



**LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY**

**STANDING COMMITTEE ON HEALTH, COMMUNITY AND  
SOCIAL SERVICES**

(Reference: [Respite care services](#))

**Members:**

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

**TRANSCRIPT OF EVIDENCE**

**CANBERRA**

**WEDNESDAY, 28 APRIL 2010**

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

**By authority of the Legislative Assembly for the Australian Capital Territory**

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

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## **Privilege statement**

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*Amended 21 January 2009*

**The committee met at 9.04 am.**

**GALLAGHER, MS KATY**, Deputy Chief Minister, Treasurer, Minister for Health and Minister for Industrial Relations

**GEHRIG, MS THERESE**, Manager, Aged and Community Care Policy Unit, Policy Division, ACT Health

**O'DONOUGHUE, MR ROSS**, Executive Director, Policy Division, ACT Health

**THE CHAIR:** Good morning, everyone. Thank you for attending this meeting of the Standing Committee on Health, Community and Social Services inquiry into respite care services. Minister, as is customary, do you wish to make an opening statement?

**Ms Gallagher:** Thank you, chair, and thanks for having us here today. In the interests of time, I am happy to proceed to questions. Certainly, I am here with respect to ACT Health, so I guess our focus would be on HACC and mental health services. For Disability, we will deal with their issues later in the day. If there is a crossover, we will try and be helpful. Certainly, Health runs a part of the respite care services in the ACT.

**THE CHAIR:** Just backtracking for a moment, I should have mentioned the fact that witnesses have a privilege card at their disposal to read, to ensure that they are familiar with the privilege statement. I presume all of you would be, so there is no need to spend any more time on that. We will push on to the actual hearing itself.

Minister, the first question is to you, regarding an issue that currently has not been resolved. It cuts across both your area, ACT Health, and also Disability. This is a matter before the coroner, so I am aware that there may be different ways of addressing this issue. There was a death; a person from the ACT died in an ACT hospital after an incident in a respite service funded by the ACT government. This happened in Queanbeyan, as I understand it. This has now taken nearly two years to get to the point it has reached at the moment, which is that there is still no coroner's inquiry instituted. This happened in Queanbeyan. I understand it is out of your jurisdiction, but my question is: what avenues are open to you or to any other ACT agency to try and get some resolution for the family of the individual that died?

**Ms Gallagher:** I know Disability ACT has certainly had much more to do with the family than ACT Health has. So it might be more appropriate, in terms of an update, if there is anything further to add to this, that Minister Burch responds to that.

In relation to the coronial process, and just talking generally, ministers can write and support an application for a coronial process, as, indeed, could you, chair. But, ultimately, it is open for the coroner to determine what avenue they take. Certainly, in a recent case, I have written to the coroner asking that a coronial inquiry be held as soon as possible in order to progress and finalise some of the issues, not related to that case. So it is something you can do. Whether it actually delivers an outcome that is satisfactory to the family, I am not sure I can answer that. But I do know in the case you refer to that, from my understanding of a couple of years ago, there was significant support provided to the mother involved in dealing with some of the concerns she had.

**THE CHAIR:** Sorry, did you say there was a report provided?

**Ms Gallagher:** No, there was support provided from Disability ACT. I just do not know; I have not been briefed on that case recently.

**THE CHAIR:** Where I am a little confused on this is that the death took place in Canberra Hospital. As such, I just want some clarification as to what processes you, as the Minister for Health, can take to ensure that something does happen. It has been two years.

**Ms Gallagher:** In terms of Health's involvement, Health will review its own response in particular cases as a matter of course. I think Health does that very well. It has a very well established patient safety and quality unit, very well established clinical processes where reviews are made, but it is restricted to the care and treatment provided under the auspices of ACT Health. So Health would not routinely go back and have a look at what led to that presentation coming to the hospital. It would review what happened in the hospital and whether there were any issues with that and, if there were, it would change its processes, and it does that in a pretty up-front way to get that clinical buy-in. But there are some protections there for clinicians as well in order to get that buy-in. So Health certainly reviews its processes, but in terms of a wide-ranging review into the events that led to that presentation, I can tell you that Health would not do that. And I do not know that it would have a role; otherwise it would be doing it in a number of cases all the time.

**THE CHAIR:** But you feel that Disability may have further information on this?

**Ms Gallagher:** I am not sure, chair, but in terms of the contact with the family, that would be the lead agency.

**THE CHAIR:** Thank you very much.

**MS BRESNAN:** My first question is in relation to the statement you made earlier about there being services funded for respite through HACC and mental health as well. One of the issues that has come up—this is through submissions also in the public forum which we held—is about that difficulty with it being a cross-departmental responsibility where you have some services funded by Disability and some by Health, and the confusion that that often causes for families wanting to access those services in knowing exactly who they can go to for what. I know this has been an issue over a number of years. Has there been any progress in terms of addressing that issue and providing people with one point where they can access or go to look for services, or at the very least providing more comprehensive information to families when they seek information or when there is a diagnosis, so that they know where to go to?

**Ms Gallagher:** I think this is an issue where we could do more work. I think it is difficult to provide a centralised intake, almost, across two agencies that do very different things, even though they have a role in providing respite care. I am not sure that I can provide much more information other than that I know Health and DHCS work very closely together in terms of meeting gaps, providing support for families and referring families between the two agencies, if it is more appropriate. I know those connections exist.

I think we can always improve our information to families on how they navigate the system. This is not a criticism or a concern just in respite care; it is a concern more broadly, particularly for those who may have a dual diagnosis. It does come up from time to time about families being unsure of or unable to navigate the system as they would like. I think we can always improve.

**MS BRESNAN:** I recognise it is a problem. It is not just an issue that comes up in respite. But it was quite clearly one of the major issues that came up in the public forum in particular. It goes to the fact that there is commonwealth respite as well, so there are literally almost four points in some instances that people have to go to, to access different areas. Again, it goes to the service providers as well, who have a multitude of contracts which they have to then report against. I know you said that you do look to improve the process, but have there been any discussions, whether it is through interdepartmental committees, about trying to progress that idea of having one place where people can go to?

**Ms Gehrig:** There are a number of opportunities for individuals to access the system. Particularly in the area of respite, Carers ACT are seen to be a significant portal. They receive significant commonwealth funding to provide the commonwealth carers respite centre and are able to refer individuals to a range of carer supports, one of which is respite.

Disability ACT also have their disability information line, and they will listen to the individual's needs and look at referral pathways. Very often, that referral pathway is to HACC services. The commonwealth also provide the commonwealth carelink centre, which is predominantly for older people but also for younger people with a disability, as one point of contact in the provision of information on the range of services that are available across the territory. Each of our funded organisations updates their details regularly with the carelink centre so that when individuals do ring, they can link across.

I also acknowledge the minister's previous comment that there are a range of services that are provided through the Department of Health and Ageing, through the national respite for carers centres, and the commonwealth carelink centre has all of those details, and there is also some respite provided through FaHCSIA.

**MS BRESNAN:** In terms of providing that information to people, is there an information package that is given to people so that they know? It came out from carers that often they do not even know who to call in that instance.

**Ms Gehrig:** Carers ACT would be the first point of call, and they have extensive information packs that deal with different carer target groups. So they have one particularly for children, they have one for mental health, they have one that is tailored for frail older people, which lets people know not only about the respite services but the other links across government—links to the carers allowance, the carers payment and a range of services that can support families.

**MS PORTER:** I want to continue on this theme of working together. Minister, have you had any approaches from the various organisations to address this problem in

coming together to work out ways that they can actually cooperate and so that, if they have a person approaching them, they can link them to other people, for instance, in another organisation which has an appropriate service?

**Ms Gallagher:** I have been, probably in the last year or 18 months, dealing with organisations under the HACC umbrella. There is a HACC stakeholders committee; I do not know what its actual formal name is.

**Mr O'Donoghue:** There is an executive directors group that has met which supplements an existing HACC network, which is more at the officer level. That executive directors group was at the request of the sector to improve their coordination and to address some of the issues that you have been raising, Ms Porter.

**Ms Gallagher:** And also to have a more coordinated, informed view about where growth funds in HACC would go.

**MS PORTER:** Yes. I remember—it is a long time ago—when I was working in an organisation that was utilising HACC, or being funded through some of the HACC programs, that was an issue then. But we did come together, as you are suggesting, to talk about how we could cooperate more. I wondered if that was still happening, and obviously it is.

Another issue was raised several times at that time, and I am wondering whether it is still the case. Because a lot of the organisations relied a lot on volunteer workers, and there seemed to be a shortage of regular volunteer workers at that particular time—I know it is not dealt with in the submission; perhaps you could take this on notice—are agencies experiencing any difficulty with recruiting volunteers that they need for ongoing work, where you need a regular volunteer to visit somebody or to transport somebody to respite, for instance? If you could find that out, it would be interesting.

**Ms Gallagher:** Yes, we will take that on notice.

**MS PORTER:** My substantive question is around the Indigenous carers program. Minister, is that one of the areas for which you have some responsibility? Does it come under your bailiwick under the HACC program? It is listed as one of the HACC areas.

**Ms Gallagher:** Yes.

**MS PORTER:** We had some elders come before us to discuss their identified need for a specific Indigenous respite service and, indeed—something which is not covered by this—a specific aged-care residential facility. They were looking for a specific respite service, if my memory is correct.

**MS BRESNAN:** And aged care.

**MS PORTER:** And aged care. As I say, aged care is not part of this inquiry. Do you have any information about any approaches you have had in this regard?

**Mr O'Donoghue:** I will ask Ms Gehrig to take that question.

**Ms Gehrig:** Yes, there is certainly an Indigenous carers program that is provided through both Carers ACT and the Ngunnawal Aboriginal Corporation. They provide a range of supports, some being community transport, as you referred to, social support and also the provision of respite care. At the moment, there is not an Indigenous-specific respite facility, nor is there an Indigenous-specific residential aged-care home. The numbers of clients across the region are relatively small. I am aware, though, that the elders have raised this as an issue that they would like to explore in the future.

**MS PORTER:** Is it being seriously discussed with them on an ongoing basis?

**Ms Gehrig:** I understand there have been some discussions between ACT Health, within our Aboriginal health unit, and, importantly, the Department of Health and Ageing, through their Aboriginal and Torres Strait Islander health section, to look at whether there are opportunities to work together to progress this issue.

**THE CHAIR:** Minister, we do have an issue with when we received the joint submission from you and the minister for disability.

**Ms Gallagher:** Yes, my apologies.

**THE CHAIR:** That is fine. But we have received a lot of submissions from people who obviously are going to be giving evidence before us, and there will be a need, I think, to either recall you or to ask other questions of you.

**Ms Gallagher:** Yes, sure.

**THE CHAIR:** So we are a little bit limited in the extent to which we can address your current submission to us.

**Ms Gallagher:** Yes.

**THE CHAIR:** One of the other submissions that we have had time to look at indicated that there was a particular gap, an area of need in respite care services out of hours and on weekends. I am referring to mental health. There are a number of issues that this individual has brought up—that mental health appears under-serviced compared with other population groups, and that there also appears to be a lack of services for people living with mental health issues who are in the criminal justice system. Can you make any comment on that? It is a fairly broad statement but it outlines areas of concern from one of the submissions that we have received.

**Ms Gallagher:** Yes, sure. Was that from a mental health organisation?

**THE CHAIR:** Yes, it was.

**Ms Gallagher:** I would be surprised if you got any submission from the community that said respite care services were at a level that they were happy with. I think this is always an area where you could do more. It is also an area where you have to manage budgets, and you can only deliver what you are funded to deliver. In terms of mental health, we have been working over the last eight years or so to increase significantly

every year our funding for mental health provision, and we have done that. You just need to go back and have a look at the budgets and in every single budget you will find more money going into mental health and more money going into community mental health services. But there is more to be done. It would not be any secret that there will be more money for mental health in next week's budget, and a portion of that will go to delivery of provision in the community.

One of the areas that we are certainly seeing more demand for, and it is not necessarily respite care, but there is certainly a view around more provision for step-up, step-down facilities. So it is not traditional respite but it relates to mental health. We opened a service which is run by the community sector about 18 months ago, and it has been full or oversubscribed since it opened. It manages different clients; sometimes they are not full, depending on what they need.

