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, 8 SEPTEMBER 2010

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

By authority of the Legislative Assembly for the Australian Capital Territory

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WITNESSES

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Amended 21 January 2009

The committee met at 12.07 pm.

PHILLIPS, MS ANITA, ACT Public Advocate, Public Advocate of the ACT, Department of Justice and Community Safety
MACKEY, Ms PATRICIA, Principal Advocate, Public Advocate of the ACT Department of Justice and Community Safety

THE CHAIR: Welcome to the sixth public hearing of the Standing Committee on Health, Community and Social Services inquiry into respite care services in the ACT. I presume you have been to inquiries before.

Ms Phillips: Not all of my staff have.

THE CHAIR: Would you read the privilege card so that you are comfortable with the information in it? Are you comfortable with that information? Are you aware of the privilege implications?

Ms Phillips: Yes.

THE CHAIR: Thank you very much for your submission. I ask you to address your submission. You can make an opening statement if you like. The floor is yours if you would like to make an opening statement regarding your submission.

Ms Phillips: I suppose, in our opening statement, I should say that the issues which have been raised in this inquiry into respite services relate to all of disability services, including mental health, and, to a large extent, services that are delivered as respite services for elderly people. As such, they cover a range of services. Some are supportive in training carers or supporting carers in other ways and providing daily respite, for example. There are both residential, overnight care, and non-residential services.

I think we, in our role, are focusing more on the residential, overnight, respite that is available predominantly for people who are carers of people with disabilities. Having said that, it does not mean that we do not have a vast amount of experience and contact with the whole range of respite services, particularly in my role as public guardian.

As public guardian, I am what is called guardian of last resort. I am guardian for people who do not have the capacity to make their own decisions and who have absolutely nobody available or willing to take on that role and make decisions for them. They can be elderly women who have dementia or they can be young men who have a significant brain injury following a motor bike accident. From all of our experiences as guardian, I am aware of the needs of a large range of people with disabilities, predominantly with intellectual disabilities, who require some sort of respite either during the day or, as I said, if they are living with family or with other people, certainly at night.

Our role also covers that of advocacy. Our main focus in coming to you today is to tell you that we have that experience because of our public guardian role and to explain that, as advocates, our role is very much to ensure that services provided to the people of the ACT are improved, that they are of a quality that we would recommend, that they meet standards and that they are able to address the demand out there.

In focusing specifically on respite that is provided in a residential context to people with disabilities, we are particularly concerned about the lack of services, the lack of supply of these services and, to some extent, the paucity of accountability, regulation and monitoring of those services. There are not enough. And we can tell you at length about our experiences of working with families who just cannot find any significant residential care that is available to them and who do make comments to us like "I wouldn't let them go there anyway".

In my assessment, it is no fault of the providing agency. It is the desperate demand. It is the enormous pressure that is put on staff in these facilities and the difficulties of agencies in providing the staff and being able to get people who will in fact work the hours, work under the conditions and provide the services that are needed. There are a lot of reasons why the services are not up to scratch. We are, as I said, primarily concerned with an increase in the services and an improvement in the quality of the services that do exist.

One of the strategies, I suppose, that we think could improve some of the access issues would be if there were some central controlling agency. There is for aged care, through the Carers Respite Centre, who organise respite for aged people and who keep an eye on what places are available in residential care. They will know if, for example, Jindalee has a vacancy for a week or another service does. This does not apply in the disability area: there is nothing comparable with disability services. So it is up to already stressed and stretched parents to go through the list of agencies that might have a facility and a vacancy and then to try to adjust their families and their needs to meet that. They might be in a crisis situation where they desperately need some sort of respite here and now, or they might ring an agency that they trust and want to use and find that they can go at the end of November for a weekend, and their whole life then has to be geared around that. But it is a matter of ringing all the agencies.

We would like to see some kind of gate-keeping role being taken on, probably by Disability ACT, but it could ostensibly be an extension of the service provided by Carers ACT, if they were funded to do this. So parents then would just need to ring one agency and they would have one port of call to find out where there might be a vacancy for some respite. Because, as it is, these facilities are run by non-government agencies who each often have their own assessment processes, so that, while a young person, for example, is able to go to one place, they might be assessed, because of their challenging behaviour, as unsuitable for another facility. And the parents have to go through this process all the time.

