's—that appropriate services were not being provided. We made a complaint to the discrimination tribunal. It was joined together with some other complaints. Four of them were related to Jack Sullivan. Three of the eventual complaints were related to my son. There were seven complaints. One of those complaints took 10 years—the majority of them took seven years—to hear. That is a fundamental failure of the legal system here in the ACT.

In that complaint, we complained about the early intervention therapy—"treatment" and "rehabilitation" are the words that I used, because those are guaranteed by the United Nations Convention on the Rights of the Child; it says every child should have the right to treatment and rehabilitation. We asked for treatment. We did not get any. That was acknowledged by the department in the tribunal. They said that the reason we did not get the services was because they made an offer of services that we refused.

Under questioning, they could not find any evidence of having made an offer of services. We cannot conceive of when they might have said that, and the president of the tribunal ruled that no offer of services was made.

The eventual decision of the tribunal was that we had not proved our argument, but they changed what our argument was. Our argument was that they did not provide any services and that was discrimination, because they provided services to other people. For some reason that I cannot understand, and I have formal degrees in logic and things like that, so I am pretty good on how you prove an argument, the tribunal ruled that we had not proved our argument, because they changed what they said our argument was. Then they said anyway that it is okay for the government to discriminate in any way it chooses, such as not providing services. So discrimination against children, against people with a disability under the ACT's discrimination act is completely legal. That is the final paragraph of the decision.

So we have made a complaint. We have gone through a very, very rigorous process in making those complaints. We believe that we made a very strong argument in that complaint, but the legal system completely protects the government in making such complaints. So the whole legal system and the whole complaints process are both really worthless.

THE CHAIR: Is that the only avenue open to you? What about the commissioner for disability and community services?

Mr Buckley: Well, that is what happens if you do not get a result there—you go to the legal process.

THE CHAIR: So you had already complained?

Mr Buckley: Oh yes. We could not have got to the legal process without doing that.

THE CHAIR: Okay. What was the outcome of the discussions with the commissioner for disabilities?

Mr Buckley: Well, it was referred directly there anyway. It was referred directly to the legal process.

THE CHAIR: Was there anything given to you in writing from the commissioner?

Mr Buckley: No.

THE CHAIR: It was just referred directly on?

Mr Buckley: Yes.

THE CHAIR: Were you interviewed by the commissioner for disability and community services?

Mr Buckley: We had some initial interviews with him.

MS BRESNAN: Mr Buckley, you said that centre-based respite is something that you have not used.

Mr Buckley: We did use it for a while.

MS BRESNAN: Yes, but you said it is—

Mr Buckley: In my submission I think there is a picture of one of the outcomes of that.

MS BRESNAN: Yes. Taking your point, as I said, that, if we had adequate services in other areas, we might not need respite, we have heard from different families and other representatives from organisations, and some families will use centre-based respite, other families will not use it. Is there any form of respite you have used recently or you would still continue to use, if it was available to you?

Mr Buckley: We certainly do use the respite service from Tandem. We are quite careful about using it, but they have been able to provide us with respite workers, and generally we find that we work flexibly directly with the respite workers, which Tandem are not comfortable about. But we have a longer ongoing relationship with them, and I think they are comfortable with the way that we are working. So we are using that form of respite.

MS BRESNAN: I have just one other quick question. We heard from a witness on Tuesday about how she was engaged in essentially a pilot with the department of disability: she was essentially sourcing her own services herself, instead of going through brokerage, and she had found that useful. That is something obviously that takes quite a bit of time for someone to do. Is that something that you would use or find useful, if that was available to you, or again is it a matter of, I guess, that situation of the time it would then take for you to have to procure the services yourself?

Mr Buckley: We have always basically brokered our own services—sometimes despite the system, sometimes with grudging acceptance from the system. And that works for us, obviously. But I do not know that there are that many families who really can do that effectively. I think it is a big ask to expect families to do that generally. I think it is the exception rather than the rule if people can do that.

MS PORTER: The government is about to commence a feasibility study around the replacement of centre-based respite houses. If you had your druthers, what would be some of the key features that you would see in the respite environment, the physical environment and the service model? What would you see, if you had your druthers?

Mr Buckley: I don’t think we have got time for that. I think the whole system needs to be radically reformed. We need the health system to actually start thinking about disability, and that goes back to the commonwealth level—the fact that our alleged universal health system, Medicare, does not cover allied health services, the fact that the whole mental health sector has had major issues with this for some significant time. They are starting to make some moves in terms of mental health. I think there is still a long way to go to start thinking about the same sorts of needs of people with other disabilities.

I think the health sector has looked at mental health and largely ignored the disability aspect of mental health for some time. But it is now starting to realise that that is not actually an economic approach. I think we have in the disability sector a sort of converse problem, in that we have been dealing with the disability issue and not looking at the health side of that. And the two have to work really strongly together. Until we actually start getting really big reform happening, with both Health and Disability working together and looking at the models that they have in these kinds of areas, working out how to provide these complex services a lot better than we do, we are really just tinkering at the edges. We are not going to get anywhere if you just muck around with that sort of stuff. You really have to start looking at the whole person; you have to have a person focus and say, “When a person exists, what do they need?”

In the case of my son, he is 19 at the moment. He is going to Black Mountain school. Both my wife and I work. He needs after-school care. But the way that we put together after-school care is that we wait for some regional group of people, who I appreciate enormously, scrabbling around and putting a completely discombobulated set of grants together, to find enough money to provide after-school care for people with a disability. One of those grants falls down—the youth links program—and the federal government did not even know which department it was in, when I was trying to ring them up. They kept referring me from one to the other. It basically caused the collapse of the after-school care system for these children. Fortunately, the ACT government stepped in, but the consequence for us as a family is that the cost of after-school care increased by 400 per cent, which is significant, and it is now at a point where he no longer qualifies for the childcare rebate because he is now 19, but he is still at school.

That is just a tiny example of the sorts of issues that we are dealing with. As a consequence, imagine how many hours of research, hours of letter-writing, hours of talking to politicians, have been involved for me, just in trying to shore up his after-school care. And that is one of the tiny services. It just ought to be there automatically. You ought to be looking at these kids and going, “Here is the set of services that the community needs to make available for these other people if we want him or his parents to be functioning members of the community.”

THE CHAIR: Mr Buckley, we are running out of time. I would like to spend more time, obviously, but we are limited. I have a final question. You mentioned quite a few things in your submission. You have just mentioned the need for after-school care and the fact that your son is 19. We have had a lot of parents with similar issues, with their children getting older and after-school care not really being an option because they have reached the post-school age. What are your options in terms of when your son leaves Black Mountain?

Mr Buckley: I am not sure at the moment. It is looking like I might have to give up work to look after him. It is my turn, because my wife has looked after him during the various years when there was not a place for him in a school. She had to give up work at those times. It is probably my turn. I will probably have to give up work until something is sorted out.

I am not sure that either the state or the federal government wants me to have that much time on my hands. It could be quite expensive for me. I am not being malicious or anything but the effort I put into advocacy could be lifted significantly if I was unable to attend work. At the moment, I am not aware of options that are really designed to meet the needs of somebody like my son.

THE CHAIR: Thank you for coming in. Thank you for your submissions as well. A transcript of this will be provided to you. If you have any further thoughts that you did not get the opportunity to bring to our attention, you are welcome to submit them to the committee sooner rather than later because we will be going into deliberative mode soon. Thank you very much. We look forward to any further information you may want to provide.

DURKIN, MS MARY, Disability and Community Services Commissioner and Health Services Commissioner
SWAN, MS KELLY, Senior Disability Adviser, Human Rights Commission

THE CHAIR: Welcome to the fifth public hearing of the Standing Committee on Health, Community and Social Services inquiry into respite care services in the ACT. Thank you for appearing this morning. I presume you are familiar with the privilege information that is before you, so I will not take you through that. We have not got a submission to talk about. I would ask you to make a verbal submission.

Ms Durkin: Thanks for inviting us to come and speak today. I have a statutory oversight role in relation to disability services in the ACT. Under the Human Rights Commission Act, I have authority to investigate and resolve complaints about disability services.

The definition of disability service in the Human Rights Commission Act is incredibly broad and very much inclusive rather than exclusive. The definition ultimately states that any service provided in the ACT specifically for people with a disability and/or their carers is a disability service for the purposes of the act.

I might mention that I also wear the hat of Health Services Commissioner at the commission. In that role, I have an oversight function in relation to services for older people. The definition of services for older people is much the same as the one in the disability services area. It encompasses any service provided in the ACT specifically for older people and/or their carers. This jurisdiction is also, therefore, quite relevant to any inquiry into respite services.

I would initially like to clarify the situation in relation to options for complaint handling at the Human Rights Commission. Page 57 of the Auditor-General’s report states:

> Clients and community members can make complaints to:
>
> …
>
> - the Disability Discrimination Commissioner or the Human Rights Commissioner.

There is no specific disability discrimination commissioner in the ACT. The Discrimination Commissioner can take complaints and allegations about discrimination on a range of grounds. Disability is one of them. The Human Rights Commissioner, however, is not able to consider complaints related to alleged breaches of human rights. Generally, complaints about disability services will be handled by the Disability and Community Services Commissioner, a position I currently occupy.

I can accept complaints related to most aspects of services provided by Disability ACT and the non-government sector. There might also be scope for complaints to be made to the Commissioner for Children and Young People, for example, where a complaint relates to an aspect of a service specifically for children or young people with a disability.

Unfortunately, the volume of complaints we get does not reflect the breadth or gravity of the issues that exist within many disability services. As an illustration of this, we received 24 inquiries related to disability services last financial year, and 18 of these became formal complaints. The number of complaints is continuing to rise steadily each year but I would argue that it is in no way a true representation of the volume of issues.

As I have stated in this committee previously, I believe there are a range of reasons why people do not put in complaints. I do not need to go through all of those reasons again. I would say, however, that I believe this is, in part, due to our inability to undertake the level of promotion and awareness raising about our services that could be expected.

In this context, I note that submission No 33 calls for a commissioner similar to the Victorian model. I actually have a broader purview than that of the Victorian Disability Commissioner. This is further evidence of people not hearing about the commission's services or that service providers are not providing information to their clients about the commission.

As I have also stated previously, our level of resourcing restricts our capacity to complete the volume of work which we should be undertaking. The disability team is my adviser, who works part time, and less than half of my time. This is nowhere near adequate. Consequently, we do not have the capacity to be as thoroughly across all the issues as we would like to be.