It is an area where we continue to look at how we provide services. One of the things that we are watching, and it will be interesting to see this under the COAG plans, is that we have been putting quite an effort into having an integrated service in mental health, so that if you need a respite service or you need more supported assistance to live in the community or you need to come into hospital for a while, you do so on a continuum and you can access those services, depending on your need.

It is one of the things that we will need to watch very carefully as we build up that system. I accept that it is not where it needs to be. One of the issues, as we move into the brave new world of health reform, is the fact that the commonwealth want to take over 100 per cent of community health provision and we will be left with managing the inpatient services, and whether that actually delivers the outcome we want in mental health.

**THE CHAIR:** Do you have concerns about the commonwealth's new directions in this regard?

**Ms Gallagher:** I think we will just have to watch it very carefully and make sure that we are able to maintain that integrated service, even if there are two different funders, so that people in the mental health system can access services and that services providing support to people with a mental illness are able to understand what each arm is doing. I would not want to see us create two silos based on funding arrangements. I accept there is more we can do in this area and we try every year, but it is about balancing all the other demands for government services as well.

**THE CHAIR:** Thank you. Ms Bresnan.

**MS BRESNAN:** My question is in relation on page 7 of the submission—the flexible family support respite program. As it says, it is flexible family support in terms of what it provides—the sorts of services families need if there are fewer restrictions around what they can actually access, whether it is equipment or a service. One of the issues that came up again in the forum related to the restrictions which are placed around some respite programs. I am just wondering about the approach which is taken to flexible family support—whether there has been any thought given to applying those principles more widely to some of the other respite programs that are funded.

**Ms Gehrig:** The flexible family support program is a wonderful program. It actually fell out of the territory's commitment to expand respite care services in the 2002-03 budget initiative. The program is delivered by three organisations—Community Options, Community Connections and Carers ACT. They have a joint intake process. When clients are referred they have a team meeting to determine which of those organisations has the best capacity to respond to that particular family need.

The program has really broad guidelines. It is about sustaining the family unit in whatever way works for that family. It may not be the provision of respite care. It may actually be providing some support to the siblings so that the mum can have more time with the disabled child. It could be paying for swimming lessons, again giving mum a break so she can have quality time with the other children. It allows a very broad dynamic. I believe the mother of one of our families was supported with driving lessons, which totally eased her burden in being able to care for the family and link her younger children with disability to other support programs. So it has a very broad base. It has been embraced by those three community organisations who work really strongly together. The other flexible part of the program is that families come on and off the program. They can come on when they require additional supports and then they can be maintained.

Your key question, though, that I heard was: could we move to have broader eligibility criteria across other respite programs? Certainly, under the home and community care program the eligibility group is defined nationally—and that is, younger people with moderate, severe or profound disability, frail older people with moderate, severe or profound disability and their carers. That puts, I guess, some boundaries around the HACC funding. Obviously we have other targeted respite programs specifically for mental health across dual diagnoses. It is a good model.

**MS BRESNAN:** You are talking about targeted groups, but I am thinking about the way this program operates. As you said, because families can go on and off it, they can access—whether it is a sibling or the parent accessing services—whatever they need to keep the family unit going. That is one of the issues that have come up. People say they cannot go on and off some of the respite programs because they have to go through the process of reapplying. It is just the principles of that program, irrespective of which target group it is targeting, because I think those principles can be applied to any group. Has there been any thought about doing that? I appreciate that HACC is a cross-jurisdictional commonwealth and ACT funded program. Has there been any thought given to actually applying those sorts of principles to look at what is it that the person needs instead of fitting them into the actual program guidelines?

**Ms Gehrig:** Certainly under the HACC program there is the opportunity to have ongoing support, but also to have short-term support when people come on and off the program. Conceptually it is great. Carers ACT are very much involved with that and link people both to short-term respite and ongoing respite.

**MS BRESNAN:** So there has been no thought given to actually applying these sorts of principles beyond this actual program?

**Ms Gehrig:** At this stage not beyond the current program that I am aware of.

**Ms Gallagher:** I guess one of the difficulties with that is that if you did expand this further and put more funding into it, it would start being a purchaser model, where the person who needed the respite had the money and could then go out and purchase—which has many benefits; I do not disagree with that—but that creates uncertainty for organisations, which have staff and services to run, like houses with beds, to manage their business.

**MS BRESNAN:** I was not suggesting it is something that you actually apply across the board, but—

**Ms Gallagher:** Yes, just have more, a larger—

**MS BRESNAN:** Even if it is not, it is actually about the principles behind it. It is whatever the family needs, whether it is something for a sibling or the actual person that is being cared for—that they can have those services. Again, one of the concerns that came up today was that families are almost being fit into the guidelines rather than the guidelines actually fitting them.

**Ms Gallagher:** Yes.

**Mr O'Donoghue:** Could I just take the opportunity to note that there is a commonwealth-funded respite carer support project in palliative care services. It is using a modified version of the flexible family support program to try and target Indigenous populations and younger people—children and people under the age of 65. It is a very small pilot program, but it is trying to use that flexible model to address those particular target groups in the space of palliative care respite services.

**THE CHAIR:** Thank you very much. We are running close to time. Ms Porter, do you have a final question to ask?

**MS PORTER:** I just was a little bit curious about the comments in the auditor's report with regard to client satisfaction surveys. The submission talks about what seems to be a fairly high percentage of client satisfaction. I note that the government has noted that.

**Ms Gallagher:** Which recommendation are you talking about?

**MS PORTER:** It is recommendation 13:

Disability ACT should revise the process of conducting client satisfaction surveys in order to improve the response rate and hence the overall validity of the data.

I note that the government has said that it notes the overall satisfaction level of 85 per cent as being good. Perhaps I should ask this question of Minister Burch, given that it says it is for Disability ACT.

**Ms Gallagher:** Yes. I am not trying to avoid the question, Mary, but I think most of the recommendations in the Auditor-General's report are related to Disability ACT.

**MS PORTER:** I will ask Ms Burch the question. Thank you very much, minister.

**Ms Gallagher:** Chair, I apologise for the lateness in the submission from the government. Certainly, I am very happy to come back and assist further, perhaps once you have had all your witnesses.

**THE CHAIR:** Thank you, minister; I do understand. We will probably be calling on you or giving you supplementary questions to consider. Thank you for attending this morning, Ms Gehrig, Mr O'Donoghue.

**Ms Gehrig:** Thank you very much.

**VIERECK, MR SIMON**, Policy and Sector Development Manager, Mental Health Community Coalition of the ACT

**THE CHAIR:** Good morning, Mr Viereck. It is good to meet you. Thank you for coming along. I am not sure whether you have appeared before a committee before.

**Mr Viereck:** I have, yes.

**THE CHAIR:** So you do not need me to take you through the privilege card and what the privilege implications are when giving evidence under privilege. Welcome to the Standing Committee on Health, Community and Social Services inquiry into respite care services, and thank you for your submission, which we have received. Would you like to make an opening statement, to talk about your submission?

**Mr Viereck:** Yes, please. First of all, thank you for inviting us to come here and speak to you. The Mental Health Community Coalition is the peak body for the community mental health sector, so we are working with organisations, consumers and carers to promote the interests of the sector and to work with government to improve the service system for mental health consumers and carers.

I will go straight to looking at respite care services in context. I think it is an important point to raise that you cannot consider respite care services on their own, outside the rest of the service system, certainly in mental health, which is obviously where my expertise is. Also, the evidence that we have is that respite care services are being used as gap fillers in terms of trying to address some of the gaps that are left by other services being perhaps inadequate or not in sufficient supply.

Respite care services ideally play a really important role in our system in supporting carers, particularly, to provide the essential support that they provide in terms of looking after their loved ones. In that respect we know that it saves the government an awful lot of money in terms of what it would cost to deliver the equivalent care and support. But, as I said, part of the demand for respite and part of the problems that arise are from a lack of appropriate services, particularly supported accommodation services.

Our submission took a broad view of a number of issues. First of all, measurement of demand, data collection, is really important. In your questions to the minister, you were talking about whether or not mental health was under-serviced or whether other areas were under-serviced. It is actually very hard to determine what the actual level of service provision and the actual level of demand are, because we do quite poorly in collecting that data, both because the data collection may not be up to scratch and also as a result of the sector being so fragmented.

What we do know is that, based on anecdotal evidence, based on what our members tell us and based on what we hear also from across Australia, mental health does seem to be somewhat under-serviced, potentially less so in terms of the full amount of service provision but more in terms of the appropriateness of the service. It does appear that there is less service available, but certainly there is a big issue around the appropriateness of that service. I will get back to that.

We looked also at barriers to access, program guidelines and criteria as part of the barriers to access, but also barriers to good service provision. Some of the barriers to access come from the fragmentation of service providers and others come from the lack of choice and flexibility, and that is related, of course, to the guidelines or their interpretation.

I noticed you also talked to the minister about targeting and about flexibility of respite care services, and that is a really important issue, certainly in the mental health area. Too often, the programs are too narrowly targeted, rendering a great number of people ineligible to be part of them, or the service provider will try and fit people into the box, as you were saying. With that targeting and with the lack of flexibility, the consumers and carers are not actually getting the type of service that they need. They cannot access the sort of service that would in fact enhance their quality of life. They can only enhance what the program guidelines say is available, which may not actually meet their needs.

There are also a number of gaps that we have addressed. First of all, it appears that mental health is somewhat under-serviced. We have addressed out-of-hours and weekends. We noted that Tandem, one of the larger providers, has had to cut their out-of-hours and weekend services due to lack of resources.

You have also noted services for people in the criminal justice system, which I think is a really important area to look at, now that we have a prison in the ACT. It is also important to consider that people can be in remand for very long periods and in that situation they are in a certain limbo in terms of having any services provided to them. There are a couple of other particular groups—siblings, young carers and the CALD population—that are under-serviced.

I would like today to briefly look at some of the characteristics of the appropriate services and a couple of examples of services. The characteristics of an appropriate service very much are to do with flexibility. We traditionally think of respite care services as an opportunity for the carer or the consumer to go away to somewhere else, often to another suburban house or flat, where they can have time out and the carer and consumer can have a break from each other. That is obviously still a relevant service, but in many cases it is not so much about the break from each other as it is about being able to do meaningful recreational and other activities together, as well as apart. It is about being able to have a fulfilling relationship as a family together that is not always coloured by the need of one party for support, and the stress that puts on the other party.

Having talked to consumers and carers about this, an example was brought up by someone who said, “Look, it would be wonderful if we could go to the coast and the carer would be in one accommodation and the consumer in the other accommodation, with each of them supported separately and being able to do activities together, and be together during the day, like a normal family.” In that sense, there would be flexibility so that each of them could be supported separately when they needed it. That sort of service is not really available. One of the real lacks in our system is that sort of flexibility to do things together but to have each party supported separately. And it is important to note that carers do need support as well.

It is really important that respite care is provided in a safe, supportive environment. An example of another real issue around appropriateness of service is a group house; the consumers can come to this group house, there will be a couple of people and staff leave at 7.30, after dinner. In a situation, particularly with the consumer, where they are in respite because they are probably stressed and at a heightened level of tension, to then be left alone overnight with other people in the same state, when the evening and night-time is often a particularly difficult time, in itself is more stressful rather than relieving any of the stress. So providing a safe and supportive environment is also about having supports there during the night, during normal hours.

It is important that people are not in a situation where they feel even more uncomfortable than they actually did at home. Having said that, consumers also raised that it can be a good opportunity to have a break from their living conditions at home, which often are in public housing and, as we know, there are often other dysfunctional—that is not a very pleasant word—families and individuals around. So their living arrangements can often be, in themselves, quite stressful.

With respect to the kind of services we need, I mentioned supported accommodation. I mentioned in the public forum the newly started housing-type program, which is an excellent program. It is modelled on a New South Wales program. The evidence of how efficient it is in reducing the time spent in hospital of people with high needs and increasing their quality of life is very compelling. That, of course, is available, so I will not go into that any further now.