So that is one of the things we think could assist parents in accessing services. As we have already remarked, there are not enough services anyway, but that would make it a little better for them to access it. But the other thing that we desperately need is better monitoring, accountability and regulation of the services that are provided. One of the recommendations that we have made in this regard is that we have a disability official visitor.

We already have official visitors who monitor the services provided in residential care in mental health. The official visitors visit the psychiatric services unit and the facilities at Calvary, as well as Brian Hennessy. We already have an official visitor who visits the AMC and who speaks with the prisoners at AMC. We also have official visitors for children's facilities, so they are able to visit. We see the role of a disability official visitor, who would be able to visit all residential care—government and non-government—and pick up issues, as being a service that would provide much more transparency and openness to the services provided.

Just as a final comment in relation to official visitors, official visitors exist in nearly every other jurisdiction in Australia and nearly all of those official visitors are engaged or are placed within a monitoring agency or an oversighting agency. Sometimes, it is the public guardian or public advocate, and sometimes it is other agencies, but it is always in an oversighting agency. We would recommend that that be the case with the disability official visitor, but I have to say, on the public record, that we have been recommending for some time that that be the case for all official visitors.

Official visitors in the ACT are engaged by the agency that they are monitoring. So the official visitors for mental health are engaged by mental health and for children they are engaged by the office of children et cetera. We believe—it was a recommendation of the FEMAG review, many, many years ago—that the official visitors all be co-located within an oversighting agency. In that case, it was recommended that it be the public advocate, and I think that is the most appropriate place for official visitors to be—and a disability official visitor should be included. Thank you.

THE CHAIR: Thank you very much. A number of the things you mentioned have become quite apparent to us over the last number of hearings that we have had. I would ask for a little more response from you on one aspect of it. I note in your report you say that it is concerning to your public advocacy that respite care services in the territory only met clients' basic needs of safety in respite care and that accountability structures were not adequate for record management, fund information systems, risk management and quality performance management. Would you include the actual certification of carers under that qualification?

Ms Phillips: Yes. We have been concerned about the carers who are engaged by the agencies. It is a very difficult field. It is very hard to get the right people to be able to deliver these services. Often people take what they can get. That is not good enough. We would not accept that quality of service for our children in day care, for aged people in residential care. They have to be qualified. We really do need to be much more rigorous about the people that are employed and that it is not just a casual job for somebody who is out of work or for students. Often students are very good at providing this care but we need a much better, more rigorous, process for engaging and training them.

THE CHAIR: Some of the information we have received leads us to believe that there are no minimum standards such as holding a first aid certificate or whatever. So we are concerned. Are you able to enunciate these concerns, which you have raised, to any other organisation that you deal with, say, the disability complaints commissioner, regarding the lack of services in some areas? Is this something that is available to you and other people?

Ms Phillips: My role as public advocate is somewhat parallel to that of the Human Rights Commission. I have direct access to both the minister and the chief executive of the department that Disability ACT falls under. My way of addressing the issues that come under Disability ACT is to direct them to the chief executive. I had a meeting with him last week. There were disability issues, including lack of respite, on that agenda. That is the way that mostly we pursue our advocacy role, being seen as an oversight agency.

The clientele that we deal with are all, by definition, lacking capacity. We have a unique group of people for whom we are advocating. That is why I have the independence to be able to advocate directly.

From speaking with the chief executive, albeit that Disability ACT does fund the non-government agencies, we find that, the further away we are getting from government regulation, control and standards, that is where the problems often arise. We really do have less control, less ability, to be able to deal with struggling non-government agencies. For example, there is one very good agency—and I will not name it; I am not being critical—that parents I know go to to seek services. It cannot do the service at the moment because it has a lack of staff.

Disability ACT are not able to do anything about that. They fund that agency. They have set in place standards for facilities. The fact that they cannot get qualified or any kind of staff is their issue. The problem is that, the further away it gets from government, the more difficult it is to rein it in without any kind of accountability and structure in place.

THE CHAIR: I will pass on to my colleagues in a moment, but I have a final question for now. You say that you met with the head of Disability?

Ms Phillips: I met with the head of Disability, but I meet directly with the chief executive, the head of DHCS—Disability, Housing and Community Services. I am referring to the head of the whole department. I met with him, yes.

THE CHAIR: Was that the first meeting regarding this or have you raised this issue before with the department?