It was for this reason that we did not put in a submission to the Assembly's inquiry and it is the reason I have come here today, stating up-front that I have not had the time to thoroughly research the issues or think through possible solutions, as I would have liked to have done. From talking with the committee secretariat, I understand that the committee, being aware of this context, is interested to hear about our complaints process and the types of complaints which we generally receive. I am happy to go through those.

I might add that, while I have noted that we have not had many complaints about respite services—we have had one in the last financial year—I do try to make as much time as possible to speak with organisations and groups of people to hear about issues and concerns they have within the disability sector. Through these forums I receive anecdotal feedback regarding a range of concerns with the delivery of respite services. Unsurprisingly, many of these are echoed in the submissions you have received.

I have heard from parents of children and young people with a disability, or ageing carers of people with a disability, or younger carers who look after aged parents. For many of them, respite care is the only service their family receives. That can be critical as the glue to keep holding their family together.

I have received feedback about the complexities of navigating the information. They have been trying to ascertain who delivers respite services, how a family can become eligible and what combination of patchwork services they can cobble together to go some way towards meeting their need.

Conversely, I have received feedback from services about the difficulty in attracting and retaining quality staff in a demanding industry, about stretching limited financial and human resources to meet an ever-increasing demand for support and about the struggle to provide services to a small number of clients who regularly demonstrate very difficult and demanding behaviour, such that workers are unwilling to continue working with them.

I understand there is a problematic lack of respite models in the ACT and that greater availability and flexibility are needed to support families and individuals. Sometimes families will need support to enable the person with a disability to remain with them as a family unit. Other times the carer may want to leave the home. Other times it may be more appropriate for the person with a disability to need to leave the home. Likewise, the need for respite can be short term, longer term, and can include weekdays, nights or weekends. I know it is no easy feat to design a system that can offer the flexibility that families require.

We have been looking at recent research from the National Institute for Intellectual Disability in Dublin which developed eight provisional principles of best practice in the provision of respite care services, one of which is that respite services be person centred and family centred. Perhaps the general approach that we use here of designing the service parameters and then fitting families into it could do with some further consideration.

Another principle suggested in the Irish research is that all coordination of respite be through one administrative point, quite a different picture to that which we currently have in Canberra where there are multiple and confusing paths for service. This certainly speaks to me of the need for greater provision of coordinated, comprehensive information for families and individuals, a sentiment that I have heard echoed across the disability sector for some time now.

Again, in my role, I am too frequently hearing that the families are either not receiving the level of service they require or are not receiving services at all. This anecdotal information seems to be supported by the findings in the Auditor-General’s report that access to respite services in the ACT has not increased proportionately to meet the growth in demand in recent years.

This finding is further compounded by the finding that Disability ACT is able to measure the known unmet demand for services; that is, those people who are on its books or who have made applications to the department and that the estimation for future funding is already known to be inadequate to cover that demand. The unknown demand is not quantified at all.

I appreciate that resources across government in the ACT are stretched and that priorities need to be assessed and funding targeted. As notified, the Auditor-General knew that applications for disability services generally in 2007-08 totalled more than $11 million, whilst only $2.8 million was granted in new funding. This degree of gap is one illustration of the level of unmet need and has been noted in other submissions to this inquiry. We have not even touched the surface of identifying the level of unknown unmet need.

Thank you for your time. We are happy to answer any questions.

THE CHAIR: Thank you, Ms Durkin. Just a couple of clarifications: you mentioned that you received 24 inquiries and there were 18 formal complaints out of those. Am I correct in saying that you only received one regarding respite care services?

Ms Durkin: Yes. That is one that we are currently looking into. I think it is fair to say that the issue in that one is differences in family opinion and service provider opinion about the level of support needed for the individual concerned, but we are only just commencing that investigation.

THE CHAIR: Were there any complaints regarding respite care services the previous year?

Ms Durkin: No, there were not.

THE CHAIR: Or the year previous to that.

Ms Swan: There was one complaint that the Auditor-General referenced in their report, which gave an indication that it was about respite, but respite was a peripheral issue in that particular complaint. The bulk of the complaint was predominantly related to how care was delivered to the particular individual, both in a respite setting, in a home setting, and in his own family’s home setting. It reads as though we got a complaint about respite, but that is not quite the case.

THE CHAIR: You have obviously seen the number of submissions that we have received and the number of complaints that we are receiving. Do you have any feelings as to why you are not getting the same level of complaints?

Ms Durkin: As I noted, one of the reasons is the level of awareness of the commission. I noted in one of the submissions that someone stated it was too difficult to get through the bureaucracy to us. I personally found that disappointing. When people call our office we generally expect that they will be answered straightaway, that they will be put on to Kelly straightaway if it is a disability services complaint. If people have contacted our office and not been able to get straight through to us, I would apologise for that. I would just encourage them to try again. I like to think that we are quite a flexible, informal complaints-handling model and that we should be able to tailor our responses to people’s needs.

I think one of the other reasons that we do not get as many complaints as we possibly should is just the nature of the sector—people are often reliant on disability service providers for a long time or a lifetime and there is a fear of repercussions if they put in complaints. Again, we encourage people to come to us and we will work through those issues with them. In my time as commissioner we have not had any feedback in any of the complaints we have handled that there have been repercussions. We would just encourage people to give it a go and see if they can let us help them to work through the system.

THE CHAIR: It is a pretty big risk to just give it a go if they end up risking losing services.

Ms Durkin: I certainly appreciate that.

THE CHAIR: Just on that—and I appreciate your comment—are there any protection mechanisms in place for people who complain, just to make sure that there are no repercussions for them?

Ms Durkin: Yes, there is a provision in the Human Rights Commission Act that basically provides that it is an offence for someone to threaten or intimidate someone for the purposes of getting them to withdraw a complaint or not to complain to the commission.

THE CHAIR: To withdraw services as a result?

Ms Durkin: Exactly. That would, in my view, be a threat of intimidation.

THE CHAIR: One final question before I pass over to my colleagues. We have had a submission just recently regarding a matter that was brought to your attention which was passed on. It was a discrimination matter with regard to the care provided to a person with a disability. In discrimination matters, what is the procedure?

Ms Durkin: The procedure is pretty much the same in discrimination matters as in service complaints. Generally, when we get a complaint we will write to the person complained about and seek a response from them. We will go back to the individual and check the facts. Often we will look at conciliation as a way of trying to resolve complaints. Certainly, the discrimination commissioner tends to use conciliation in a lot of complaints.

The only real difference is that, with disability service complaints, when we have reached the conclusion of our investigation and issued our findings, that is the end of the matter. With discrimination complaints, I understand that the complainant has the option to take the matter to the ACAT, the tribunal.

THE CHAIR: Thank you. Ms Bresnan?

MS BRESNAN: You talked at the beginning about providing us with a bit of an understanding of how the complaints process works. I would find it really useful if you could do that.

Ms Durkin: Sure. Basically, anyone can complain to the commission, the service user, but if it is difficult for the service user a representative appointed by the user can complain. Often the parent or guardian will be the person that will complain. If there is no-one who can satisfy the criteria for being a complainant, the commission also has a function under the legislation of being able to appoint a person to the complainant.

We can also conduct what is called a commissioner-initiated consideration if there is the absence of a suitable complainant. Sometimes, for example, if an issue is raised with us that is of real concern and the person does not want to follow it up with a formal complaint in writing but I consider that it is serious enough to look into, I will commence a commission-initiated consideration and look into the matter myself.

Basically, we strive to provide a complaints-handling process that is open, fair and transparent. We are not advocates for either party. Because it is generally the service user that comes and complains to us, when we go to the provider they often think that we are advocating on the part of the service user. That is not the case. We have been set up to be impartial and independent. We fiercely protect that reputation.

That is not to say that, when we reach a conclusion and we think that the service user has suffered because of something that went wrong, we will not advocate for proper outcomes, but we are certainly very much open and fair. Complaints are very much confidential—

THE CHAIR: I am sorry, but on that point could I just ask: what is the extent of your powers to actually enforce some of the situations that you come across that you think require action?

Ms Durkin: We have a range of powers in the act. One of them is that if people do not want to respond to a complaint we can require people to attend and be interviewed. We can issue what is called a section 73 notice requiring people to respond to our inquiries. It is an offence under the act to not respond to a notice or to attend if you have been required to attend.

In relation to conciliation, we also have a power to require people to attend conciliation. It is not one that any of us ever used, I think, because really you want people to come to conciliation willingly and freely. In my jurisdiction, where things do not go to the tribunal, we have recommendatory powers only, but I think they are quite strong recommendatory powers. It is an offence for someone not to respond to us when we make a recommendation, although it is not an offence not to implement the recommendation.

If people do not respond to a recommendation or do not come to the party in working with the commission to get to a resolution, we have the opportunity to issue what is called a third-party report, which can go, basically, to anyone the commission considers is appropriate. It can go to the minister and it can go to the Assembly. We can go to the media. There is a lot of impetus there for people to cooperate with the commission and try to get to resolution of matters.

THE CHAIR: Are you comfortable with the number of your recommendations that have been acted on?

Ms Durkin: Yes. With all the recommendations that we have made over the years in both the disability jurisdiction and the health jurisdiction, we went out to people and said, “This is what we are thinking of recommending,” and gave them a draft. We basically say to them, “If you have got a better way of getting to the same outcome, we’re happy to hear it.” It is a negotiation process. When we make final recommendations they are usually recommendations that have been discussed and people are happy that they are able to implement them.

MS BRESNAN: As to the offence provision that you have, is the primary way you can act on that offence through the issuing of a third-party report? Is that the main provision you have to act on that?

Ms Durkin: To date we have never actually gone through the process of trying to activate any offence provisions. There have been occasions when we have needed to remind people, “This is an offence.” We have always got cooperation when we have sent that reminder. I would imagine that if we did want to pursue offence provisions, we would be talking to the Government Solicitor’s office and the DPP about how we would go about that.

MS BRESNAN: Just by way of clarification, regarding the matter Mr Doszpot mentioned—and I guess it is in relation to other matters you may have—do you think that it would get referred directly to the ACAT, or the tribunal, from you?

Ms Swan: In the discrimination area?

MS BRESNAN: Yes.

Ms Swan: Not to my knowledge.

Ms Durkin: We might have to take that one on notice for the Human Rights and Discrimination Commissioner to respond to.

MS BRESNAN: Sure, thank you.

THE CHAIR: Ms Porter.

MS PORTER: I would like to just talk a little more about how you think you can get that message a bit more clearly to people, so that they feel that it is easier perhaps to negotiate their way through.

Ms Durkin: Yes.