We also need more recovery and rehabilitation-based day programs. Obviously, respite can also be an opportunity during the day for the carer to have time to do other things that they need to do. But it is important that programs that are available are recovery and rehabilitation oriented, so that they are not just putting consumers in a holding space but helping them to develop, and particularly to develop their skills in independent living.

In your conversation with the minister before, you talked about step-up, step-down facilities, subacute services. They are obviously very important. She mentioned that the current adult facility that we have in the ACT is always full. There is certainly plenty of evidence for the need for that sort of facility. There are a few other services that provide a similar type of service and they are also very well subscribed.

It is important that we remember it is not just a step-down facility. It is easy for Mental Health ACT and the hospital to want to call on those places when they arrange to ship people out of the psychiatric unit, but there is perhaps even more to be gained from having the step-up places available for people, not when they are starting to reach crisis point but when they are clearly starting to be unwell, and that they have somewhere safe and supportive to go that will help them to avert that crisis and not end up in hospital, which often is not only traumatic but also is a situation where people do lose independent living skills. So earlier intervention provides a much better outcome. Again, the evidence for that is clear and compelling.

We have already discussed after hours and weekends, so at this point I will rest my case and take your questions. Thank you.

**THE CHAIR:** Thank you very much, Simon, for a very well-prepared and thought-out submission. You make a number of very good points. You have mentioned how the health sector in your area is fragmented. Do you have any recommendations regarding better management and collection of information that would obviously help improve the circumstances that we currently face?

**Mr Viereck:** Obviously there is one fundamental problem—that is, there is both commonwealth and ACT funding for this centre, which clearly leads to some fragmentation. Again, reporting requirements et cetera would be different for those two funding bodies, as well as between funding bodies within the federal and the ACT governments. They can be different.

You talked before about the flexible family respite program. It has a couple of organisations and social providers working together to have a common entry point and an entry process. That is a very good partnership. It is very much the sort of model we need to look at. I have with me reports from the partners in the respite project which the Mental Health Community Coalition ACT was a partner of. It was an Australia-wide project. The focus was very much on creating partnerships which would reduce that level of fragmentation and create a better overview of what services were available. It would lead to better outcomes for consumers and carers by having clear referral points and a better overview of what was available. The ACT did not get any extra funding out of that program, but there was extra funding for new services and new partnerships in other states.

**THE CHAIR:** Are you aware why the ACT did not get any extra funding for that?

**Mr Viereck:** No, not really. It is not clear exactly why. Certainly, the work that was done around this project in the ACT brought together a number of the service providers to discuss models of partnering. The intake process is important. Using obvious common data collection tools and collecting the same data are all very important. What we showed is that it is possible. The services are quite willing to do it, but it does require some work. At the moment it is probably beyond their scope because they are stretched enough trying to provide the services that they provide. Essentially, it is not a hugely difficult problem, particularly when we are looking at services with the one funding body in terms of the level of government. That would be fairly straightforward, if it is encouraged by the government.

**THE CHAIR:** A supplementary before I pass on to my colleagues: you also had some very good points about respite not just meaning physical removal of a carer and consumer from each other. We have found through a number of outlets so far, such as the forum that we had, that the sharing of information about what is available is not necessarily all that good either. From your point of view, are you aware of the companion card and is mental health able to exercise the advantages of the companion card?

**Mr Viereck:** I believe they are. Mental health falls under that. That is a great initiative, absolutely. There are a number of programs also catering to the mental health sector which are about providing a body or a friend on an informal basis for consumers to go out and do social activities. In our case, that is a very important part of that sort of rehabilitation—to rebuild confidence in oneself, to go out and be in a

social situation, to be out in town, to go to a cafe, to go to the movies—to just rebuild those social skills. It is certainly an initiative that I think is positive.

**THE CHAIR:** Thank you. Ms Bresnan.

**MS BRESNAN:** One of the issues which you brought up and which I raised with the minister was about flexibility. With mental illness often there is episodic illness as well. At times people may well need respite and at other times they may not. Have you found, through the consumers and carers that you come in contact with, that this has become an issue for them in terms of them fitting into the program rather than the program fitting them because of that episodic nature?

**Mr Viereck:** It is certainly an issue. People would also benefit from and would like to have more regular respite, so there is certainly a role for that. As I say, due to the episodic nature of the illness, it is an issue to get the respite when it is needed and to get the sort of respite they may need when they need it.

If we looked at programs which are about being together in a meaningful way and which can be provided in a more regular fashion it would add greatly to the quality of life of carers and consumers, which is where we perhaps see the more urgent respite. Some of those are available and we have talked about the step-up, step-down facility, which, as I said, is always full. Having more of those facilities and more of those types of services available would really be important. People are finding it difficult to access the respite when they need it.

**MS BRESNAN:** Your submission mentions after hours and weekends, because that is often when something will happen to people. It is about being able to access that type of service—

**Mr Viereck:** Yes, and I think we have to be aware that, to some degree, mental health can be different as a sector than perhaps physical disability. One interesting thing is that for carers of people with mental illness it has been shown that there tends to be a continuing upward trend of stress. People continue to get more stressed—the carers tend to get more stressed—as they go along; whereas with physical disabilities they are very stressed, obviously, at the beginning when they realise what is happening but then it sort of levels out because things stay the same. With mental illness, we are talking about the episodic nature and you just never know what is around the corner. The stresses are very significant. Evenings and weekends can very often be times when there are very few services available. Most of our other services are nine to five as well. The time when a person is sitting at home alone with their thoughts can be, in fact, one of those difficult times.

**MS BRESNAN:** Thank you.

**THE CHAIR:** Ms Porter.

**MS PORTER:** I do not think the pages of your submission are numbered, but under the heading “Key issues for the inquiry”—the second paragraph down under “Measurement of demand, data collection”—which you mentioned before, it talks about some of the services not being utilised to their capacity. Can you talk about that

a little bit more?

**Mr Viereck:** Yes, that is true. I know that there are some services which are not being used or not being used fully. There are a couple of issues. First of all, with the fragmentation and the difficulty of navigating the system, in some cases people are not aware of the service. That can be an issue in terms of it being used—that people are simply not aware that it exists. The more important problem, I suppose, is where the service is just not appropriate.

As I was saying before, there is the example of a service that the Mental Health Foundation delivers. That is not to say anything necessarily bad about the Mental Health Foundation, but this group house is not staffed at night. The staff leave at 7.30. Consumers who use that service feel extremely uncomfortable being alone with other people, with other consumers, in a stressed situation after hours. The last thing they want to experience is someone else becoming psychotic—being in a strange, unfamiliar house with someone else who is psychotic. There is also the appropriateness of the service. If the service does not deliver to the needs of the consumers or carers and if it is not flexible enough to deliver to their needs then it will not be used. In fact, it does happen, as this example illustrates. It is simply not being used because it is not appropriate.

**MS PORTER:** You mentioned the building capacity project and how people came together and talked about the various issues that were affecting them. Do your organisations give feedback to other organisations about the appropriateness or inappropriateness of the service so that they are aware of why those services are not being utilised effectively?

**Mr Viereck:** Yes, we can be one of the avenues providing that sort of feedback. That is something that I imagine has been taken up. We will keep following up those sorts of issues. We have, as part of our organisation, a forum for consumers and carers, the Consumer and Carer Caucus. That is a platform where these things in particular can be raised and brought back to the organisations from a carer and consumer perspective.

**MS PORTER:** Are consumers and carers getting together in a forum on an ongoing basis?

**Mr Viereck:** Yes.

**MS PORTER:** Is there a joined-up kind of meeting with consumers and carers and organisations?

**Mr Viereck:** There is. That forum has not necessarily been very successful recently. The Carers Alliance really is the forum I am talking about. That is something that we as the peak body for the sector need to monitor and support all three key stakeholder groups getting together more regularly. It happens already through some of the other forums we organise. There is certainly a role for a more informal meeting just to discuss some of the issues on an ongoing basis. We are, in fact, today revitalising our directors and managers group for the organisations. That is yet another forum where we can bring people together.

**MS PORTER:** You mentioned it has not been all that successful up to this point. I will not presume anything, but could you say why you have experienced that?

**Mr Viereck:** The Carers Alliance brings together particular carers and organisations and at the moment not a lot of people attend that. Part of that is due to the fact that there are many forums for consumers and carers to attend and many options for having an input, and obviously there limited resources. If a forum does not appear to be effective, it is likely to lose some momentum and lose membership.

That is certainly something that we struggle with across the sector. We have struggled with it with our own Consumer and Carer Caucus as well in terms of supporting them to have a meaningful interaction in that forum and to feel that it is worth while for them to come to that forum. That is something that we have worked on. We are working on it with our caucus. The caucus is more likely to be a good forum than Carers Alliance at the moment.

**THE CHAIR:** Thank you, Mr Viereck. We have, unfortunately, run out of time. We thank you for your presentation. A full transcript of this morning's hearing will be sent to you, so if there is anything that you wish to provide any further information on and just check the accuracy, we would appreciate that. Thank you very much for attending.

**Mr Viereck:** Thank you.

**LAI, MR MICHAEL**, Senior Audit Manager, ACT Auditor-General's Office  
**NICHOLAS, MR ROD**, Director, Performance Audits and Corporate Services, ACT Auditor-General's Office  
**PHAM, MS TU**, ACT Auditor-General

**THE CHAIR:** Good morning and welcome, Ms Tu Pham, Mr Michael Lai and Mr Rod Nicholas, to this Standing Committee on Health, Community and Social Services inquiry into respite care services, which you are partially responsible for us having, because we are examining a lot of the issues that you have highlighted in your Auditor-General's report No 3 of 2009, *Management of respite care services*, and we thank you for your report. Would you like to make an opening statement on your report, Ms Pham?

**Ms Pham:** Thank you, chair, for the opportunity to appear before the committee and to contribute to the inquiry. The audit office conducted an audit into respite care about a year ago, in May 2009. At that time, the audit identified a number of significant issues with the provision of respite care services, ranging from policy and procedure issues, the process of determining eligibility and access to the service, and the quality of the respite care provided in government centres.

The audit made 14 recommendations to the department for improvement, particularly to ensure that the clients receive quality respite care services and to protect the wellbeing of clients with high and complex needs. The government and the department have responded positively to our findings and have agreed to implement most recommendations. I am glad to say that the department has kept us informed of the progress of the actions to address the findings, and we hope that later on we may have the opportunity to talk about the recommendations and the process in implementing them by the department.

From the submissions of other organisations and individuals, there is much to be done in terms of addressing the growing demand for the service and the need to provide a more flexible range of services appropriate to individual needs. As one submission pointed out, respite care is only one service within the whole range of disability services and should not be viewed in isolation. So there is a need for the committee to look at respite care together with disability services, and, of course, ageing and mental health, to have a holistic picture of the provision of disability services. Of course, there is a lot to be done to make sure that the quality of life of people with disability can be improved.

My colleagues and I are very happy to respond to questions on our audit report and we hope to contribute to this inquiry.

**THE CHAIR:** Thank you very much. We are very keen to examine some of the matters you have just referred to in the recommendations and the response from the government. Can I just start with a question that actually deals with a person from the ACT who died in an ACT hospital after an incident in a respite service funded by the ACT government. This happened about two years ago. Within your report, Auditor-General's report No 3 of 2009, *Management of respite services*, it is declared repeatedly that:

There was no report of any incident causing death or severe disability (level 8 outcome).

Did the time frame have any impact on you not being made aware by, I guess, the department that there was an outstanding issue waiting for a coronial inquiry?

**Mr Nicholas:** We audited at a particular point in time, and I guess we may have been aware of some of these incidents but not necessarily to the extent that they had been finalised or gone through coronial inquests or anything like that. We felt that it would have been inappropriate for us to have commented in any detail or made any specific reference to them under those circumstances.

**THE CHAIR:** Okay. I guess we are being quite careful about the wording of the way we are addressing this at the moment, but we have received a number of submissions to this inquiry—some of these are confidential due to the nature of what we have just talked about—but I guess what we are concerned about is the time frame and the lack of action that has been taken by a coroner not within our jurisdiction and what avenues are open to the government to seek an escalation to an inquiry. Would that fall under your charter at all?