Ms Phillips: No. I meet with Mr Hehir and have met with his predecessor, Ms Lambert, for many, many years. Disability Services is always on my agenda, unfortunately. Sometimes it is different aspects of it that become known to me from the work that my staff do in dealing either directly with clients through our management assessment panel—that process—or that we find out about through guardianship.

It can be things like unacceptable behaviour that are allowed to go unmonitored or unreported in a facility. It might not be more than the teasing of a particular resident. But for that individual, this is his home; this is where he lives. To have to come home there every day, as is the case, and to be relentlessly the butt of jokes is not the kind of service that we want to be delivering. Every time I meet with the department, there are issues that come up under the Disability Services category. My staff also meet with the head of Disability ACT, Ms Ford, on a regular basis.

MS BRESNAN: I want to ask about the official visitor and how it will possibly work in the ACT. I apologise if this is laid out more in your submission. Would you see it working as having a specific disability official visitor, given that we have those other official visitors already in the ACT? Or would you see it working more along the lines of some of the other state-based ones where they have a community visitors program—whether they be volunteers or acting in some other way—in various facilities? How do you see it working best in the ACT? I guess that depends too on the legislative means through which it would have to be implemented in the ACT.

Ms Phillips: Yes. Initially, we would be very keen and very happy to have a disability official visitor. As you are perhaps aware, the other official visitors are very limited in terms of the times they are engaged. They are only several hours a week. Other jurisdictions have expanded the whole official visitor monitoring program to include community visitors at every level, particularly in the children’s area which is very important. They are able to monitor children in out-of-home care in a much more comprehensive manner than what happens at the moment. Our official visitors—for example, with children—only visit the residential, as do the mental health visitors and as do the others. They actually only visit where there is a facility.

In other jurisdictions where they have a whole army of official visitors they are able to go into out-of-home care, into foster care. They are able to then monitor other kinds of facilities that are delivering services. As I keep saying, they are able to go to people who do not have the ability to take their issue to, for example, the Human Rights Commission. They do not have the mental and intellectual capacity to be able to access their rights like other people in the community.

That is why we need to be there to advocate for them. For example, someone in the health system who is not happy with the service can go to the Health Services Commissioner. If it is one of our clients or a person with a lack of capacity, they are not going to do that because they do not know that they have the right or do not even sometimes appreciate that they are not being treated the way they should be. We need to be in there advocating. That is why we are very keen to have as many people out there as possible.

Ms Mackey has done some research into the role of official visitors in other jurisdictions. She has also been coordinating on my behalf meetings of the official visitors. She might like to add something to this.

Ms Mackey: You were talking about community visitors as opposed to official visitors. Community visitors, from my understanding, operate in the aged care sector as volunteers who go out and befriend, and there is a structure to supervise that where they are trained volunteers. The model that we have put forward here is of the official visitor scheme, which is about an oversight role that looks at standards, that looks at ensuring rights are upheld, that gives consumers and clients a voice in the process. So it is a different model of service.

MS BRESNAN: Do you think establishing the role of the disability official visitor can be encompassed within existing legislation that we have in the ACT? I am presuming it would have to be established under legislation. Is there existing legislation that it could be established under?

Ms Phillips: On my reading of the Disability Services Act, it does not include the capacity and it would have to be added. All of the official visitors are legislated for under their portfolio acts, which is why they are then engaged by that agency. So, if they were to be changed administratively in accountability or co-location, it could perhaps be done at the same time to do it under the Public Advocate Act, for example, or under the Human Rights Act. If they were going to be co-located, the legislation for their engagement could come under those acts.

MS PORTER: I just had some questions around the way people actually get into the system and start to receive help. You made several comments about that in your submission. You talked about the fact that there needs to be an increase in knowledge by people about what is available. Also you talked about the needs of individuals being clarified through a comprehensive assessment. You also talked about expectations and the mismatch of expectations between the people who are actually asking for the help and the help that is on offer.

We are talking at the moment about a no-wrong-door approach, which is all that information being held, I guess, by every agency that a person can go to so they can be assessed at that point and given all the rest of that information at that point and then go out from there to be put in touch with relevant organisations and various other bodies.

Do you think that that approach would address some of the issues that you raise, or would you see a separate assessment body, using that common assessment tool that you talked about, as the way to go? What would you recommend?