MS PORTER: In your introductory remarks you said, “People are not really clear about it,” and, “I just want to explain how we fit into the pattern.” Although I consider myself a fairly intelligent person, I got very confused listening to you.

Ms Durkin: Sorry.

MS PORTER: I found myself trying to track it through circles, and I thought, “Obviously, if I saw that in a diagrammatical form, I would probably get it a little bit better.” I know that you said that resources is one of the issues, but is there a way you can get the message out there in a small pamphlet or on a website or something which actually tells people, “Okay, this is who we are, this is who this person is—or this body is—and this is what happens. If you make a complaint about this, this is where it goes, and this is the appropriate trail to go on.” You are already feeling somewhat stressed, I would imagine, if you are about to take this step—people would not take this step lightly—so I think that, if there were some very clear way of them understanding how to navigate and negotiate that, it would be better. I do not know if either of you has any comments about that?

Ms Durkin: There is a range of measures we are trying to pursue. We established a new website last year. It tries to clearly delineate each of the commissioner's roles and functions. There is a provision in the legislation also, called section 95, which requires any service provider, if they are providing a service at premises, to basically inform users about the ways in which they can provide feedback to the service provider and about the fact that they are entitled to complain to the human rights commission. So we are in the process of developing what we are calling section 95 notices that people can put up on the wall when they are delivering services from a premises and that will enable them to comply with that provision of the act.

I think in the disability sector it can be quite difficult, because lots of times people are just being provided services in their homes and that is not really a premises where a service provider is operating from. So we are developing brochures that people can be given. We have been through the process in the last financial year of developing commission brochures, and now we are going into the process of developing disability services commissioner brochures, human rights brochures and discrimination brochures, to get down into the real information that a target audience needs. We are hoping that we will be able to get them out very soon.

Ms Swan: They are at the printers at the moment.

MS PORTER: Good.

Ms Swan: Can I mention one other very simple measure that we have actually already completed and we are distributing around? We have what we call wallet cards, specifically for people with a disability or their carers. They are just tiny little cards, of a size appropriate to fit in your wallet, and they just say, "Are you a person with a disability or a carer? Do you have some concerns? Then call us." They have my name, Mary's title, and our telephone number on them. And we find that sometimes, if people try to work through the breadth of the sorts of matters that we can consider, it can possibly be confusing, and if they take the opportunity to call the commission and speak to somebody like myself or somebody else in the commission, who is well-informed about what we do, then we can assist that person to work through a process quite easily. And many times I personally have found that people have been surprised about the breadth of what we can assist them with. So that is a simple measure we have recently implemented.

Ms Durkin: The other thing we have recently done is have a number of radio ads on a commercial radio station.

Ms Swan: They have been on 104.7

Ms Durkin: I think there are some more of those coming up this month as well. So we are trying, within our resources, to use different methods that will be useful for different sectors, but it is always a challenge.

MS PORTER: Have you contemplated social media too?

Ms Durkin: I know the Children and Young People Commissioner is certainly using that method to consult with children and young people. It is not something that

Helen Watchirs or I have looked into at this stage.

THE CHAIR: Are you aware of the number of complaints on disability related services that have gone to the human rights commissioner?

Ms Durkin: No, I am not. What happens, when people ring up and they say they have a complaint, they will outline to our intake people what it is about. They will be channelled into whether it is a disability discrimination complaint or a disability services complaint. So, as I said before, the human rights commissioner does not have a complaints jurisdiction, so they would not be channelled that way.

THE CHAIR: Can there be communication between you and the human rights commissioner regarding the matters that are referred, so that it should alert you to some issues that are fairly common in the community, if that is the case?

Ms Durkin: What happens is the legislation requires that the commission has to allocate complaints to commissioners, so at each of our commission meetings we look at the new complaints and we agree on where they are best handled. So the human rights commissioner is aware of the sorts of things that are coming into the commission anyway.

Both the human rights commissioner and all commissioners have the opportunity to do what is called commissioner initiated considerations. That will mean that, if we have resources at some particular time, we can look into a particular issue. So, for example, in the health area, I did an inquiry into the psychiatric services unit at the Canberra Hospital in 2008. The human rights commissioner also was involved in that inquiry by providing advice about human rights law, to tailor the report on that inquiry. So we do work together, and we both have the jurisdiction to mount particular inquiries if we want to.

THE CHAIR: You mentioned that you received 18 formal complaints this year. Can you tell us about the range of issues that were raised with you in these formal complaints?

Ms Durkin: Because there are so few, I would not say that there are any really general themes. There have been two or three complaints, none of which have been finalised, indicating that there is probably some room for improvement in terms of financial accountability. When you have so many players in the game sometimes, with people having individual service packages and having brokers involved and having individual service providers involved and then individual workers and bookkeepers, it is really hard to track the money trail and see that people are actually getting the best value for money. We have actually got someone on to assist us at the moment who has a bit more financial expertise than us, to help us sift through that sort of information. So I think there are probably some issues there that we will be able to make some recommendations about to a range of organisations, to improve accountability for funding.

The other sorts of complaints we have been having have been around access to therapeutic goods, such as wheelchairs. A couple of complaints are around carers in group houses and their attitudes, but again conduct and attitudes—

THE CHAIR: Are they current matters or are they—

Ms Durkin: They are current matters, yes.

Ms Swan: There are a couple that are finalised; the complaints are closed.

Ms Durkin: But generally there are not any greater things than that from the complaints that we have had. We are about to start writing our annual report, and I will certainly flesh out any themes that we can identify from complaints in that.

THE CHAIR: When will that be published?

Ms Durkin: I have not got the details in my head at the moment, but I know I have to get writing and have it done within about two or three weeks.

THE CHAIR: Thank you. Any other questions?

MS PORTER: I was just going to make the observation—and correct me if I am wrong—that you said, "We had 24, and then only 18 went through to the formal stage," and you said that you had a capacity to investigate yourself, if you were concerned. So one could deduce from that the rest of those 24 were not matters that you felt you should independently look into?

Ms Durkin: I think that would probably be fair to say: that I did not think that they were so highly serious that I should do so. But, if I had more resources, I probably would have chased them up and said, "Can we assist you to put in a complaint?" Kelly is obviously the person who has taken those phone inquiries, and there are certainly none that she has raised with me and said, "We have really got to look at this." But they are probably of a level of seriousness that it would be ideal that we could follow up, if we had the capacity.

Ms Swan: And I do, as much as possible, always follow up from an inquiry, just to ascertain the person no longer wants to, or is interested in, following through with the formal complaint. And I guess in some ways one of the beauties of having such a small team is that I do have very easy access to Mary, and she is receiving very regular updates about the sorts of matters that come to my attention. I also find, between the point of inquiry and the point of closing the inquiry, at times the matter resolves itself.

So it might be a person having concerns with a situation in school, and they are very upset, and then they will ring and explain to me that they have a meeting next week and they have the therapist in, or the principal, and so on. These things are happening. By two weeks later they have been able to say, "I have spoken to the human rights commission and had that meeting," and they have talked through their issues and they have been able to resolve the matter. So sometimes there is actually no need for us to take it any further, which is positive, I guess.

THE CHAIR: Unfortunately, time has run out. We have to stick to the schedule, but thank you very much, both of you, for coming in and explaining your role in such concise detail. If there is anything else that you feel would be appropriate for this committee to be aware of and that comes to mind after you leave here, we would love to hear from you in the next two to three weeks, if that is possible. Thank you for coming in. A full transcript of this will, of course, be sent to you as well.

Ms Durkin: Thank you.

Ms Swan: Thank you for having us.

ROBINSON, MR TREVOR, Community member
ROBINSON, MRS JEANETTE, Community member

THE CHAIR: Good morning, Mr Robinson and Mrs Robinson. Thank you for joining us at this fifth public hearing of the Standing Committee on Health, Community and Social Services inquiry into respite care services in the ACT. Mr Robinson, you have been here before. I am not sure whether we need to talk about the privilege statement. You are quite comfortable with that?

Mr Robinson: Perhaps for my wife’s benefit.

THE CHAIR: Have you read it?

Mr Robinson: We went through it this morning.

Mrs Robinson: Yes.

THE CHAIR: Are there any questions on it?

Mrs Robinson: No.

THE CHAIR: By way of clarification, what happens at this hearing is that everything is recorded through Hansard and everything that we say to you is made publicly available through Hansard. So it will be on the internet and so forth. If there are any matters of confidentiality, you need to think about whether you want to introduce those topics. If you wish to make confidential statements, we can have an in camera part of our session. But even when we say it is confidential, the committee evidence is normally kept, but it is up to the committee to actually publish that information as well, if required. I am not sure if that adds any further knowledge regarding the privilege statement. Do you have any questions on that?

Mrs Robinson: No.

THE CHAIR: We look forward to hearing your statement.

Mr Robinson: Thank you very much. Both my wife and I are here as individuals and as a family unit representing our views, and our views alone.

Thank you, Mr Chairman, and members of the standing committee, for providing Jeanette and I with the opportunity to respond to this inquiry into respite care in the ACT. We hope that our evidence goes some way to impart to you, the ACT legislators, an understanding of respite from a family’s—our family’s—perspective. Perhaps you will appreciate, by the end of our evidence, that respite care is not a luxury and certainly not a privilege. It is a social necessity to ensure a harmonious, egalitarian society. A quality, demand-driven respite care system is as essential as any community structure such as hospitals, jails, road networks or tourist attractions.

We would like to make one thing perfectly clear from the outset. Neither Jeanette nor I have any political affiliation and, as such, our evidence is inclusive of governments of all political persuasions and tiers, although specific to this jurisdiction.

It is obvious from continued indifference that governments see the provision of disability services as an economic encumbrance, administrative burden and political risk. This is evidenced in countless ways—the unacceptably high level of unmet need, the lack of scrutiny in areas such as accommodation and the unnecessary repetitiveness of reviews such as wheelchair-accessible taxis, respite care or education. Australia goes to war and spends hundreds of millions of dollars, and unfortunately lives, on nothing more than a hunch and guesswork, yet we have tens of thousands of Australians who, right here, right now, experience social isolation, being shunned in employment and recreation, and receive only tepid therapy and care.

A prioritisation shift must occur to assign disability above such ethereal topics as parking, energy efficiency and sport and on a parallel footing with public health and education.