**Ms Pham:** We would not be in a position to comment on that particular issue. When Mr Lai did the audit a year ago we looked into the incident reports kept in the departmental database, and there were reports of incidents and different level incidents, including a high level of violence, yet we did not find a report of death. We did a different level of reporting altogether, so there may be a lack of proper information in the system.

At the time we knew that the system of recording incidents was not complete because we did find that incidents were not entered into the database for the government to be aware of and to monitor, but for that particular incident we could not comment that it was within the period of the audit, was omitted in the system or for whatever reason that was not reported to us at the time.

**THE CHAIR:** Thank you very much for that.

**MS BRESNAN:** Thank you. My first question is in relation to something which is in the report which you did. It was about one particular point and audit conclusion:

Deficiencies in supporting systems and operational practices in the government respite houses led to inadequate management of high-risk clients.

I know you have talked more about the reporting and also the applicability of the service standards and how they were used. Were they two of the main things which led to that management of high-risk clients being inadequate or were there other factors which you found to be affecting that particular aspect?

**Mr Nicholas:** The conclusion there is probably wrapping up a number of issues. We have looked at, in the course of the audit, the underlying framework for the provision of respite care in those facilities we examined within the ACT government—the accountability framework, the policies and procedures, the staffing levels, the amount

of training people were going through, and a range of matters like that. We then significantly tested the individual client files within the group homes and found deficiencies. I guess the way we looked at it is that, if the underlying framework is not as supportive as it needs to be, then it creates risk. If we have got circumstances in homes where there is incomplete documentation on client files et cetera, that creates risks, so it is a gathering together of, I guess, our views on a range of matters that leads us to conclude that some of the clients, particularly at the high-risk end, are not receiving necessarily the depth of care that they require.

**MS BRESNAN:** When you are referring to the high-risk clients, are they those clients that have very high-level needs or are they actually some of the clients which may have lower level needs being placed at risk because of, I guess, your having a lack of information about the sort of clients in those facilities?

**Mr Nicholas:** It is a combination of both of those. If we have the pure fact that many individual risk plans or individual plans were not up to date, that indicates to us that the staff at the particular facilities may not be aware of the specific needs of those individual clients. They may be high-risk clients or clients with a high level of need, or they may need other levels of support, if you like, but the particular characteristics of the individuals within the homes, if they are not known to the staff, certainly increase the risk. It does not necessarily mean that there is going to be a problem, but it increases the risk that there could be some adverse conduct or arrangements or circumstances arise.

**Ms Pham:** I think the statistics that we found in terms of the percentage or number of client files which are not up to the standards are quite high. To provide quality care, the information about individual medical conditions and the nature of the disability has to be recorded properly. We found that information was missing or not updated. A client, for example, needs to have an individual respite plan in an individual file. I think we found that most of them were missing, or some of them were done back in 2007 and not updated to take into account any current situation or new development.

So, in terms of record management—and it is not just normal admin record management; we are talking about very important documents essential for quality of care—we are talking about client files, we are talking about individual respite plans, and I think these were missing in the houses that we audited. I think Michael looked at quite a large number of client files in these houses. Do you want to add anything more to that?

**Mr Lai:** During our visit of houses, we examined about 86 client files, which accounted for about 46 per cent of the total clients at the time. They have about 186 clients on the list, so, based on the result of our visit, it is quite a significant number of files. For example, as we just mentioned, individual client files are not updated or not reviewed in accordance with policy. About 60 per cent of the total client files reviewed identified that as an issue. Also, the plans had not been properly reviewed and signed off by the appropriate delegate with an indication of whether the plan, even the update, had been actioned by an appropriate level of authority.

Also at the same time we looked at consent by the parents or guardian in terms of exchange of information. All this had not been updated at all; it is not current. So

again we identified that there will be a potential risk to the department in terms of legal dispute or some kind of communication issue again; that it should be updated and also agreed by the parents or guardian in that sense. Overall we consider the record management needs to be improved.

**THE CHAIR:** If I can just ask a supplementary on that, recommendation 8, I think, is the one that this response is parallel to. The government, both Health and Disability, have put a joint response into our inquiry and there is a response from them agreeing to your recommendations and the status of where they currently are. Is the actual methodology, the utilisation of Riskman, state-of-the-art practice at the moment? Did you have a look at that as well?

**Mr Lai:** We did look at the system as such, as a database record. It is only a management information system, which I understood had been used by Health for many years, recording all those incidents of risk. I think the department has adopted the same system—I think it is only a database system—but again in our review of the training issue we noticed that a number of staff had not been trained in how to use the Riskman—

**THE CHAIR:** That is the question I was getting to.

**Mr Lai:** That is another issue: they have a system there, but the implementation side needs to be improved.

**THE CHAIR:** So the actual update of the system requires a little bit more knowledge of the technology that they are utilising.

**Mr Lai:** I think it is something like, using a computer system, it could be updated by the staff.

**THE CHAIR:** Okay. Thank you very much.

**MS PORTER:** To continue on this theme just for a little bit, it is the organisations which are providing the respite and the staff that are working within those organisations that are required to record this detail on a computer-based program? Is that correct?

**Mr Nicholas:** That is Riskman, yes. RiskMan is a—

**MS PORTER:** So they are not making notes and then transferring them? I am just wondering if handwritten notes are part of the issue as well or whether it is—

**Mr Nicholas:** There are individual files in the facilities, in the homes, for each client, and they record a range of matters, including details of risk assessments for the individuals, plans for their care, records of visits—a whole range of matters like that. Some of those will clearly be hand-prepared documents and will be used for just maintaining the record base within that particular facility or that home.

Riskman is a product that is used across the department, and I guess it is probably more involved if there has been an incident. Details of that particular incident need to

be recorded into the system and then it tracks the process for identifying what went wrong, how it went wrong, how it has been handled and how it could be handled in the future. So it is a bit of a combination of both.

I guess what we would say is that we have no reason to believe that Riskman is not a suitable system. It seems to us to be acceptable. As I said, it is used across the department for a whole range of purposes associated with managing risk. But, like any system, it needs to be well understood within the organisation. The parameters that are required to make sure that it works include that the staff are aware of what they are supposed to be doing, that they actually do it, and that the information in there is validated, if you like, reviewed, then works back into the system so that the feedback occurs the way it should. So, if you have got a risk, it is identified, it is addressed and it comes back to what improvements we need to make within the system overall or in the structure of the organisation.

**Ms Pham:** To answer your question, there are many ways for the information to be recorded in the system. I would think the normal process would be for the staff in the house to fill in an incident report form to indicate the incidence of injury, such as epilepsy, coughing, choking, medication and some of the neglect or physical assault. Some of that should be in some paper form first, and that will have to be reviewed by the supervisor. According to the policy and the procedure, a supervisor or the manager has to review that incident report and put the information back into the risk database.

So the risk database should have information reported from staff at the house to a manager who looks at it and approves it and decides what needs to be done. I would assume that it is not necessary for the staff at the house to enter the information directly into the computer system, more like the paperwork, but it has to be reported to a manager.

**Mr Lai:** There are different ways of recording the incident. That is why in the personnel file there what they need to do is, for any client who stays in the house, the carer had to record the status of the visit. For example, if they stay a whole day, they need to file visit summary reports. The summary reports will outline what happened during the stay, like, for example, if there is an incident. That is how we pick up, from looking at the visit summaries versus the record in the Riskman, that there is some missing link; either it is not recorded in the Riskman system there, or, as we saw with that, the Riskman would not be able to provide a full picture of the incident that happened.

The review process occurred in such a way that not only do the staff report the incident and it is reviewed by the supervisor, like the DSO2, at that level, but then for a serious issue it will be reviewed by a senior manager in head office and senior management would have a regular meeting to discuss the incidents so that they could have a strategic approach to managing the risk. It is not only an individual client's issue but across the board: how do we mitigate such kinds of incidents in the future? I think that was actually what it is intended to do, and that is what we suggest, that the records need to be updated to reflect that. Because with that information, it is for the senior management to look after the issue overall.

**MS PORTER:** Mr Nicholas, is that what you meant by the underlying framework is

not sound?

**Mr Nicholas:** That is part of it, yes, the understanding of what the system is supposed to do and how it is supposed to work. As Mr Lai has indicated, we have noted that there were some incidents that were recorded on client files that were not recorded in Riskman. Our suggestion then is that some of the people involved do not fully understand the processes, so it is a staff training issue. That is one of the components of the underlying framework that we were concerned about.

**THE CHAIR:** Just a general comment or question to all of you: did the question of independent support packages and management of these independent support packages come up and do you have any comment to make on the way that is being administered?

**Mr Lai:** We did not look at individual support packages in much detail, because our focus for the audit was on how to manage the respite care services. But, during the course of it, we looked at the funding applications, whether or not they complied with what was intended. We looked at a number of samples and we were satisfied that the process is okay; they comply with what they intend to do. With respect to the outcome of that, because during the audit they still had to process the application, we just did a brief review to see whether the intended policies were applied, in order to have an equitable assessment of the application. That is all we have done.

**Ms Pham:** Our conclusion, in terms of the process to approve applications for the individual support packages, was that it was done well by the department and that the people with the most need got the allocation for funding. The key issue is that there are not enough funds to go around; hence there are a lot more applications for individual support packages than the funding available. I think that is the issue—in terms of the shortage of funding to meet the growing need.

**THE CHAIR:** We have received quite a number of submissions from individuals as well as government agencies and other service providers, and part of the information that is coming through to us—obviously this is not quantitative; this is just information that is second-hand to us at the moment—is that the amount of the individual support package could perhaps be better utilised when there are not other leakages, from the actual amount going to the recipient, to administrative tasks. I am not sure whether that is something you may want to have a look at in a future report. Does that make sense?

**Ms Pham:** Yes, but we would not have enough information to comment on that.

**Mr Nicholas:** Certainly not in the context of this audit. But the administrative cost was an issue that we did identify. We did note that the costs of the ACT government services appear to be higher than those delivered by the non-government bodies. It is a concern to us, I guess. Part of the process is to minimise the amount of administrative activity and obviously transfer that funding, if you like, back to the clients and to the carers and to those who need the care.

**THE CHAIR:** We make the point that to maximise the actual impact of the support package, for as much of that to get to the recipient as possible, is what we are looking

at. Thank you.

**MS BRESNAN:** I have a quick question in relation to that as well, in relation to some of the key findings around funding and unmet need. I note that you said that the current funding model does not take into account unmet need because it is based on annual funding applications rather than actually looking at the total level of unmet need. Do you think that is, in part, because of the way the data is collected or the type of data that is collected? You have made the point there about funding applications rather than, I guess, looking at it in a broader sense. I know it is a difficult thing to collect, unmet need, but do you think there are other ways that it could be done?

**Ms Pham:** We believe that a better process in planning for future services requires a more robust system to identify demand than currently is adopted by the government. The government know what they call known unmet need, but they do not know the unknown unmet need. The known unmet need is very much based on the number of applications they have in place but have not been able to fund. So that is only one component of the future need.

I guess it is a common understanding that, when you know the government has a shortage of funds and it is unlikely that you will get the application approved, many people are deterred from applying. But there is a better way of accessing need by looking at the population, ageing, the statistics available, for you to identify long-term demand, in addition to what you know in terms of applications for funds which are not able to be approved due to the shortage of funds. I believe there are a lot of studies done regarding how best to assess the future demand according to population, ageing, the state of the health system et cetera. All sorts of other information should be taken into account.

**THE CHAIR:** Thank you. Time has, unfortunately, beaten us. It is incredible how quickly time goes when there are so many important things to talk about. We may ask you some other questions, perhaps in a written format, as the inquiry unfolds, if that is okay.

**Ms Pham:** Yes.

**THE CHAIR:** But we would like to thank you very much for attending this morning's session and also for the performance audit that you conducted. Thank you very much.

**Ms Pham:** Thank you.

**Meeting adjourned from 10.31 am to 10.43 am.**

**BURCH, MS JOY**, Minister for Disability, Housing and Community Services, Minister for Children and Young People, Minister for Ageing, Minister for Multicultural Affairs and Minister for Women

**FORD, MS LOIS**, Executive Director, Disability ACT, Department of Disability, Housing and Community Services

**OVERTON-CLARKE, MS BRONWEN**, Executive Director, Policy and Organisational Services, Department of Disability, Housing and Community Services

**THE CHAIR:** Good morning, and welcome to this public hearing of the Standing Committee on Health, Community and Social Services inquiry into respite care services. We thank Ms Joy Burch, the minister for disability, and members of the department for joining us here this morning. I presume that you are all aware of the instructions, and that I do not have to talk about the privilege implications. As is customary, Ms Burch, would you like to make an opening statement?

**Ms Burch:** I will say a few brief words. I understand that we are here for an hour. By way of context, ACT respite services are provided by the government and the non-government sector. The categories of respite are own-home respite, centre-based respite, flexible respite and host family or peer support respite.

I understand that we are looking at the Auditor-General's review of respite services back last year. You will note that the Auditor-General made a number of recommendations and in the government's submission it is noted that we have agreed to and implemented 10 of those recommendations. We agreed in part to recommendation 3 and agreed to note recommendations 7, 13 and 14, and have indeed worked across our systems to make improvements.

On the whole, the Auditor-General found that the services provided by DHCS meet the safety and respite care needs of people with a disability. The Auditor-General also stated that the ACT government is doing many things well. For example, policies and procedures are in place that direct service delivery and there are sound policies for risk management. The Auditor-General also noted that a person-centred approach is still being implemented across the ACT.

As I said, there is a mix between government and community sector respite. Just to put it into context around the split between those, Disability ACT provides \$3.4 million and the community sector provides \$2.7 million, so our community providers are indeed significant partners within our respite environment here in the ACT.

Yesterday, I looked through a number of the submissions and we will continue to look through the submissions as they are uploaded onto the website. What I saw to be some themes within those submissions were matters around case management, workforce and models of respite.

Just briefly, and I am happy to go through the details, there was comment about whether we do case management. We have a mix of case management, case coordination, local area coordination and a family and person-centred approach to care. With respect to workforce, any community sector provider will acknowledge the stresses and the efforts to secure and retain an adequate workforce; it is an ongoing

matter. On models of care, because we have a person-centred and a family-centred approach, we do look at flexible models of respite care. I think that is evidenced in our submission but also in our response to the original Auditor-General's report.

**THE CHAIR:** Thank you, Ms Burch. Looking at the recommendations of the Auditor-General and the response which we received late yesterday afternoon—thank you for getting back to us on that; a little bit late but better late than never—recommendation 3 states:

Disability ACT should formalise its procedures and guidelines to ensure that the process to determine eligibility for access to specialist disability service is consistent, transparent and accountable.

This is the ACT government's position:

Disability ACT will continue to use the definition of disability in the national agreement as the eligibility criteria for specialist disability services.

You are obviously aware of the Shaddock review. One of the primary elements of the Shaddock review is the recommendation of a clearer definition of disability overall. Firstly, has there been any dialogue on that within your department and, secondly, has there been any dialogue with the minister for education regarding the definition of disability?

**Ms Burch:** I talk with the department of education and Minister Barr on supporting children with disability in schools. There are a range of disability options within the general school area, whether it is in specialist learning units or specialist support units within different schools, or whether it is in the general population of our government schools, and indeed our non-government schools. How the Shaddock review and Disability ACT partner in providing comprehensive support to those children within the school system is being worked through. That will be something that I have a personal interest in. My responsibilities in supporting people in our community are front and foremost, and the divide between portfolios will not deter me from having that conversation to ensure that there is coordination, dialogue and support across the sector. Ms Ford, do you have anything to add to that?

**Ms Ford:** There has been a lot of dialogue about eligibility. Eligibility is as it is stated in our now national partnership agreement, which is a fairly broad eligibility. But we have taken a very clear approach and have had quite a lot of dialogue with the Auditor-General in relation to this recommendation. Out of the Gallop inquiry there was a very clear direction around a person-centred approach. A person-centred approach, in terms of looking at access and support, means that you look at the person first, not at the diagnosis. Also, you look at the level of need and do not attempt to categorise it in low to medium, medium to moderate, moderate to high, and then try to determine what services would be available as a result of that.

An example would be that, internationally and also nationally, in some areas, they categorise—and particularly in aged care it has been a favourite, for all the time I have been in human services—and try to level a person's need on a one, two, three or four basis and, depending on the number, which equates to a level, it would equate to a range of services that you may be able to access. It does not mean that you can

access them; you may be able to access them.

We chose not to go down that line. We felt that that created an unnatural barrier for people with disability to access the full range of support needs that they may require. Also, with that, because we are under an eligibility and not an entitlement program, where people are eligible for a service, anybody can apply for a service; access will be determined on the level of need and the level of priority within the resources that are available. So we would not, unless forced, go down a numbering, category or diagnostic pathway to access to services.

However, in Education, they have a slightly different purview in relation to delivering services to young people with a disability; that is, within an educational environment—and I would say the word if I was not going to stumble over it with my mild dyslexia, which is pedagogy—because they work within that framework and an educational framework, therefore the learning modules have to be tailored towards the particular diagnosis or disability that a person would have. Therefore, I could understand them looking differently at eligibility and how that might be applied in education, but I would not see that as a direct transfer to the access to support services.

**THE CHAIR:** A supplementary issue between Education and Disability on which we would like to get some clarification is the reduction in the school leaving age for children with a disability from 20 down to 18. What advice have you received to come to that conclusion? Did you make the decision, was it made by Education or was it made between both of you?

**Ms Ford:** That is a decision that Education undertook. There has always been a policy that there would be a year 12, and the years 13 and 14 beyond that were more by stealth, I guess, and culture, over the years. In discussions with Education, when they were looking at how to advantage young people leaving school, we agreed that, for young people with a disability to stay at school for longer than year 12 may not be in their best interest. I understand from Education—and we have done a lot of work around this—that that rule is not hard and fast, and that young people may do a year 13 and, if there is an educational imperative, go on to year 14. So that is the first clarification. The second part of it—

**THE CHAIR:** What advice have you as a department received on this?

**Ms Ford:** From Education?

**THE CHAIR:** From Education and also from your own Disability Advisory Council?

**Ms Ford:** The Disability Advisory Council have only recently started to look at the information around the education review. I understand with the Disability Advisory Council that there are some differing views, particularly from members with young families. They have some reservations about that. The reservations, as I understand it from my discussions with them and with other families, are about the ability of the support mechanisms to transition young people from education to adult life.

**THE CHAIR:** In a submission titled *Needs of ACT students with a disability* by the Disability Advisory Council, which was presented to another committee, they

recommend that students with a disability be able to remain in school for an extended time if they do not have an appropriate place to transition to, such as employment, further study or a post-school option program. So that is the recommendation from your own advisory body.

**Ms Ford:** Absolutely.

**THE CHAIR:** How is a decision like that taken? Is it by Disability? Is it by Education?

**Ms Ford:** Education.

**THE CHAIR:** Has there been dialogue, Ms Burch, with Minister Barr on this?

**Ms Burch:** Yes. With these decisions, there is no fast rule that every child within school will leave at X year or X age, and the transition is important. If we do not get those transitions in place then we expose vulnerable people and families—

**THE CHAIR:** Parents have been told that their children will not be able to go beyond 18 years of age at particular schools.

**Ms Burch:** Are you answering your own question, Mr Doszpot, or would you like me to answer it?

**THE CHAIR:** I am letting you know what feedback we have had from the community.

**Ms Burch:** I am saying to you that we work with families around how they transition out of school. Some families, as Ms Ford has indicated, will be looking to transition out of school at an earlier age because that suits the needs of those families. The Disability Advisory Council are a group of people who are impassioned about disability support. They are entitled to put their views forward. We will work with the education department to ensure that transition plans are in place and that, when transition out of school occurs, at whatever age or year, we have the appropriate structures in place.

**THE CHAIR:** So, if you have advice from the Disability Advisory Council, comprising parents with probably the best knowledge at hand with which to advise you, are you saying you are ignoring that advice?

**Ms Burch:** I get advice from a range of areas, and that advice informs me, Mr Doszpot.

**THE CHAIR:** And that advice will be passed on—

**Ms Burch:** I could get advice from you, Mr Doszpot, and that could inform me. I could agree to disagree with you on that.

**THE CHAIR:** I am still waiting, Ms Burch. But more to the point, the advice that you are getting is from people who are very much on top of the issues that are at hand.

Is that information provided to the minister for education? Have you discussed this school leaving age with the minister for education?

**Ms Burch:** I have just said, Mr Doszpot, that I talk with the minister, Andrew Barr, about the Shaddock review and how we can better support what support processes are in place for children at school and also those transition arrangements.

**THE CHAIR:** Thank you, Ms Burch.

**MS BRESNAN:** My question relates to what is in the submission about unmet need. That has come up as a fairly big issue. Also, we just discussed it with the Auditor-General, because she had commented on that. In your submission, there are a couple of paragraphs about how the ACT compares with other states. You say that proportionally there is higher expenditure when you look at other states and territories, other jurisdictions, and when you look at it nationally. But essentially how you assess and address unmet need is not really covered here.

With respect to the findings in the Auditor-General's report, one comment that I asked her about in particular was about the current model—and obviously it relates to funding as well. Unmet demand is very much based on what the annual funding application processes are, rather than looking at what the total estimate of unmet need is. I acknowledge that this is something that is very difficult to determine. The Auditor-General commented that there are particular studies that exist that look at unmet need, and that includes looking further based on population, ageing and other such factors. That is not actually in here, so I am wondering whether that is something that is being looked at in more detail with respect to unmet need—not just looking at how we are comparing nationally but at how we actually assess that.

The Auditor-General also noted that, when we look at other states and territories and as demand has grown, what we are providing has not actually increased proportionally when we look at other states and territories. Is that something which has been looked at in more detail, because that is obviously a key issue that has come out through this whole inquiry?

**Ms Burch:** Certainly, there is an unmet need. We acknowledge that there is an unmet need. I was listening to Tu Pham before I came down to the committee room, and we only know what we know. We do not know what we do not know. I am sure wiser men before me have said that and acknowledged that. We work through it; we do have a funding envelope, and there is no doubt about that. Can I put on record the increase in that funding envelope since 2002. We have increased flexible respite hours by 96 per cent, respite bed nights by 11 per cent, accommodation places by 31 per cent, community support places by 55 per cent, and community access hours by 70 per cent.

I think we started in 2002 with a \$14 million envelope in the community sector, and that has increased to \$26 million. Generally, overall, for Disability ACT, it is \$67-plus million. So we have continually increased and stretched our funding envelope. But you are right: there is unmet need there. I think Lois is probably the best person to work through the details about how we manage the need that we know about, and how we assess what we do not know. Throughout all of this, the other quite

exciting discussion is the national insurance conversation.

**MS BRESNAN:** Whether it happens or not is another thing.

**Ms Burch:** But just the fact that we have got it on the table as a conversation does allow all of us to really have a look at the shift, should it occur, from eligibility to entitlement. I think that is one of the fundamental shifts that we as a society need to make. If we are having the conversation around meeting need, we also need to have, and should have, in my view, that conversation as well.

**Ms Ford:** In terms of unmet need, you are right: a lot of the calculation of unmet need across the whole of Australia is based on the known demand. So that is people who are either applying for services or in services and want more. With respect to the national minimum data set, which gives us all of our information in relation to our known demand and service use patterns, the ACT has two additional questions—about the support you are getting, whether you want more, and for how many additional hours. That data has not come through yet because I think those questions were only added last year, so they have not come through yet. But that will give us a better indication of what people perceive that they need more of—a very good calculator of unmet need.

We are working very closely with Treasury on the predictions, so looking forward into the future of ageing, people who are ageing, ageing in situ, and what that likely population will be. With people coming into the system, we already know. This is the known demand. We already know that we have approximately 11 families a year whose natural support or current formal supports will break down and there needs to be some additional intervention there. We already know that we will have somewhere in the range of 14 to 24 young people leaving school in any one year that will require a response. We already know that we will have three to four people with an acquired brain injury requiring a very intensive response from government and who may fall outside of compensation claims.