To view respite care simplistically as nothing more than extended day care for flustered, tired or perturbed parents is to misunderstand the significance of respite care and the loving relationship that occurs between a parent and their child with a disability. In most cases, and ours is one such case, a parent chooses to stay at home to assume the role of therapist, nurse, advocate and educator—and carer, of course. They clean their child, of any age, after bowel and bladder accidents, they wear the verbal and physical abuse of a child, of any age, with challenging behaviour, and they attempt to conduct normal activities such as shopping and household chores while tending to and protecting their child, of any age. And unlike conventional day care, which essentially provides parents with nothing more than a financial gain, parents of a child, of any age, with a disability enjoy, for their altruistic love and devotion, incredible isolation, significant increased mental anguish, financial hardship bordering on poverty, and a sense of hopelessness that their community has forsaken them.

To this end, I would like to make the standing committee aware of this: do not think that a lack of submissions to this inquiry or any other consultative mechanism signifies satisfaction with respite care in the ACT. It is just that ACT families are too focused and too fatigued to concern themselves with yet another bureaucratic inquiry, to answer yet more questions that have been asked a thousand times and see the same tokenistic action. For many families, this is both frustrating and emotionally demoralising. The perverse paradox is that many families prefer to have a feeling of false comfort that relies on having no hope than building up expectations where only false hope and insincere promises exist.

As the parents of a 25-year-old with a severe intellectual disability, Jeanette and I have considerable experience with reading literally hundreds of grandiose and ostentatious statements regarding the objective, ideals and plans from countless disability bureaucrats in, again, literally thousands of expensive, glossy pamphlets, booklets and reports. While this eloquent and lofty language is right out of marketing textbooks, and one may wonder whether these documents are more to sell than inform, it is a shame the authors do not have the same skills with numbers. In most documents, the only number to be seen is a page number—no hard targets, no hard, fixed numbers of respite beds and facilities.

Governments can count cars, tourists, patients, prisoners, passengers, school children, professions, crimes and employment. Governments are also confident forecasters on car movements, tourist attractions, patient numbers, prisoner profiles, airline passenger numbers, school demographics, skill needs, crime prevention and employment statistics. Yet governments seem unable or unwilling to acknowledge the genuine level of unmet need in disability employment, disability education and, importantly, disability accommodation, which includes respite. Perhaps a course in remedial mathematics would help refocus that it is people, not livestock or consumer products or money, that these glossy publications provide numbers on.

One area that the standing committee sought comment on is the performance report on the management of respite care services. While the audit was comprehensive, the report clearly demonstrated that the existing audit regime is flawed. Poor self-assessment and an inadequate external audit regime of non-government service providers have allowed a widening disparity in the quality of services delivered by government and non-government providers.

Would it be permissible for the Alexander Maconochie Centre to be audited on an eight-year cycle? Would it be permissible for any of Canberra’s hospitals to also be audited on an eight-year cycle? And would it be permissible for any of Canberra’s aged-care facilities to be audited on an eight-year cycle? If the answer to any of these questions is no, as I am sure it is, then why is it okay to audit respite care facilities for people with a disability on an eight-year cycle? Are they less vulnerable than patients, prisoners or the elderly? Or is it because a lower standard of quality assurance is deemed acceptable?

Before leaving the performance audit report, we would like to note that a considerable gap exists in the area of consumer or client feedback. Our son has been in emergency respite care provided by a non-government service provider for six years. In those six years, we have only twice received a questionnaire from Disability ACT seeking feedback and comment on the service provided. With few questions in the questionnaire and even fewer topics using valid statistical measures, it would be impossible to garner any meaningful data from the questionnaire that contained significant and sufficient credibility to measure quality or satisfaction. It is as though the client and the client’s family are unimportant when measuring the quality of respite care or the satisfaction with the service. Better and more often feedback mechanisms are needed to ensure quicker responses to issues.

Another area of growing disparity is that of funding. Non-government providers, at their current level of funding, are unable to attract and, importantly, retain quality respite workers when competing with employment conditions offered by their government equivalents. Non-government respite providers are constantly battling to attract quality staff at existing income levels and employment conditions. Canberra is an expensive place to live and work. Again, a shift in thinking must occur.

Staying a little longer on comparing respite with other similar facilities, could the standing committee inform us of an instance where a convicted felon was refused entry to a prison or where a patient was refused emergency treatment in an ACT hospital? Again, we surmise the answer is never. Yet families have to book their child into respite care well in advance and are generally restricted to a quota of respite hours based on their funding. This is an arbitrary quota of respite hours, not actual need, which determines a family's available respite.

A child, of any age, with a disability, having high and complex needs, is extremely wearing on a family. Many families have only negligible family or social networks to call upon. This is particularly so if the family unit consists of a lone parent with additional children. No-one—not the bureaucrats, not the social workers, not even the parents—can foresee future needs of their child in respite care. The behaviour, health and wellbeing of the family can shift in an instant and, in that instant, urgent respite care is needed.

Shifting to respite care itself, we appeal to the standing committee to become very aware of the type of clientele that uses respite care. While the term "high and complex needs" is often used, the term easily rolls off the tongue. What exactly does this term mean? Does it mean labour-intensive or costly care or difficult care? In most cases, the answer is yes to all of the above. However, respite care should not be restricted to just accommodation. Respite care facilities should also act as centres for ongoing physiotherapy, speech pathology or speech therapy, occupational therapy and counselling, not just for the client but for the family as well. For many people with a disability, access to the therapeutic treatment door shuts once you leave school or hospital. It is as though you miraculously recover at a government nominated time or age.

The truth, however, is quite the reverse. Contractures and twisted limbs from cerebral palsy do not ease when you reach 18 or 20. Aggressive behaviour does not explicably stop when you graduate from high school. Your communication abilities do not magically appear once puberty finishes. Therapies should and must continue at the same level of intensity throughout a person's life to offer people with disabilities the best opportunity for social inclusion and personal wellbeing.

For the government to lessen or restrict therapy at an arbitrary age or time sends the message that people with disabilities have reached their maximum potential and nothing further can be achieved by continuing therapy. So much for human rights. It is just as well that we do not treat our elderly in the same manner; otherwise, once you reach a certain age, say 75, you can forget about any form of medical care because the government reckons you are not going to get any better. The same principle applies.

Again on respite, we would like to encourage the standing committee to look beyond stereotypes. Respite care, for many, conjures up images of young children with severe intellectual and physical disabilities being dropped off at accommodation facilities in order to give the parents a break. While for the most part that is true, respite is also a necessity for many others that do not fit the general stereotype. Respite is also a necessity for a husband or wife whose partner has a disability or for parents or siblings who look after adult family members. To this end, adult and child respite should have greater separation, to the point of even grouping people according to their age and ability. After all, doesn't everyone cluster according to age?

The philosophy behind the delivery of respite care also needs to change. The current approach is for clients to adapt to a routine dictated by the facility—generally, eating, showering and performing activities of daily living at a time not of their choosing but of the choosing of the respite facility. Despite facilities having a small resident population with low carer-client ratios, the rights of clients or client families to determine their daily schedule is either dismissed or ignored. The care should match the individual, not the individual adapting to the care. For many that use respite care, the respite care facility is considered either their primary or secondary home and, as such, they should be allowed the right to determine their routine, as they would in their own home. Perhaps if the Human Rights Commission visited the respite care facilities, as they do many others, this would change.

In closing our official statement, Jeanette and I would like to recognise the incredible work done by many Disability ACT officials and both government and non-government respite care facility personnel. This statement is not a slur on any individual or group but a pointed synopsis on the negative treatment disability receives. The work performed by disability support officers, carers and attendants goes under-rewarded and underappreciated by many outside who have little understanding really of what these people do. Our statement is, however, an indictment of the political and bureaucratic system that views respite care and disability in general as a social and economic burden rather than, as it should be viewed, a social and ethical necessity.

We have a prison that is regularly visited by human rights officials, the Ombudsman and the Public Advocate. Yet disability facilities are seemingly ignored by these people. We have a government spending millions on accommodation for cars at a hospital but a fraction on accommodation for people with a disability.

The ACT experiences verbose public and political discussion over the preservation of trees or kangaroos or recycling, carbon trading, skill shortages or same-sex unions. Disability is the elephant in the corner of the room that is hardly, if ever, mentioned in the front pages.

Disability needs to be assigned a far greater priority in funding, in resources and in the consideration it currently receives. If a wealthy urbane society such as Canberra cannot look after its meek citizenry in the here and now, why should we ever worry about the future?

THE CHAIR: Thank you very much for such an excellent and concise summary. You captured a lot of the angst that we have heard from a lot of people who have presented submission. For the record, we have had 43 submissions, 32 of which are from families. We are very much aware of the issues that people are raising. You have raised a range of issues that we will not have time to talk about. Rest assured that we will be examining your complete statement. Thank you again.

I have a couple of opening questions and then I will pass over to my colleagues. One of the things that we are hearing from everyone is that there is a great dissatisfaction with some of the things that should be done but are not being done. There is a mechanism available at the moment. Do you feel that mechanism for discussion or complaint regarding some of these issues is adequate or would you have other suggestions in that regard?

Mrs Robinson: Obviously, things do not seem to change; so, no. The short answer is no. What is the solution to it? It seems that more parents speak up. From a personal point of view, I feel there is a brick wall and I am hitting my head against it. It just does not seem to change. We get a lot of pats on the back and “yes, we understand”. But nothing changes. How do you address that? I do not know.

Mr Robinson: An example that occurs is where failures in the system occur either in the long term or in the short term. Certainly, our son has aggressive behaviour. He was taken out of the residence that he was currently residing in, as I mentioned in the statement, and put for six years in emergency accommodation. We had an emergency plan. I have brought with me a copy of that plan for you. It gave contact details. It was fairly simple; there was not a lot in it. There was a priority of people to contact, telephone numbers, his date of birth, the type of behaviour et cetera. Three weeks ago that failed—

Mrs Robinson: It has failed on numerous occasions.

Mr Robinson: He was in the mental health unit of the hospital from his accommodation facility. The police got him there. Two weeks ago he had an epileptic seizure. It failed a second time. It is concerning when you put structures in place for an emergency contact or for care—for any sort of behaviour you may care to describe—yet it fails. It failed, as I say, from a number of different providers, both government and non-government—the police, the hospital, the mental health care unit at the hospital, accommodation providers and a supported employment provider. It failed categorically. It seems as though there is not a desire to stringently follow protocol or procedure.

Mrs Robinson: We have guardianship, obviously, simply because of the age of our son. That is disregarded on numerous occasions by government officials and by private organisations. We are constantly hammering and reiterating the need for our guardianship to be honoured and respected, and it just gets ignored.

THE CHAIR: Regarding the issue that you just spoke about, what was your first step in making someone aware of what you have just told us? Who would you go to?

Mrs Robinson: We had a meeting with them.