The funding plan is on our website. It is actually being updated as we speak. So we already have a reasonable idea of some of the indicators of what the current demand is. But you are right: predicting demand into the future is a very complex piece of work, and we continue to work away at that with Treasury.

**MS BRESNAN:** Are those things that you have just mentioned being built into the funding plan?

**Ms Ford:** They are built into it, and we build them also into our funding as it comes through. So we are aware that we will be providing an emergency or a crisis response to a number of people within any one year, and that a percentage of those people will go on to need quite considerable and intensive lifelong support.

**MS BRESNAN:** That work you mentioned that is being done with Treasury, at what stage is that, and how is that going to be built into the planning process?

**Ms Ford:** The initial work is through our funding plan that we already did the work through, in 2006 I think it was, and that funding plan has been updated. We used that

successfully to negotiate with the commonwealth government on the funding increase that we received in 2008. We also used it to manage the funding that we get from the ACT government, which has been the additional almost \$27 million over the last six or seven years. So we use it as the basis for our planning into the future.

You can see trends coming through very clearly. Accommodation support is always going to be the big ticket item, for want of a better word, because people look forward to having supported housing tenancy for their sons and daughters into the future. So it will always be something that will be built considerably into our thinking, our design and our planning—and, because this is respite, flexible ways of using respite to provide additional support from a vocational and community, social and recreational point of view, as well as for relief for families and individuals from the intensity of caring.

**MS BRESNAN:** We have already mentioned children leaving school. There is that gap there, and it is a difficult gap to address. But there is that gap, particularly, in those adolescent years, and at that point when they leave school.

**Ms Ford:** Transitioning into their adult life.

**MS BRESNAN:** Yes, and there are services there as people become older, particularly for that group. Autism is probably a good example where there is quite a gap in terms of need, and particularly around living options and supported accommodation options. Is that a particular target area that you are looking at?

**Ms Ford:** The transition area, which is the gap in anyone's life, is definitely a real focus for us, both transitioning from school to adult life—and I will tell you a little bit about the work that has been done around that—as well as transitioning from home to more independent living. What we are getting more now than we have had in the past is people transitioning from employment into retirement—people with disability transitioning from employment into retirement.

With the transitioning from education to adult life—I will very quickly contextualise it for you—previously there was a program involving three years of non-recurrent funding for anyone transitioning, called the post-schools option funding. It was highly sought after, highly priced and very dependent. What happened at the end of that three years? It was non-recurrent funding, and, of course, a person's disability or a young person's need transitioning to adult life does not change. So we have shifted considerably the way in which we utilise funding in that post-school transition to the funding of a transitional program that works with young people that are likely to move into employment, supported employment, and a range of opportunities to transition through there. Then, with this much smaller group, it is a matter of working with them on looking at the lifelong supports that they will need.

Initially, there is a small package for day activity, to look at different ways in which you might engage in an employment opportunity or a social opportunity, recreational opportunity, an ongoing vocational opportunity, but more particularly in life skills. That is alongside the respite that you may well be receiving or any other supports that you are receiving. From there, we look to what the other additional needs are that you are going to need as you transition through.

We also fund quite differently now through quality of life grants, which is a small, one-off, non-recurrent direct grant to support a person to do a whole range of things. It might be to purchase some technology, some equipment, some additional training—there are just so many areas that that covers. As well, we are now looking at the grants program—a direct grant, so that some of that package that you get when you leave school will be in the form of a direct grant. One of the examples is where a family has used those dollars in the first instance to support, in a particular instance, their son in an employment opportunity that he would not have otherwise received through transition programs. So they have worked with the organisation and the organisation has taken that on. With the funding that we are getting to support him there, they are now using it when he goes home from work, because he finishes work at 3 o'clock, and a support worker is supporting him and he prepares the evening meal now.

That is just an example of the flexibility with which people use their funding, and over the last three to four years we have been able to introduce a range of different models.

**MS PORTER:** I have a couple of questions that arose in previous hearings, in submissions and also in evidence this morning. You mentioned, minister, the number of organisations, non-government and government, providing respite care. You also mentioned that there are ACT-funded and commonwealth-funded programs. How is the government working with the sector to bring people together to have more coordination, more cooperation and assisting them to share information? It seems from what a number of people are saying to us that one of the problems they have is with actually negotiating the system. Our last witness before the morning tea break mentioned that some respite services are not even utilised appropriately because people do not know that they exist.

**Ms Burch:** Lois can go into greater detail, but suffice to say we recognise our community partners as strong partners and a viable link in the provision of services. I can see some sitting there, so congratulations on the contribution, and thank you for that. It is important that we do all work together, in that one service may be stretched and other services may have the capacity to accommodate. That is why we have a focus on family and person-centred so that we best meet their needs. We continue to do work to streamline those entry points and those information exchange points.

Certainly, I have trouble navigating service systems, and I have the time and I do not have a particular stress. So if a family is in stress, we clearly recognise that it is important that we have a no-wrong-door policy. So when a contact is made, the system behind that should be responsive enough to that family that they do not have to pick up the phone again and again to find it. Our future directions, our strategic policy, quite clearly talks about the right service at the right time in the right place, and that there is a no-wrong-door program. That will go to addressing some of those hiccups in transition and seamlessness across services. Ms Ford might be able to comment further on that.

**Ms Ford:** We have got quite a lot of feedback about a hub and a whole range of things—a central point of access. The research is out, as you would know, on whether a central point of access is the right way to go, because people more commonly need

the information wherever their point of access is. So we have a range of things. We have the information service, we have CanAccess, we have a contact list. Through Carers ACT, there is the commonwealth-funded portal for access to respite.

There are two areas that we are really focusing on now. One area is the no wrong doors program. I think it is in Western Australia that it has been very successful. When a person approaches an organisation, traditionally the organisation will give that person the information about their organisation or the type of service that they deliver. Often the person needs a much broader scope. With no wrong doors, we are working through a program at the moment that we will be rolling out. The program has not quite got there, but I will put some suggestions while it is in the development phase. Each organisation signs up to giving a person, at their first point of call, a fulsome amount of information in assisting them to make those links, and people know that this is a no wrong doors organisation, so they know when they go there what they can expect. We would support the agencies with the information to ensure it is fairly fulsome.

The other part of that is working with the National Disability Services to look at the way in which demand is managed across the whole sector. You would be aware about the issue in relation to each agency holding its own waiting list and prioritising within its own agency. Some of the work that we will be doing in 2010-11 with the National Disability Services is looking at how we can better manage access to services across the sector, and the relationship between that and no wrong doors is yet to be worked out. But we are very aware that having people going to one place to get information does not necessarily work when you use a range of services or you are looking for something in particular.

If one agency can give you not just the information about what it delivers but the broadest information possible, that seems to be the best result. In Western Australia—I am pretty sure it is Western Australia—they are finding that that is actually a better way than the hub, the one-stop shop or whatever.

The other piece of work that we are doing is around local area coordination. We have refocused that on people at the entry point into services—young people with their families, newly diagnosed, or people who do not necessarily need a range of formal supports but who really do need to be linked into the generic supports within their community. That is also about providing a broader range of information and a higher focus on the planning process, on individual planning, to assist people in identifying more clearly what they want. So there is no one strategy.

**MS PORTER:** I asked this before of the Minister for Health. It is not mentioned in your submission to us; it is something that was happening in the past and I am not sure whether it is continuing to happen. Maybe you can take this on notice. The number of long-term volunteers or volunteers available on a weekly basis was drying up some years ago, and I am not sure whether that is still the case. I know numbers of these organisations do utilise volunteers, particularly in support services that provide support to families that may be accessing respite care. For instance, transport is one of them. There are other ones—friendly visiting and so on—that would apply.

As you know, a lot of these services rely on volunteers that can be available week in,

week out rather than spasmodically. The trend was towards spasmodic and episodic volunteering. Could you take on notice whether organisations are still experiencing that stress in recruiting and retaining volunteers?

**Ms Burch:** I will take it on notice but I can give some information on a couple of organisations. I met up with Communities@Work last night, who have a head count of slightly over 300 staff and a head count of over 200 volunteers. So there are some organisations—and I am not saying they are not struggling to attract volunteers. I think UnitingCare over in Kippax had a fantastic volunteer support base. I think there is a mix. We will take it on notice. The ACT has a fairly good record of volunteer support but it is also worth looking at what sort of function those volunteers do. With some of these services, the requirements and needs are quite complex. We need to look at supporting the workforce in addition to supporting the volunteer base.

**MS PORTER:** Yes, of course, the total workforce, paid and unpaid.

**Ms Burch:** That is right.

**MS PORTER:** Thank you very much for that.

**THE CHAIR:** I would like to come back to the discussion we had towards the outset regarding the definition of disability. The Auditor-General referred to the need to look at the definition of disability. The Shaddock review sought a re-examination of the definition of disability. The special education reference group talked about the need to re-examine the definition of disability. The Disability Advisory Council has talked about the need to re-examine the way we define disability. As late as yesterday, the paper we received from you talks about Disability ACT continuing to use the definition of disability as it is at the moment. The Shaddock review with regard to children with special needs and their particular requirements is obviously concerned about looking at other learning disabilities, such as ADHD and dyslexia, which currently need a lot more attention. What steps are you taking, minister, to listen to all of these organisations that are asking you to redefine the definition of disability?

**Ms Burch:** I am happy to listen to organisations, but, as we have said here, we use the national agreement for our eligibility criteria. That is a national agreement that we are signed up to. Mr Doszpot, are you asking me to breach a national agreement, a partnership that brings funds into the ACT? I talk with a number of organisations. You made mention of ADHD and I have spoken with a lot of people from Asperger's and autism. All those needs are clear. We do not support people on a badge of a diagnosis of a disability. Therapy ACT provides a range of support to children that have developmental delays, that have challenging behaviours, but they do not have a disability diagnosis. We support those, but I think it is quite clear from what we have said that we will continue to use the disability definition in the national agreement as an eligibility criterion. Having said that, we do afford and we do offer and we do provide services to those that may not fall into that definition.

**THE CHAIR:** Minister, you just said that you are willing to listen to people. You are also telling me that you are sticking by the national standards of disability. We have the situation at the moment where a review has been conducted, an extensive review, into special-needs children and education. It makes a very straightforward statement

regarding the adoption of changes. What I am asking is: who makes the decision to change this definition that the Shaddock review has called for, and what undertaking can you give us that there will be discussions with the minister for education? Between the two of you, surely you would be listening to what a review that this government commissioned has said?

**Ms Burch:** I think what you are asking me is: do I talk with the minister for education around the definition of disability falling out of the Shaddock review for education? Has the government responded to the Shaddock review?

**Ms Ford:** No, they are still—

**THE CHAIR:** You're asking me? I mean—

**MS PORTER:** No, they have not.

**Ms Burch:** I had not thought so, but I thought you might have known something that I did not know, strange as that concept could be, Mr Doszpot. One, the government has to respond. Two, I have already indicated that I am having conversations with Andrew Barr, and I have had a conversation with our department about—

**THE CHAIR:** I am finding it difficult to understand, minister, how you can ask me whether you have responded, if you are not in discussions with the minister.

**Ms Burch:** how we consider the Shaddock review in terms of our levels of support. The definition of disability is very broad. It is still linked to the national agreement. As I have said, I continue to listen to people. We have said that we provide services to a range of children that are outside the definition of disability in here.

So, if it is around service delivery, we are providing that. If you are just wanting me to commit to talking with Andrew Barr around the definition, I am happy to have that agreement, but I cannot pre-empt the result from that, because this is very broad and complex. You are asking me to make a decision around the Shaddock review, and I cannot do that.

**THE CHAIR:** Minister, have you read the Shaddock review?

**Ms Burch:** I have read the Shaddock review.

**THE CHAIR:** What does it say about the need to define disability?

**Ms Burch:** I am not going to give you the verbal word-for-word definition. I thought we were actually here on the Auditor-General's report focusing on respite services—

**THE CHAIR:** It focuses on the same issues, minister—on respite services, which are all part of this same equation. So how would you define disability under the Shaddock review?

**Ms Burch:** Mr Doszpot, I am here, and I have said to you that we, the department of disability and community services, define disability as the national agreement. That is

our criterion.

**THE CHAIR:** Okay. Minister, I am not trying to get you to do anything you should not be doing. I am simply trying to ask you to focus on disability as a very important part of an education review that has been undertaken. So far, you are telling me that you are willing to listen, and yet you still keep repeating that this is your current stance. I am not asking you to do anything other than respond to the Shaddock review, so please read it and talk to your minister and between the two of you come up with some recommendations or adoption of the options that have been put forward by the Shaddock review. That is what I am asking you.

**Ms Burch:** Well, I have told you that I am talking with Minister Barr.

**THE CHAIR:** I am now reassured.

**MS BRESNAN:** I have got a respite question in relation to one of the terms of reference of the inquiry, which is addressed in the submission, about the interaction between government and non-government providers when it comes to respite care. Often there is a situation where a service might be contracted out and it is contracted out to a third party. That does sometimes happen with the provision of services, where there is a need and the need needs to be accommodated.

I appreciate you have talked about the compact and the way you deal with providers, but I am just wondering how you deal with that situation, that contracting down the line, and what happens then to responsibility, and as it applies to the department, and if there is any auditing process of that when it is going out to a third party beyond where funding has been provided to a particular organisation. How is that situation dealt with by the department?

**Ms Burch:** Again I will go to Ms Ford on the detail, but again just as a preamble, so to speak, we have strict contractual arrangements with the services that we provide. We also have service standards and service systems and processes and procedures around assurance of quality and deliverables that are meeting our purchasing agreements.

The third party payout or buy-in from other services is sometimes at the direction of providers, to meet their own needs. Individuals are able, through different arrangements, such as ISP, to buy in services that suit their needs, and they are indeed in control of what services that they buy in. But the contractual—

**MS BRESNAN:** I know there are the disability service standards and they are applied to service, but how is that quality assured when—

**Ms Burch:** When it becomes so far removed.

**MS BRESNAN:** How does the department ensure that those services are reaching a certain level?

**Ms Ford:** First of all, I think it is important to note that in the ACT there is no accreditation or regulation of respite services, but we are working on a

prequalification framework for Disability, Housing and Community Services and we have got cross-government advice on the group that is working on it; it is called an outcomes-based purchasing framework. And the prequalification framework, which we hope to start trialling later this year, will give us an added layer of reassurance in relation to services meeting a whole range of criteria before they are even able to get, in this case, DHCS ACT funding.

The areas that are most likely to use a private business or subcontractors that you are referring to are more likely to be in respite and it would be through the aspiring agencies where a person has an individual support package and the actual aspiring agency is responsible for coordinating and providing the support. If we are directly funding or engaged with an organisation, private or otherwise, we do ensure that they meet the quality standards through self-audit and we do a range of random audits.

However, outside of it, in the service funding agreements, agencies—and it is really the aspiring agencies—have to make sure, when they are devolving any funds, that those agencies have a level of accreditation or quality assurance and we put the responsibility on them to ensure that. We do not have a mechanism—

**MS BRESNAN:** Does it get reported back to the department about what services they are using and making sure that those services that they are purchasing are meeting some—

**Ms Ford:** Sometimes no, because a person's package can be made up of three, four, sometimes five service providers, and sometimes the service providers can be delivering two hours of support or two hours in the morning twice a week. So, no, we do not, but we do know the range of agencies in the ACT and we do know the quality of care that they are providing.

**MS BRESNAN:** So, if they went outside the ACT, there would be no sort of process there?

**Ms Ford:** If they are outside the ACT, if it is through an ISP funding, we often do not know.

**Ms Burch:** Can I just add to that that ACTCOSS is funded to train raising the standard, which is a continuous improvement program across our funded services.

**THE CHAIR:** Thank you, minister.

**MS PORTER:** The Auditor-General's report, recommendation 13—and this is dealt with on page 9 of the government submission—raised the question around the process of conducting client satisfaction surveys in order to improve the response rate and hence the overall validity of the data. You deal with this, as I said, on page 9 of the submission. It seems to me, from looking at that, and also from the government's response to the Auditor-General, that the overall satisfaction rate, as reported, is fairly high. I was just wondering if you want to make a comment. You just say, in your response to the Auditor-General, minister, that it is noted, and I wondered if you wanted to make some remarks about why you think the Auditor-General may have made that statement, or that recommendation, in light of what I would have thought

was a high satisfaction rate.

**Ms Overton-Clarke:** The Auditor-General was really highlighting the response rate and requesting that Disability ACT make more of an effort, I guess, to get a greater proportion of service users to respond to the survey. As we noted in the submission, the response rate has increased to 57 per cent, as compared to the 2007 survey of 26 per cent. So we are very pleased with the result of the survey. Obviously, with an increase of users you tend to get a slight reduction in satisfaction, but I think the Auditor-General was, in particular, highlighting the need for an increase in the response rate, and we have achieved that.

**MS PORTER:** Thank you.

**THE CHAIR:** Minister, the Auditor-General's report No 3 of 2009 *Management of respite care services* declares repeatedly on pages 7, 46 and 56 that there was no report of any incident causing death or severe disability or a level 8 outcome. Two years ago a person from the ACT died in an ACT hospital after an incident in a respite service funded by the ACT government. Can you give us any further information on that?

**Ms Burch:** As you know, and I know you have asked this of other witnesses, there is a coronial inquiry into this, so I really cannot discuss the details.

**THE CHAIR:** I do not believe there is a coronial inquiry into this at the moment. What I am asking you is—

**Ms Burch:** There is.

**THE CHAIR:** There is a coronial inquiry underway?

**Ms Ford:** I do not know if it is a coronial, but there is an inquiry underway.

**Ms Burch:** Sorry, I stand corrected—an inquiry underway. Is that right?

**Ms Ford:** Yes, most definitely.

**THE CHAIR:** By whom?

**Ms Ford:** New South Wales.

**THE CHAIR:** The New South Wales government?

**Ms Ford:** New South Wales justice department.

**Ms Overton-Clarke:** Are you talking about the Queanbeyan facility?

**Ms Ford:** Yes.

**Ms Overton-Clarke:** Yes, that is right. There is an inquiry.

**Ms Ford:** There is an inquiry underway.

**THE CHAIR:** Okay. We have received representations from the family of the individual who are not aware of what is happening. That is simply what we are trying to find out.

**Ms Ford:** Sorry?

**THE CHAIR:** Can you elaborate on whether there is a coronial? You do not have to answer right now. I do understand the confidentiality of it.

**Ms Ford:** There is an inquiry underway and during the inquiry, obviously, we cannot comment on the inquiry—

**THE CHAIR:** I am not asking you to comment on it.

**Ms Ford:** or any of the conditions around it, so—

**Ms Burch:** So you are wanting clarification—

**THE CHAIR:** I am simply asking for clarification whether—

**Ms Burch:** of the status of an inquiry into that incident?

**THE CHAIR:** Correct.

**Ms Burch:** We can provide that.

**THE CHAIR:** Thank you very much for joining us here this morning. The transcript of this will be provided to you in due course.

**Ms Burch:** Sorry. I might need to make some clarification on funding. Earlier, I might have said we had increased our funding to around \$67 million, Disability ACT. It was actually \$63.7 million. I would like to make that correction.

**THE CHAIR:** Thank you.

**McGRATH, MS DEE**, Chief Executive Officer, Carers ACT  
**GEARY, MS LESLEA**, Respite Assistant, Carers ACT

**THE CHAIR:** Welcome to this hearing of the Standing Committee on Health, Community and Social Services inquiry into respite care services. Would you like to make an opening statement?

**Ms McGrath:** Yes. Carers ACT supports around 5,000 caring families across the ACT, including many of those who have children and adult dependants with disabilities. We have made a submission to the inquiry. I hope it has been received. We tell the story basically of the carers. We are here representing carers, as we are constitutionally mandated to do.

**THE CHAIR:** Thank you, and thank you for the submission that you have placed before us. You raise a number of concerns. You say that the care you are able to provide is subject to the funding that you get, and when there are funding cuts that obviously has quite an impact on not only your organisation in terms of the service you are providing but also service recipients. Can you elaborate on some of the major issues with regard to cuts in funding that you have experienced?

**Ms McGrath:** I am not sure about cuts, necessarily. I just think the problem seems to be, having listened to many, many, families, that, No 1, it is difficult to find services and, No 2, there seems to be a little bit of squabbling about the size of the slice when the real problem is that the pie is probably not big enough to start with.

The other point that is quite important to understand, particularly in the context of disability, is that the purpose of respite is to help families by giving them time out from their caring role to pursue other things to ensure their own wellbeing. However, I think respite has taken on a whole different meaning in our sector. Respite is now trying to be used by families to enable them to earn a living and get to work. That really is not the intent of respite.

Families with particularly high needs and complex disabilities require more than respite. Since deinstitutionalisation in this country, that ongoing support just is not there. It is very hard to find it. It is not there anymore. Families tell me that, and what is frustrating them is the lack of transparency about what is available. There seems to be a tension around trying to understand what the processes are in accessing sustainable support—in other words, individual support packages. I introduce Leslea, who is a carer of two children with disabilities.

**Ms Geary:** Three.

**Ms McGrath:** Three children with disabilities. Leslea is also a part-time worker in our disability respite cottage in Fraser House.

**Ms Geary:** That is right.

**THE CHAIR:** Ms Geary, thank you for joining us.

**Ms Geary:** I apologise for being late.

**THE CHAIR:** That is not a problem. I am not sure if you have ever appeared before a committee before.

**Ms Geary:** No, it is the first time.

**THE CHAIR:** I would just like to make you aware of the privilege statement that is before you—if you would care to have a read of it. Essentially, the committee has authorised the recording, broadcasting and rebroadcasting of the proceedings and all witnesses making submissions or giving evidence to the Assembly are protected parliamentary privilege. I just wanted you to be aware of that.

**Ms Geary:** Thank you.

**THE CHAIR:** “Parliamentary privilege” obviously means the special rights and immunities which belong to the Assembly, its committees and its members. These rights and immunities enable committees to operate effectively, and enable those involved in committee processes to do so without obstruction, or fear of prosecution. Witnesses must tell the truth, and giving false or misleading evidence will be treated as a serious matter.

While the committee prefers to hear all evidence in public, it may take evidence in-camera if requested. Confidential evidence will be recorded and kept securely. It is within the power of the committee at a later date to publish or present all or part of the evidence to the Assembly. Any decision to publish or present in-camera evidence will not be taken without consulting the person who gave the evidence. Are you comfortable with that?

**Ms Geary:** Yes.

**THE CHAIR:** Thank you very much. Welcome to the inquiry.

**Ms Geary:** Thank you.

**THE CHAIR:** Back to you, Ms McGrath.

**Ms McGrath:** As I was saying, respite programs, while they may have a particular purpose, are often used to prop up families who do not have that sustainable support available to them. I think that is part of the problem that we have today. In essence, it is difficult to get enough ISPs to cover them and people fall through the gaps. Services often do not have the resources to support those with high complex needs.

We have a family at the moment where there is a boy who is now 16. The mother cannot lift him anymore. Physically, with her back, she just has not got the capacity. She has her own significant health problems. We have been trying to find sustainable support. We worked out that there are about eight different service providers trying to prop up the system and it is just not working. She has had to learn to become an advocate to try and work her way around it, but there is no central coordination. That is the frustration for these families. For those with complex care needs, it is really hard. Every day is a very difficult day. Many carers tell us that that is where the

problems lie.

**THE CHAIR:** Thank you. Ms Bresnan.

**MS BRESNAN:** My question is about the complexity and the way people have to access services. It is a question I asked both the health minister and the disability minister. Disability ACT say that they are working on a no wrong door policy. The issue that came up in the forum was about having a central point of access. They said that they did not think that was the best way to go—that the best way to go was to have a no wrong door policy and organisations would be recognised and as part of that policy they would have a wide range of information to give people. I am just wondering what your thoughts are on that, as opposed to having a central access point.

It was interesting to hear something which Ms Gehrig said about home and community care. I may have misinterpreted it, but she said that carers have almost come to be seen as the point of access for some people to go to, rather than being officially recognised as that point of access. I am just wondering if you have a comment on that as well, and if you find that?