Mr Robinson: In the first instance when our son had errant behaviour at our house we had people from the mental health unit and people from Disability ACT, the ITAS people. We had people from the accommodation provider and from work, as well as ourselves—Jeanette and me. We discussed protocols, we discussed emergency. Everyone got a digital printout of the emergency contact list. That was the first time. The second time, I must admit the accommodation providers were not a problem but the employment providers were. As I say—

Mrs Robinson: And the hospital and the police.

Mr Robinson: And the hospital and the police. It just tended to be that they were going to do it their way, irrespective of the person with the disability or the family of the person with the disability. It was almost like: “Yes, we’ll do that,” and then they forgot about it. Jeanette and I ring them up and we are quite robust—not rude—in our annoyance and disappointment in the failure of the system. But that is all you can do.

THE CHAIR: Are the employment providers private enterprise?

Mr Robinson: They are non-government.

Mrs Robinson: No, they are non-government.

THE CHAIR: Non-government?

Mr Robinson: LEAD.

Mrs Robinson: LEAD.

Mr Robinson: These organisations, with the funding they have, do an excellent job, but there are flaws and there is almost a nonchalant view in following the wishes of people.

MS BRESNAN: You mentioned the plan that you had developed. Was that something you developed as a family or had it been developed in consultation with—

Mr Robinson: In consultations.

Mrs Robinson: It came out of necessity simply because of issues and managing his behaviour.

Mr Robinson: Growing bad behaviour.

Mrs Robinson: The police had been called on several occasions. We were not told until hours had passed that things had happened. We thought, "This needs to be addressed. We need to be told." Things were being discussed with people who had no need to know information. As his guardians, we just were not being advised.

MS BRESNAN: Do you think it is because often those plans are not legally recognised, that there is not a legal imperative—

Mrs Robinson: A guardianship order is a legal—

MS BRESNAN: No, I know that. Even though it may be the wish of the family, because there is no sort of legal basis for them often they will not be—

Mrs Robinson: If we state, as his guardians, "This is what we would like you to follow in case of an emergency"—

MS BRESNAN: I recognise you are the guardians. This is in relation to advance directions. It often comes up as an issue that even though the family say they are set and everyone works to them, because they are not legally recognised sometimes they get disregarded. That does happen.

Mrs Robinson: I suppose you would have to ask them. I honestly don't know why it is not—

Mr Robinson: When we got together, the organisations were quite happy with the information—the way we collected the information, the way we packaged the information and the way provided it to them. We did it in a way so that it was short, abridged and easily got to. They could adapt that to their own emergency. We did this to mitigate risk. It obviously shows that, in our view, they have inappropriate risk mitigating protocols, procedures and policies. You would think that they would want to have this sort of critical information to mitigate risk on their behalf as well as our behalf.

MS BRESNAN: Just one other quick question: you mentioned inspecting facilities and so on being an issue. Other witnesses have mentioned that a disability official visitor would be a useful thing to have, someone who can visit these sorts of facilities on behalf of people.

Mr Robinson: In my profession I was an auditor for the Civil Aviation Safety Authority. If there was a place that we were going into that we had no experience of, as just a base auditor, we would get a subject matter expert in. I believe that auditing disability organisations and respite accommodation facilities requires a level of expertise that someone who would audit anything else would not have—so, yes, someone with expertise, preferably someone with a disability. I am sure that there would be people out there.

They necessarily need to look at not just the occupational health and safety procedures but the perspective of the person with a disability. Are they respected? Are they allowed to shower when they want to? Are their recreation requirements and needs fulfilled, rather than saying, “At this stage we’re all going to do this”? It is a home for them. Respite is not just a place which people should be happy to get—it is a home. They should be allowed that—so, yes, a specific person. We should not be saying we are accepting a certain level of accommodation from government providers and a lower level of provision from non-government providers. It should be the same across the board. There should be no difference.

MS PORTER: I have a quick question in relation to the two matters that you just talked about—the incidents where you felt that the system did not work for you. You said you had—

Mr Robinson: Can I correct that? The system did not work for our son.

MS PORTER: For your son; I beg your pardon. You said at the end, when we asked how you had made your dissatisfaction with that known, “There was nowhere else to go.” We have just been talking with the Disability and Community Services Commissioner and she said that sometimes people find it difficult to actually know that she is there. So you did not believe that was somewhere you could go?

Mr Robinson: We find that a good organisation should be able to amend or fix a problem directly, so on most occasions we go direct to the organisation. I think that even the disability complaints mechanism would seek that as well—that you go to the organisation. It is a systemic problem. It occurs at various levels. “Who are you complaining about?” There is so much to complain about. In our case, the hospital failed, the mental health unit at the hospital failed, the police failed. I can do a thesis on how many tiers and systems and elements within a system failed. And at the end of the day, many of these organisations become defensive. So the organisations are not open to commentary. They think that any comment is criticism, the shutters go up and they get very defensive. But we take the view that we look at the organisations one on one, as best we can.

THE CHAIR: In your written submission that we received, you state:

> … in respite care … therapeutic treatment is either not performed at all, or left to unqualified, untrained carers to perform in a vague, haphazard manner.

This has been coming through to us from quite a number of other people. What I was asking at the outset of my question to you was, I guess, related to that as well—to focus on the problem, and you have identified the problem very clearly. How is the problem being addressed? Are there mechanisms in place? Have you lodged formal complaints regarding this? Were those formal complaints acted on by the organisations? This is not having a go at you. If we are going through all of these issues, I am simply trying to understand how we can focus on these issues and not just let it fester until the next inquiry comes along in eight years time or whatever. These things ought to be looked at now. So what are the mechanisms that are in place? What else can we do to ensure that your criticism or your complaints are looked at?

Mrs Robinson: Certainly, in our case, personally, we would sit down and talk about diversional therapy, activities for the day, and try and schedule for these activities to occur. I could not tell you why, but they just seemed to stop. We would have excuses of not enough staff or “We had to concentrate on this particular person and therefore we couldn’t go out and do what we had planned today.” Our son would sit in front of the TV all day. They would turn the TV on and he would be quite happy to sit there. We would quite often, regularly in meetings, say, “He needs to be out, he needs to be engaged, he needs to be stimulated.” A lot of his behaviour came from the fact that he was not getting that. So a program of diversional therapy in these centres would be ideal, one that is formatted appropriately and managed appropriately. I do not expect that would need to be managed by those within the respite centre themselves; it could be done by an external provider who goes around, much like in nursing homes. But there certainly needs to be stimulation in the centres.

THE CHAIR: If people are unqualified, obviously, that begs the question: how could they provide that stimulation? Are people acting according to regulations that are in place? Are they employing people who are properly qualified? These are the sorts of things that we are getting questions on, and I am asking the question in return.

Mrs Robinson: As far as we are concerned, no, they are not properly qualified. With respect to the carers that are provided in accommodation, it is a very high turnover area as well, as you can appreciate. You may have a staff member start and within a month they are gone. I do not know the number of times we would go around to our son’s accommodation provider and there would be new people and I would have to ask, “Is this a new staff member or who is this?” We just did not know because the turnover was so high. How you address that—

Mr Robinson: A lot of these respite care facilities are employing people who are new migrants. Perhaps lower level jobs are filled by people who are migrants. Their English language skills are not great. We have a lot of problems with some of them in trying to understand them. If we have problems trying to understand them, I am sure our son would have, and other children or people with disabilities would also have trouble. Therefore you are starting to get a communication problem. So that is exacerbating the problem in respite care because of the type of people that they are starting to employ. They pass a certificate III in disability care, and that is great, but it would be good if the ante could be increased in respite care. The problem is, of course, if you do that, as education rises, so does income, so do costs et cetera.

A lot of what we look at with regard to disability is based on the mindset of "this is the funding". As I said in my statement that I gave at the beginning, this all needs to change. We cannot sustain disability at that level. It needs to be changed; it needs to be prioritised and thought of in a different way. While I do not balance the books in the ACT or anything like that, it certainly needs to be closer to hospitals and less further away than footpaths, because that is where we sometimes feel it is—in the footpath area of funding.

THE CHAIR: Mr and Mrs Robinson, thank you for your submission and for your answers to our questions. If any other areas of opportunity arise from the discussion or other things that you think of that could be beneficial for this committee to look into, please let us know in the next couple of weeks. We will be considering the report and recommendations. Thank you for coming in. Unfortunately, time has defeated us again. You will get a copy of the transcript, and we would love to hear from you if there is anything else you can think of.

Mr Robinson: Thank you very much.

POLLARD, MS CHERYL, Committee Member, National Disability Services ACT
STRANG, MS JANE, Manager, National Disability Services ACT

THE CHAIR: Good morning, Ms Strang and Ms Pollard. Thank you for joining us for the fifth public hearing of this Standing Committee on Health, Community and Social Services, inquiring into respite care services in the ACT. Ms Strang, if this is your first inquiry, I am not sure if you have read the privilege statement. If you have not, please take a couple of moments to read it.

Ms Strang: I have read it, Mr Chair.

THE CHAIR: Okay. Do you have any questions on that?

Ms Strang: No, sir.

THE CHAIR: When we start proceedings, could you give your name and the name of the organisation you represent. You have met my colleagues on the committee. Welcome. We have received a submission from your organisation, so I presume you are going to make an opening statement.

Ms Strang: Yes, if that is okay.

THE CHAIR: Thank you.

Ms Strang: Good morning. My name is Jane Strang. I am the manager for National Disability Services ACT. I am pleased to be joining the organisation at this exciting time in disability services. I will just address a few points in our written submission, if that is okay.

National Disability Services is the national industry association for disability services, representing over 700 not-for-profit organisations in Australia. In Canberra, we represent disability service providers across a wide and representative range of service types, including respite care. As the peak body for disability services, we are well-placed to provide input into this important inquiry.

Our submission is in four parts, as you will see. Number one, we believe firmly that respite care is part of the disability services spectrum. We have a concern about the impact of an ageing population on the disability services sector. We believe that we need to grow the sector to meet demand, and we have made a gentle call for transparency in government action.

With respite care as part of the disability services spectrum, we note that respite care plays a significant role in disability services and cannot be viewed in isolation from other disability services. It is important that respite services be considered in the context of increasing demand for supported accommodation. If the current demand on supported accommodation increases and cannot be met, many individuals with a disability may need to remain in their family home. This will have a flow-on impact on demand for respite services to support those individuals and their families.

The linkages between respite services and community access services should also be recognised, with some individuals and families using community access programs as a form of respite. The potential for cost-shifting and distortion of estimates of demand are linked to this interconnectedness of disability services.