**Ms McGrath:** I might digest that one.

**MS BRESNAN:** Yes.

**Ms McGrath:** In general response, yes. We are finding when families come to us that they are trying to get help with what I call navigating the system and understanding the system. I hosted a forum with about 30 families recently. They do not understand the system. Frankly, I find it hard to understand what the system is and what is available. There are so many little pockets everywhere. It is really hard to pull all that together and find it. It is also difficult to find whether there is any capacity to refer people and families. Really, there is just not enough there. I think that is part of the problem. The system, as I see it, with all the little buckets of funding and different organisations, is complex. It is a very complex thing to try and navigate.

**MS BRESNAN:** What are your thoughts on having that policy which the ACT seem to be pursuing—the no wrong door policy—as opposed to the idea of having a central point to go to? The feedback which came through the forum was that the central point seemed to be the favoured model. I am just wondering what you think about that no wrong door idea.

**Ms McGrath:** Whatever model we come up with it is really important for the ACT to recognise two things: No 1, it has to be an easy model to understand and access; No 2, we have to understand that this is still a relatively small population base. The wrong door model has been very effective in other states, particularly in Victoria, for example, where there is a wider geographical spread. But in the ACT a central access point is probably a smarter way, at least to start a system, before we go to a wrong door model. That is just based on my personal experience.

**THE CHAIR:** Can I just ask a supplementary? This is a slightly left-field question. What sort of paperwork is required of a carer when they attend to someone they are caring for? What paperwork do they have to provide to the department about the job

that they have completed that day?

**Ms McGrath:** Again, the carers tell us frequently that every time they access a different service they have to go through what they call an intake and assessment process. Often they have to do a revised intake every few months. That is probably a bit of a nonsense, particularly as many disabilities are permanent and do not change.

**THE CHAIR:** Correct.

**Ms McGrath:** And status does not change. In fact, if anything, the care tends to get higher and more complex. Perhaps Leslea can add to that.

**Ms Geary:** No, I would agree with you. Do you mean the day-to-day things that we need to do?

**THE CHAIR:** Yes. Just give us an example of a day.

**Ms Geary:** As a professional carer or as a family carer?

**THE CHAIR:** As a professional carer, I should imagine, in this regard.

**Ms Geary:** As a professional carer, we certainly keep a checklist of activities, needs, medications—that happens routinely—but as a family carer, none at all.

**THE CHAIR:** I understand that, yes.

**Ms Geary:** But we frequently have to keep giving the date of birth for our children, where they were born, their gender—all those things that absolutely do not change at all.

**THE CHAIR:** I guess I am referring more to the record keeping aspects, so take it as professional carer. What sort of information do you have to provide to the department regarding the care that you have just given?

**Ms Geary:** I will hand you back to Dee.

**Ms McGrath:** When you are providing support, as we do as a service—to provide quality and professional services—there is a considerable amount of compliance work that is required. There are quality standards and national standards and a lot of processes, policies and procedures that must be in place to ensure good quality. We take quite a bit of time and resources to do that well in our organisation. For example, we see Fraser House, which is a disability facility, as one of the highest risks of our business because it is one of the few direct services we provide. We have brokered most of our services. We have a registered nurse, for example, who oversees all our policies and procedures. It is very thorough, very time consuming and costly, but that is the balance we have to make to ensure we are doing things consistently well and to national standards.

**MS PORTER:** In your introductory remarks, Ms McGrath, you commented on people squabbling. I was not quite sure what you meant by that. Do you mean that

service providers are squabbling with one another? I was not sure what you meant by “squabbling”. My substantive question is this: we have heard from a number of organisations, as reflected in Ms Bresnan’s question, about the complexity of the services that are available and how to navigate the system. We have also heard that organisations meet together and discuss how they can support one another and how they can share information. What is your perception of how that goes? If the minister does not seem to think the idea of a centralised point of access is necessarily something that they are looking at at the moment, but more the no wrong door policy, what is your assessment of the organisation’s willingness perhaps to do the initial assessment so people do not have to go through another assessment when they go to the next organisation?

**Ms McGrath:** There are four questions there, I think. Just to clarify my point. I think a lot of families are trying to get some support. So I am saying that they are kind of frustrated that their application for an ISP, for example, is not successful and they are wanting some support. So my point is that it is not about trying to fight for the little bit that is there; the bigger problem is actually the size of the pie. That was just a metaphorical; there is no particular squabbling.

In terms of collaboration amongst the community sector, I think that is at a stage where it is beginning to mature and become a bit more sophisticated—the level of collaboration. But there is still some way to go there. There have been some examples of good collaboration that I have witnessed in my five years in this sector. But certainly a common denominator with all of the service providers is getting the right outcome for clients and people. So I think we are on the right track but there is more to be done.

In terms of no wrong doors, a central access point and which model might be best, I think it is important to understand that, for a no wrong door model to work, you need a lot of education and you need time for that education to work. You also need to have a sector that is a bit more sophisticated in its collaboration.

**MS PORTER:** The other one is about the organisations being an assessment point. You were saying that a person goes to one organisation and they are assessed, and they go to another organisation and then they are assessed again. How can we best tackle that issue?

**Ms McGrath:** A lot of organisations are concerned about breaching the privacy legislation. I really think there needs to be a sensible approach, without breaching legislation. There must be a better way for families to be able to tell their stories less and to be sent to a number of organisations. I think there could be a better system with a centralised coordination point.

There does not seem to be a lot of support in funding rounds for case management. Some families probably need that to help get them get around the system and get the services in place. It takes a lot of work and a lot of energy and people need to physically go in to some organisations to get a response and find out how things actually work. Leslea has three children; how do they do all of that? That may be something that needs to be looked at in terms of that model.

**Ms Geary:** I think a case worker would be wonderful—somebody who knows the family, knows the situation and can put us in touch with what is out there. That is my biggest frustration, just finding what to do next.

**Ms McGrath:** I would like to make a remark about home and community care. Carers ACT is funded by the Department of Health and Ageing, the commonwealth, and the focus of Carelink is ageing and some disability, but because of the different jurisdictions, it is often more difficult to get a clearer picture about what is funded in the ACT and where to go. We work very effectively with Disability ACT, and I have frequently brought particular cases to them to assist in getting through processes and systems more easily, but it is only a limited piece of funding.

**THE CHAIR:** The ACT government uses an instant reporting tool called Riskman. Are any incidents that occur reported? How do you report these to the ACT government?

**Ms McGrath:** The contract we have with Disability ACT is pretty limited in what it is actually asking for. We have to prove in an audit—not an independent audit but just an audit—what our policies and procedures actually are. We provide all those to them, although we are not necessarily asked for them, but we do those. We also do an annual risk management plan and a six-monthly register update and review. So we consistently do that ourselves and we would provide that to them.

**THE CHAIR:** That is the plan itself.

**Ms McGrath:** Yes.

**THE CHAIR:** You do the planning for it?

**Ms McGrath:** We do that, yes.

**THE CHAIR:** If an incident occurs with one of your carers on site, what is the procedure for documenting and passing that on to whoever?

**Ms McGrath:** We absolutely do. We have to report that up.

**Ms Geary:** Absolutely. Anything that happens that may cause damage or has caused damage, or has a potential to cause harm, we absolutely do document, and I pass it up to my house manager and it then goes on to the overall manager. Where it goes from there, I am not sure—the department. But, yes, absolutely, and we keep records of that.

**Ms McGrath:** We do not just keep a record; we also record how the risk can be mitigated in the future as well.

**Ms Geary:** That is right, what has happened, what steps have been taken and what will follow from that.

**THE CHAIR:** What I am asking is: when you get that report from one of your carers, who do you then pass that on to and in what form? Is it a written report, is it a computer entry that you have to make, or how do you do it?

**Ms McGrath:** We have all of that in a system at the moment. We have just invested in a new business system where we will now be doing all of that electronically and will be able to roll out reports electronically. So we are trying to reduce the risk of manual recordings. But we are not asked and we are not required in our contract to provide that, although we are required to provide feedback. But we take the risk of these cottages that we run quite seriously and we have our own risk management plan—as I say, ISO standard.

**THE CHAIR:** I will give some background on why I am asking these questions. There is an Auditor-General's report that outlines certain concerns which the department is addressing and we have got the fact that they are addressing it. What we are trying to understand—Ms Porter asked the question this morning on this—is how the detail is then transferred into the Riskman system. What you are telling us is that you provide written information on an incident or whatever has taken place; that then goes to the department. Obviously from there, you are not aware of what happens?

**Ms McGrath:** No, incidents do not necessarily go—day-to-day incidents are not required to go to the department. They are managed and mitigated internally through an ISO accredited system. That is what I am saying. So there is no requirement in our contract to actually provide daily incident reports or any incident report. If there is something that we see as a risk, a significant risk, we certainly would include that. We would offer to include that and we would put it in our report as our own decision. That is part of our plan of management.

**MS BRESNAN:** I have a question around the flexible family support program. I know you are one of the organisations that is funded for that.

**Ms McGrath:** Yes.

**MS BRESNAN:** I asked this question of Health. Obviously, it is a very flexible program, as it is named, and it is more about fitting the program around the carers rather than fitting the carer into the program. Do you think that the guidelines that it uses or even the principle would be applicable to other respite programs? Do you think it would successfully translate to other programs? It is about providing more flexibility to families and to carers and about that principle of actually fitting the program around the carer and not the opposite.

**Ms McGrath:** It is interesting that you should raise this. With an organisation such as ours, we have about 26 different programs sourced from all sorts of different commonwealth and ACT portfolios. Even within DoHA, which is 50 or 60 per cent, they are all different little buckets of money that have to be reported on separately. It is very easy, because of their compliance requirement, to think of programs in silos. We changed it so that it does not matter where a person comes in; we look at their holistic need and worry about which bucket to put it in afterwards. Other organisations tend not to do that. So we have identified this. Carers have said, "Don't put us in the boxes, look at our holistic needs." So we are trying to work that model and find the bucket and put it in. It is a philosophy, I think, that underpins the change that we feel we need to make. But you can understand why organisations would work in program silos.

**MS BRESNAN:** Yes. It is more of a philosophy. But because of the way the funding system is set up, like you said, there is all sorts of funding coming from different departments and different jurisdictions. People then operate within those boundaries. So how can we actually make this better suit carers in terms of what they can actually access? They are not wanting to become a purchaser-provider type model but how can we actually make this work better?

**Ms McGrath:** I have to say in the ACT, if we are talking disability-specific, the relationship we have developed with Disability ACT is such that they are far more flexible around guidelines. It is really around meeting need. I think that is fantastic. I wish some of the other funders were the same. But that is what actually needs to happen. We have been able to sit down and renegotiate, even to the extent of age groups, target groups, and be able to include people where their needs are actually greater. So that flexibility has been tremendous.

**THE CHAIR:** Ms Porter, you have the honour of asking the last question.

**MS PORTER:** I thought we had run out of time. I would like to ask you a question that I have been asking of everybody, so you might take this on notice. Is it your experience that, with volunteers that are available to support organisations, long-term volunteers that are available all the time, rather than spasmodic or episodic volunteers, are those numbers harder to recruit now or are organisations finding that they get enough support in that regard? I am not asking you to answer that now. You could probably take that on notice and get back to me on that. There are a number of organisations, not necessarily providing respite but supporting the individuals to get to respite on a number of occasions.

**Ms McGrath:** I will get back to you on that. It is very important for government to understand that volunteers and access to volunteers is not the answer to shortage of services.

**MS PORTER:** However, a number of organisations do rely very much on volunteers.

**Ms McGrath:** As we do for certain parts of our business.

**MS PORTER:** I understand, also, that carers are not volunteers, very clearly; I understand that. But there are a number of organisations involved in, particularly, transport, getting people to and from places. A number of clients rely on that or carers rely on that. So it would be good to be able to hear from you on that particular subject.

**THE CHAIR:** Ms McGrath, Ms Geary, thank you very much for giving evidence today and thank you for your submission as well. It is much appreciated.

**The committee adjourned at 12.05 pm.**