Respite services offer early intervention and prevention for families and individuals. Providing carers with adequate access to respite services, whether for planned or unplanned activities, can offer significant benefit in helping to reduce stress—hopefully before it becomes distress. Carers can continue to provide support for much longer, if they can be confident of having a break when they need it. Respite services reduce pressure on other areas and types of service, and the picture of this is a pyramid, with our informal support services of the families and carers at the bottom and specialist disability services at the top. Obviously, your costs shift from your informal supports to your specialist disability support services, which is what has brought us to this table today.

With respect to the impact of the ageing population on the disability services sector, we note that ageing affects both the people with disabilities themselves and their carers. These issues are probably better addressed in the Australian Institute of Health and Welfare report *Australia's welfare 2009*. I am sure the committee has seen that.

With respect to growing a sector to meet demand, we are keen to see service levels grow to a level that will provide greater assurance to the community that the support needs of people with disability and their families can be met in both the short term and the long term. We believe that increased funding for the non-government disability service sector will assist in ensuring that services are able to meet this growth in demand.

In preparing for appearing today, I did note that in 2000 there was also an inquiry and, as part of that, it was quoted that ACROD ACT, which was the name of NDS, before it was rebadged, reported that the availability of respite care services in the ACT is limited not so much by the number of agencies currently available or the range of services offered, but more by the limitation imposed by funding constraints placed on existing agencies. Further, I note that the Auditor-General's report that has brought us to this table makes comments with respect to the funding of services:

> Analysis of the trend movements in the ACT indicated that access to respite services had not increased proportionately to meet the growth in demand for service in recent years. Further growth in demand for services is anticipated as a result of increased number of aged primary and informal carers.

So, with respect to services, we do know that there is unmet demand, we do know that demand is going to grow, and NDS will be happy to help the government to meet whatever services we can.

As a last point on growing the sector to meet demand, I note the Productivity Commission's *Report on government services 2010* highlighted a range of issues for the disability sector, including providing useful statistical information, and I would direct the inquiry to that.

With respect to transparency of government action, we have noted that transparency of government action is vital, otherwise trust goes and rumours abound. There are three points here with respect to the Auditor-General's report that has brought us to the table. First, equitable access to services is important. Next, we consider the identification of unmet need to be an essential component of effective planning for service capacity and capability across both government and non-government sectors. My understanding is that identification of unmet need still needs to be substantially done, and NDS will be happy to help the government to identify that unmet need. We are in discussions with the government at this stage about what needs to be done and how it can be funded.

Lastly, NDS ACT notes that the audit found the cost per respite user in government services to be significantly higher than in non-government services. NDS believes that this warrants further investigation, with potential to consider wider outsourcing of services and to increase funding to non-government services. We note that there is an inherent tension for the government acting as both a direct service provider and a funder of NGOs providing the services.

So, in summary, NDS ACT and its members are well-placed, willing and able to assist to plan and advise about the service systems and the delivery of services. Obviously, the delivery of such outcomes is subject to the provision of sufficient funds to deliver the services at a level and quality that the ACT public expects and is entitled to. Thank you for your time.

THE CHAIR: Thank you, Ms Strang. One of the themes that we have heard about from a lot of the people who have made submissions to us is that there seems to be a lot of concern from people regarding carers who are, in the main, untrained having to perform tasks for which their qualifications have been drawn into question and regarding the fact that there is a lot of movement in the employment of carers. Is this seen as an issue within your industry nationally or, more to the point, here in Canberra—the way that carers are employed, what sorts of regulations are in place and what sorts of expectations are placed on them, and are you satisfied with the delivery of the services that are provided by carers?

Ms Strang: At this stage, do you mind if I ask Ms Pollard to help you with that? She is one of our committee members. As you may know, I have only joined NDS very recently. Up until a month ago, I was actually employed by ACT Health, so I am trying to come up to speed with the sector.

THE CHAIR: That is fine. Thank you.

Ms Strang: I will hand over to Ms Pollard.

Ms Pollard: My name is Cheryl Pollard. I am CEO of Tandem, a respite agency in the ACT, and also, as Jane was saying, a member of the NDS ACT committee.

I think the answer is yes to everything you said. I think there is a real challenge nationally and also in the ACT to have staff that are adequately trained and qualified. That in part is due to the low unemployment level in the ACT. The opportunity to find employment elsewhere, particularly within the two rungs of government—and even in private business—means you can probably be better paid elsewhere. I suppose within

Tandem there is a casualised workforce, and that fits with our work cohort. But, having said that, across the board within the disability sector and, I would say, the mental health sector, it is a transient workforce.

Being support workers within respite agencies is not something that I think people tend to do for life. They might be skilling themselves up whilst they are working—at university and so on. Interestingly, we have a diverse mix of very old support workers, who are absolutely excellently skilled, but they are 60 or 65 and onwards, so their time is coming to an end. We have lots of young people. It is that middle age range where I think probably women are now choosing to work in, I suppose, more highly paid, regular type work.

I think there is a little bit of mischief there regarding training. I think there is a lot of training that goes on within the sector, and each agency does their very best to train their staff up—whether it is informal training or supporting them to get Cert III or IV or diploma and so on qualifications. I think we work—

THE CHAIR: Just on that, is there any minimum requirement for someone to start work as a carer?

Ms Pollard: No. Actually, that is another interesting aspect: there is an expectation that the support workers will be professionals, but in fact they are not. There is no professional body, as, say, with nurses or social workers or doctors and so on. There is no professional body that recognises them, so there are no codes of practice and so on. They are all there internally, within each organisation.

I believe that the human rights commission office or the health complaints commission office a year or so ago were looking to try to bring something in across the ACT sector, but I have not heard of anything happening at this point in time.

THE CHAIR: On that, is there a police check done on anyone who comes to work as an—

Ms Pollard: That is now a requirement. It was not when I first started in the sector. There is a police check on employment. We do a new police check every 12 months but that is not a requirement. There is a new system coming into the ACT government but that is only every three years. That raises a whole host of issues. Whilst it is welcome, there are a whole host of issues that come out of it. For Tandem, there are the first aid qualifications but that is not a requirement elsewhere.

THE CHAIR: A first aid qualification is a Tandem requirement?

Ms Pollard: Yes. They must maintain it or we suspend their employment. Certainly Tandem does induction training. That covers some of the basic employment terms and conditions. We do manual handling, understanding autism, epilepsy awareness, OH&S and so on. That varies from agency to agency. It can only be done as the agencies are funded. We have to scrimp and save to be able to put that money aside and to budget for it every year to be able to do that, to provide as high a quality service as we possibly can.

We do not generally, but occasionally have to, purchase from other agencies. We expect a similar type of service. There are the brokerage agencies, for instance. Where they are getting their staff is a bit unclear. It is a hard one for agencies because, within government, all of the add-on costs to the cost of the service delivery to be able to provide as good a service as we possibly can are not recognised. Then you have that transient workforce that absolutely love their time with Tandem but that just need to go on to other employment, for whatever reason. A serious overhaul of being able to support agencies and being able to fund our organisation properly could be looked at.

THE CHAIR: As the national industry association, should NDS not be in a position to set some standards such as, minimal as it may be, first aid being a standard requirement across all agencies and should not require the Human Rights Commission to do it?

Ms Pollard: NDS is doing significant work on that and about what the workforce should look like and minimum requirements. They have been talking to all their member bodies to try to gather together a paper to be able to move forward. Ideally, we could be moving towards it with Disability or Home and Community Care. But where does that money come from? Tandem can carry quite a bit of it but, when you have got the tiny little agencies that might only be one or two or five or 10 people to attend some sort of training, they just would not be able to afford it.

THE CHAIR: There is the risk assessment and, if it is not done, what opportunities are there for the organisation to be protected if qualified people are not employed. That is, hopefully, something that is being looked at.

Ms Pollard: Yes.

MS BRESNAN: Following on from that, and I am probably pre-empting it, I was going to ask: if there were to be some mandatory training that would obviously impose a cost on agencies and organisations, how do you then deal with the issue, which Mr Doszpot referred to and which has been raised a couple of times, of the qualifications? There are the issues around it being a transient workforce and all those things that come with that, which makes it difficult to retain workers.

Is it a process of having a mandatory code of practice that organisations have to adhere to or is it something which should be legislatively based? Would a code of practice work? I may be pre-empting it because there may be concerns from a range of organisations around that limiting the flexibility of the workforce and all those things that come with it. It is obviously an issue. It is something which has come up from a number of witnesses and organisations.

Ms Pollard: The consumer generally has an understanding of our contractual obligation to our funding bodies. I do not know that that would necessarily give the transparency so that people would know what we do. A code of practice, in a way, would probably be a good first step because it would be out there. If we did not adhere to a particular code of practice, then that could be challenged, maybe in a different environment to our funding body, our contract.

MS BRESNAN: On the requirement for workers to have certificates and training, one of the other things which have been brought up is trying to achieve that balance between training and getting someone who has an empathy for, understanding of and ability to deal with the difficult situations. I know it is a big question to ask, but how do you think you strike that balance between the two—getting staff that have the qualifications and an understanding of the situation they are going into and want to go into that?

Ms Pollard: Personally—and I can only really talk on Tandem's behalf but I am sure it is similar across the board—part of our recruitment process is, and the question we ask, to try to draw out people's values and understanding of disability. I suppose a very simple example is: you would be asking, "What have you done in your life to be able to support a person with a disability and to achieve something positive? What do you see as their place in society?" If the answer is that they were an active, robust, member of whatever—as opposed to "I really think they would be better placed somewhere where they can be fully cared for 24 hours a day", which, to me, is the answer that would not be steering us towards that person—that person sees people with disabilities as part of the community. That is the value-based stuff.

I am not a huge believer in finding someone who is a nurturer, a caring-type, mother-type, person. I think empathy is the right word. Otherwise, it is about the workers themselves, not who needs to be cared for. I am not a big believer in that. We are there to do a role, to support people to live as they are choosing to live, as opposed to wanting to smother them and do everything for them. A lot of our questioning is around that.

On top of that, we employ people with no professional experience. They might have had a family member affected. They might be a babysitter. There are a whole host of different people. It could be people who have retired from the bureaucracy. That is really good because you get a cross-mix that can match all sorts of circumstances.

MS PORTER: The government is about to commence a feasibility study around the replacement of centre-based respite houses.

Ms Strang: That is the $250,000 in the budget, is it?

MS PORTER: Speaking as a national representative organisation, what would you see as some of the key aspects of respite in the future, both in terms of physical environment and in terms of the service model? If you had your druthers to suggest something, what would you be suggesting?

Ms Strang: At this stage, what I would say is that there are a couple of things. National Disability Services actually has a position paper on respite care, and I will provide that to you. I think the key thing here is going to be funding to give both the carers and the recipients the support that they need. As you know, there is a national proposal. The Productivity Commission are doing an inquiry at the moment into a national disability insurance scheme. Some of the issues of unmet need are being canvassed in that sort of forum. We are hoping that once that scheme is in place, there will be some extra resources to support the sector and the services that people require. The bottom line here, from everything that I have read, is that the sector, not just in the ACT but throughout Australia, is broke and broken.

Ms Pollard: I think that what the sector needs is choice. There is limited choice in the ACT, and I think the ACT is doing better, maybe, than other jurisdictions, than New South Wales, but there needs to be a variety of models to best fit the needs of both the carer and the cared-for person.

MS PORTER: For you, Ms Pollard, choice is the key element of that?

Ms Pollard: Yes. In fact, Tandem is moving in that direction. We have always provided in-home community-based respite, but we are opening a respite house with Lions Youth Haven in the near future because we have identified that there is a growing need for alternative options.

THE CHAIR: I have a couple of questions that I will address directly to Ms Pollard because these are more historical. Ms Pollard, as a board member of NDS, is there any attempt to work with the government to see how the sector could be strengthened, from your industry's point of view?

Ms Pollard: I think there has been, particularly over the last couple of years, a really strong, solid relationship in working with Disability ACT. That has come about in part because, I think, of the calibre of the EOs—Louise Gray previously, and so on—and because of very much working together to have positive outcomes. Some of that work has been around strengthening the sector. There have been a number of reports, and I cannot remember the names of them. Some of it has been in agreement and some has not, and there have been recommendations. Our chair, Sue Healy, would probably be able to talk better about those. For instance, Jane mentioned the conflict with the government being the provider and also the funder. It certainly costs the government a lot more—there is a lot of evidence about that—to provide services that the NGO sector seems to be able to provide well without the cost attached to it.

THE CHAIR: Are you aware of what other jurisdictions or what other state governments are doing with respect to the certification, for want of a better word, of carers? Is there anything in place in other states?

Ms Pollard: I believe there is. In other sectors like aged care, there is a minimum cert III qualification. That is managed nationally, but that was phased in over about a three-year period. So all of their staff must be properly qualified. When Disability ACT first started there was a committee set up to look at the workforce issues. They were looking very closely at Victoria because they had gone down that path. That was probably about six years ago. We have had a number of different workforce committees with not a great deal of anything coming out of it. But, yes, I think there are other states that are doing better work in that area. I think it has to be brought in, but there needs to be the opportunity to introduce it over a period of time rather than just saying, "Next year everyone has to be qualified."

THE CHAIR: From the number of complaints or submissions that we have had, I would urge the organisation, NDS, to try and escalate that process as much as possible.

Ms Pollard: Having said that, I think it would also be worth while doing an audit and actually seeing the qualification level out there. I know at Tandem we have a lot of qualified staff and I think there are a lot of assumptions made.

THE CHAIR: This is not meant to reflect on your staff.

Ms Pollard: I know, but I am sure that would be across the board.

Ms Strang: There is actually a workforce group that does have NDS representatives and departmental representatives on it. There is an audit tool that is available from a Victorian organisation that we have been looking at and that NDS in Queensland have used. Obviously, there is a cost associated with that, both for access to the audit tool and for the organisations to be able to put the time and investment into using the tool. That may be useful for us as a jurisdiction. However, obviously, it comes down to funding, unfortunately.

THE CHAIR: I think we are reaching the end of our time. Is there anything that you want to say that we have not asked you about, that you may want to make a further statement on?

Ms Strang: There are a couple of things that occurred to me as we were talking. I visited NDS in New South Wales a couple of days ago as part of my induction program. They have got a really good program called care careers that they have spent a lot of time on, with the support of the New South Wales government. They found some things that were quite interesting with respect to workforce. One of the key things that they pointed out to me was that we need to shift the workforce from believing that working in care or disability services is admirable to making it desirable. In the ACT, I think we are probably extra special, in that we have a very tight labour market and the community sector is fighting, for want of a better word, with government for people resources. So we do need to be very aware of that.

With respect to whether or not a mandatory code of practice or legislation would be the way to go, I totally support Cheryl in saying that self-regulation through a mandatory code of practice would probably have to be the first step. Legislation really is a very hard and blunt instrument. Thank you for your time.

THE CHAIR: Thank you very much, both of you, for coming along and making your time available and for the work that your organisation, NDS, is carrying out in the ACT. A copy of the transcript will be provided to you. If anything else occurs to you that you think would be beneficial for the committee to be aware of in this inquiry, please get back to us. We welcome any further input. But it would need to be sooner rather than later because we are getting towards the end of our inquiry process. So thank you once again.

BAKER, MR KEITH, Chair, St Margaret's Aged and Disability Committee
BISHOP, MR JEFF, Member, St Margaret's Aged and Disability Committee

THE CHAIR: Welcome, Mr Baker, and Mr Bishop. Thank you for joining us for the fifth public hearing of the Standing Committee on Health, Community and Social Services inquiring into respite care services in the ACT. Have you had an opportunity to read the privilege card that has been made available to you?

Mr Baker: I have, yes.

THE CHAIR: You have no questions on it?

Mr Baker: No.

THE CHAIR: You are quite comfortable?

Mr Baker: Yes.

THE CHAIR: Thank you very much. I presume you know our committee—Ms Mary Porter, Amanda Bresnan and me. Our secretary is Grace Concannon. We are a bipartisan committee, representing all parties within the Assembly. Thank you for the submission that you have given our committee. I invite you—Mr Baker, I presume—to make an opening statement regarding your submission.

Mr Baker: Thank you. St Margaret's Aged and Disability Committee is responsible as a committee for an organisation called Stepping Stones for Life, which has been working since 2002 with people with disabilities, particularly ageing parents who have a disabled son or daughter and are very keen to make arrangements for the care of their son or daughter when they are no longer able to do so.

I have asked Jeff Bishop to come with me to this hearing because I am speaking as the chair of the committee. I do not have direct experience of respite care. I have some experience in disability in the community and in the family but not in respite care, whereas Jeff is the parent of a disabled daughter. He is the former chair of our committee and still an active member of the committee. Jeff will be able to give more practical examples if we need to go into depth in some of those things. I will just go through a few of the highlights of our submission, if it would be appropriate to do so.

THE CHAIR: Certainly.

Mr Baker: With regard to the Auditor-General's report, we could not agree that the access to respite services was provided to people in the greatest need to the extent that the report claimed. We saw the inadequacy of present funding meaning that, in the figures that were given, only 25 per cent of the need was being met. While that was probably prioritised to give services to those with the greatest identified needs, we believe that there are still people with high needs that are not being met either by them not knowing what is available to them or they just do not fit into the pattern of things that are provided. One of the comments that have been made to us a number of times is that people that need things the most get less service on many occasions than those who fit into the normal arrangements.

We were quoting from the inquiry that Senator Humphries chaired where he believed there was an additional $11 billion needed in the disability sector as a whole. I think there has been a lot more emphasis since then. I am talking about the need for funding for disability services. We are optimistic that something is happening now, but we see a big need still there. As to the substantial need that there is for disability service, we believe that a significant part of that should be for respite care. That is a very cost-effective part of providing services for people with disabilities.

Regarding the needs of the care recipients, we thought there was very much a need to distinguish between various degrees of disability and to take a person-centred approach to caring for the individual’s needs. This we highlighted by a case study of the need to pay particular attention to aggressive people who, through no fault of their own, may be aggressive to others who are in a group care situation. We gave an example of that where someone had been harmed while they were in care outside their home.

As to the needs of the staff who provide respite care, we recognised in our submission that there are many staff members who provide wonderful care—and that is very much appreciated—but there are certainly cases of staff members who are inadequately trained or insufficiently experienced, or not supervised, so that the service that they provide is less than it could be and in some cases it does not happen because of a lack of organisation. We can elaborate on that further and give an example, if you like.

There has been an emphasis in the welfare area, which we were talking about, on the social role—valuing the individual. That applies particularly to people with disabilities, but we felt it needed to be applied more to the staff concerned as well, to recognise the important role that they are providing and make sure that they are trained appropriately and paid appropriately so they can be retained. I know that across the board in the care sector, when I compare the level of responsibilities with what I am familiar with in the public service, there is a huge difference in what people are being paid for similar levels of responsibility. I believe that needs to be addressed.

I have already made the point regarding the people who have the greatest need not necessarily being able to avail themselves of appropriate care. Regarding unmet need, one of the things that we identified was the greater need for advocacy. We strongly believe that there should be the appointment of a liaison person or an advocate to make sure that people know what services are there. We identified the need for long-term care more than just the sort of care that is often available.

We made some other points, but if I can just go to our recommendations. There were five recommendations in our report. One was for greater funding, which I have spoken about. One was about advocacy. One was for more emphasis on the training and systems that needed to be provided. One recommendation was for a greater range of options and physical facilities for the care that can be provided. We gave an example of a project that we are doing that we thought would fill one of the gaps that we identified there. We are providing that for longer term care, but we saw a similar model for respite care would be very useful.

We also saw the need for greater length at respite care for families so that they could function as a family as well as being a family with a person with a disability—that the other members of the family could get away for holidays sometimes and that there was a sufficient length of respite to enable that to happen. We provided some attachments to our report, but I will not go into those. I think that covers basically the list of points we were making.

THE CHAIR: Thank you very much, and thank you for your submission as well. It was very concise. I have a couple of points. In your opening statement you mentioned the unmet need. Your submission states that Stepping Stones for Life supports nine families. Does this level of service meet the current demand or do you have a backlog, for instance, or waiting list of people to come into it?

Mr Baker: We are not actually providing the respite services. We are trying to advocate for the people concerned. We have the equivalent of a full-time coordinator, but we have that split between several part-time people. The nine families that you refer to are what we call our focus families. We cover a wider range of people than that. In the service arrangement that we have with Disability ACT, we are contracted to provide assistance to 10 families in an intensive way and a further 10 families—and we would do more than that—in providing them with more general sorts of things that help them to fit into the community and be valued and more satisfied people with disabilities. We have services like providing art classes and music therapy classes. There is a YMCA exercise class for people who are ageing.

The intensive group are families where there are ageing parents who are trying to plan out over the course of the next few years what will be the options for their son or daughter. So of the original 10 that we started with, I think there are about five so far that we have now placed into reasonably independent care that has been purposely provided—in one case for three of the women concerned, or in other cases they have been able to fit into other services that are available. They have been housed in a way that they are able to have a planned achievement of independence from their parents, but still be close to their parents where it is appropriate—so that they can manage that transition.

THE CHAIR: What I was asking was: is there a backlog of similar parents who need the same service?

Mr Baker: Yes, we believe there is. There are younger parents as well. We have been concentrating on the aged parents, but we are having a lot of referrals to us for younger parents. We can only manage those to the extent that we are staffed to do so. I believe there is certainly a need for a much wider type of service similar to what we are trying to provide.

THE CHAIR: In your own area, can you quantify what sort of unmet need there is?

Mr Baker: I cannot put figures on it, but certainly in our reporting back to Disability ACT we report on specific cases of referrals to us. Jeff, do you have any indication of that?

Mr Bishop: I am a member of the Aged and Disability Committee of St Margaret's, a past chair and, as Keith said, a parent. Our family is one of the nine focus families currently, and we have been since the beginning.

We are deliberately keeping our Stepping Stones for Life project small. It is a deliberate decision. I am sure we could have 20, 30 or 40 people, because our lead coordinator, Annette Matheson, does get requests frequently from people who would like to join Stepping Stones. But it was a conscious decision of the committee that we needed to keep it small, we would like to see it replicated and we would help anybody who wanted to develop a similar program. To come to your specific question, yes, there is a big unmet need out there. We cannot quantify it but we are satisfied that there are a lot of people seeking help.

Mr Baker: As people find themselves in the situation where the planning for their son or daughter is being implemented, they become part of the less-intensive group. We have recently taken two more families into our group to keep up the numbers. Certainly, there is no shortage of people who would be interested in filling in those numbers.

MS BRESNAN: In your submission, talking about the unmet need, one of the things you raised was about having more of those liaison-type or advocacy roles. Would you see that as being similar to the type of program you offer or is it about resourcing different organisations to have that position or government actually providing funding for an advocacy-specific service that would help people, whether it is with respite issues or ongoing planning? How do you see that role working?

Mr Baker: I think it could be all of those things. We are certainly providing some of that information to the families that we are in contact with. The work that is being done by Stepping Stones in developing family governance arrangements for people living in group houses and with their parents or guardians still having some role in the management of a place has helped to expand the horizons of the focus families that we have. With the other activities, I think we provide some outreach or indication of what services are available.

I think there is probably a need for government to be more open in some ways in saying, “These are the services that are provided,” and telling people that these are their options, more than having to know what questions to ask.

Mr Bishop: Yes, I think that is the point. A lot of people, particularly parents of people with disabilities, are busy looking after their family member with a disability. They do not always get out and read and follow all the things that government might think they have provided. So there is a role for government to provide much more information.

To come back to your question about government or other providers, we think one of the reasons for the success of Stepping Stones is the very good cooperation we have had as a non-government organisation with the government organisation. Disability ACT and Stepping Stones have worked together very well, and that has been one of the secrets of our success, I think. So I think there is a real role for government not only to promote services that are available but to support other organisations such as Stepping Stones. From a financial point of view, non-government organisations do it more cheaply than government organisations. As I said earlier, we would like to see the Stepping Stones model being replicated, if possible.

Mr Baker: One of the members of our committee, when we were discussing our submission, made the point that from their experience in New Zealand the advocacy role is covered quite strongly by government there and they had not seen anything to parallel that in Australia.

MS BRESNAN: Mental Health in New South Wales have been funded for some carer advocate roles, which is similar in that they are regionally based and there is basically a role in each region. Do you think that sort of model would possibly work? We are a small region but it might be the sort of position where people know they can call and they can be given that assistance, whether it is to seek information or to actually contact a provider—that kind of in-between position or communication-type role.

Mr Baker: I guess, if it is someone that has the specific role of informing people. In some places there is a natural tendency, when you know you have not got the funding to do the services, to not try and promote it more. There are non-government services that are there, and sometimes people might not be aware of them.

MS PORTER: You provided some discussion in your submission around appropriate models of housing for respite and longer term accommodation as well, so thank you for that. My question is around that. The government is about to commence a feasibility study around the replacement of centre-based respite houses. Further to what you have said in your submission, what do you see as the key features of future respite, in terms of physical environment and in terms of service model, from your experience?

Mr Baker: Jeff might have more to say about this than I would. One of the key things we see is a variety of models that suit people with different sorts of needs, so that the respite that a disabled person receives provides them with not just a break but with some stimulation when that is appropriate. So they are not just housed passively, if something stimulating would be of more value to them.

There is a difference between the need for respite for short term and for longer term and what we have suggested, with some weekday respite and with the disabled person being able to be home at weekends with their family. So we would see quite a range of things as different models that are suited to people with different needs and to the families that are providing the care for them as well.

Mr Bishop: The comment I would make is that I think everybody agrees that we should not work on a one-size-fits-all model, yet as far as accommodation for respite in the ACT goes, it is one size fits all. We would like to see more models. There is what we have at the moment and the one that our daughter uses at Elouera. She is there for a week about once every seven or eight weeks, which is very good and very helpful; we are very grateful for it. It is a group house, basically. Some group houses work very well if they are properly managed; some of them are pretty terrible. I can say something about the group house at Elouera later, if you wish.

That is one model, but I think there ought to be more individual housing for people with behavioural problems because some people in a group house can cause a lot of trouble for the other five or six residents there. So if you had individual housing for people with special needs, with perhaps just one or two people, that would cater for them. On the other hand there are people whose needs are not terribly high and we think there is probably room for a third option, which is more of a semi-independent option.

We are trying to build, with assistance from the stimulus package, on the corner of our church block at St Margaret's, six bedsitters under one roof, with a communal kitchen-dining area so that residents can have as much independence as they wish or as they are able in their own little home. They have the security of being together and they have the social contact with others. I do not want to say too much about that but that model could also be applied, we think, as a respite house for the less disabled people. We can see three models at least. You may come up with more.

THE CHAIR: I invite you to talk to the personal submission that you put in, which would be relevant to the discussion we have had so far.

Mr Bishop: Thank you for that. My wife and I did put in a separate submission, supplementary to the ADC one. There are a few points that we made. Our comments were that we think respite is very useful and does help people. Could I come back to the point that Keith was making earlier about the financial advantages of providing respite care?

MS PORTER: I did not catch what you said.

THE CHAIR: The point that you wanted to get back to.

Mr Bishop: I am going to elaborate a little on the financial side. Keith mentioned that. When we were starting Stepping Stones—and this is going back eight years now—information we received from Disability ACT was that the cost of accommodating people with disabilities in a group house at that stage was well over $100,000 per year per person. I do not know what the figure is now. No doubt it would be more. That is a lot of money.

The longer a person with a disability can stay happily and productively in their family home, the much better off the government is. The point I make is that an investment in respite is much better than an investment in permanent accommodation. That could be used as leverage.

The other point I made was that respite is designed to take pressure off carers but our experience has been that it has also helped our daughter. It is getting her into a different environment. She is making more friends. She is seeing a different lifestyle. There are advantages for the person with a disability as well as for the carer. I talked earlier about the different models. Instead of one size fits all, we need different models.

Another point that we speak to very strongly is the point that Keith made in his opening remarks about the importance of staff and physical location. We have looked at different models. We have talked about different models over the years. The conclusion we come to after all of this is that the model is important but the way it is managed is more important.

That gets back to the staff. You need good staff. They need to be trained properly. If they need that, they need to be paid properly. If they need that, government needs more money. We come to that. The importance of a well-trained staff is most important.

The key word is flexibility. A lot of respite care does not have to be live-in accommodation. It can be day care in the person's home. There is much greater scope there for provision of services in the home to help bathing, to help take people out. Our daughter, for the first time, won an improvement in life grant, I think it was called. She gets taken swimming one afternoon a week for two hours. It does not cost very much but it has made a big difference to her and it is very good for us.

The final point we made in our personal submission was the obvious one. We said that it was no less relevant because it was obvious and that underlying all the needs of the disability sector, including respite care, is the need for adequate funding. Neither government nor non-government agencies can do what should be done without resources. We believe that a groundswell is needed through governments and through society to recognise the huge need that exists in the disability sector, the mental health sector and other sectors.

This is a personal thing now. You asked me to speak to our personal submission. We can see a huge need for a complete sea change in our attitude to the needs of vulnerable people in our society. In disability, mental health, aged care, we have got to accept our responsibility. Today we live in a wonderful society, brought about mainly by the efforts of our grandparents and great grandparents. I would like to think that our great grandchildren will be able to look back and thank us. To do that, we have got to get money and we have got to be prepared to get those resources.

I know it is not the ACT government's fault. The money has got to come from the federal sector. I think we have two options. We have got to increase taxes. That would be very popular with the three political parties! The other alternative is to really get down and reassess our priorities. Instead of putting lots of money into this—I could nominate a lot but I will not—it should be going into helping vulnerable people.

THE CHAIR: We are running out of time. We will have a couple of quick questions. Before I hand over to Ms Bresnan for her questions, what is the physical location of St Margaret's? Where are you?

Mr Baker: In Antill Street, Hackett.

MS BRESNAN: One issue that you raised in the St Margaret's submission was staffing and qualifications. That is something we were discussing with NDS. In terms of having minimum requirements, do you think something like a mandatory code of practice across sectors for workers would be something that could possibly work, in terms of ensuring that there are those qualifications as the base minimum that people do need in order to be involved?

Mr Baker: That sort of thing is very useful but I think it needs something that enforces it as well. The requirements for paying people at an appropriate level if they meet those requirements as well as not being allowed to employ them if they do not meet those requirements would be important.

MS BRESNAN: One of the things that NDS said was that, in considering this issue, legislation might be too blunt an instrument and that a code of practice allows a bit more flexibility in the industry and how they apply it to people and all that sort of thing. Other industries have a code of practice. Do you think legislation would be too blunt an instrument or do you think something stronger than a code of practice is needed?

Mr Baker: I cannot speak specifically in terms of that but I know that, in other areas of regulation, doing things through industry associations and the like can be quite helpful in lifting standards if you have got the commitment of the people that are involved in it as well as them just being told that something is to happen.

THE CHAIR: Thank you both so much for coming in and for your submissions. We are nearing the end of our hearings. It is very useful to get direct involvement from parents. Thank you very much for that. A full transcript of this hearing will be made available to you. We have one more hearing. If anything else comes to mind that you feel this committee should be made aware of for our deliberations, please get back to us in the next couple of weeks. Apart from that, thank you very much for coming in and for giving your submissions to us.

The committee adjourned at 12.30 pm.