Ms Phillips: I imagine that it is a new or a revised approach to coordination of services. Because most of the service delivery is done by not-for-profit and non-government agencies, it really has expanded and there is not that coordination. As I said, families do not know about different services that are available. For example, they might use one service and think that that is all there is, and when they ring them and they say, “No, we haven’t got any vacancy,” they do not know where else to go. So a coordinated approach is needed.

Part of the role of the coordinating, gatekeeping facility or service—as I said, I am not sure where it is going to be located—would be to do an assessment of the needs of that person who is coming into care. That would then be passed on to other agencies, to the agency where the person is going. So it would not be for the agency then to say, “This is the first time you’ve rung us. We don’t know if you’re suitable for us. You’re going to have to fill out this form. Also, you must adopt this letter, and you’ve got to do this as well.” Families must go through that every single time that they go to a new agency. So what often happens is that parents stick with a service that they may not be happy with because they just do not want to have to go through all of that again.

MS PORTER: Have you had the opportunity to discuss this approach either with the people in the department that you have been having your meetings with or with people in the agencies who have been receiving these people individually and behaving in that way? Have you had an opportunity to say to them, “Would this be a better way to go and how do you feel about that?”

Ms Phillips: The agencies, certainly, when we talk to them, in general, they are all for this approach. Part of the problem also is that some of the agencies are administered by out-of-town, large organisations, so they are the local branch here of an agency, or sometimes they are a very small and unique and different agency that just deals with a certain group of people. But, yes, in general, they are all for some better kind of coordination.

I have not discussed this at length with the department, because I am not yet really convinced where that coordination might lie. There would be some resistance from some parts of the community if it were located perhaps in disability services, if it were seen as a government agency. That is why I think, as I said, the aged care service runs so well, because it is run by Carers ACT, which is an agency that is outside the government, although it is funded by the federal government out of their aged care programs.

THE CHAIR: You mentioned in your opening statement the fact that your main problem is with government agencies and some private providers fall outside of your care or authority. In your conclusion, you are saying that findings from the Auditor-General indicate the need for more robust and comprehensive policy development, adherence to risk management processes, prudent communication with staff, better case management process hook lines and more robust management. You are saying that these recommendations may be relevant to this sector as a whole, which are all logical recommendations. But they would only relate to the areas that come under your control, so government agencies. Is there any way that something could be done to incorporate some of the private service providers to ensure that the care and the better case management of clients are universal throughout the ACT?

Ms Phillips: Just to clarify, because our clients access government and non-government services, we are involved with all of those agencies all of the time and visiting them and knowing about the quality of service that is provided there and placing residents with them. In just about every permanent facility in the ACT I would have somebody either for whom I am guardian or for whom I have been advocating strongly. So we have a very extensive knowledge of government and non-government.

In addressing the issues, I go to government because, primarily, they are the funders and, therefore, they set the standards in their tenders and in their engagement of these organisations. Just as in childcare, we need to, I think, be more rigorous in the licensing and the standards that these non-government agencies undertake. They are going to say that it is going to cost them, and that is just the hard fact of reality. The facilities physically have to meet licence standards in terms of fire and health and safety regulations. We should also be quite confident that the service delivered by the carers is also of a very high standard.

THE CHAIR: Can you give us an indication of the number of clients that you act for in a typical year?

Ms Phillips: As public guardian, as I said, I have nearly 200 clients. So they are people for whom I have to make sometimes daily decisions on their behalf. They are the people for whom I am negotiating with agencies. They could be people for whom I am litigation guardian, so I am in court cases with them. Two of my staff are in court today; I was at the tribunal yesterday. So we have a lot of those kinds of interactions with our staff.

But in terms of advocacy, where we see even a one-off situation where someone rings us and says, “I’m not happy with this service; I’m not happy with the service my son is being delivered,” that runs into thousands.

Ms Mackey: We are just doing our numbers now for our annual report. We have had in excess of 1,200 people brought to attention just for the Public Advocate side of the business. We have provided an advocacy response for in excess of probably 50 to 60 per cent of that client number. In the children and young people area it was 75 per cent. So we do have a number of issues that come to us across the whole spectrum involving children and young people through to people with a disability who do not have anyone to speak for them.

THE CHAIR: We have heard from other people in similar sorts of capacities—not the same as yours—who felt that there is not enough information available to people in the community that your services do exist. Do you feel that your services are adequately marketed, if you like, to the disability community?

Ms Phillips: Perhaps not. I would not like to say that we do not try to promote the service but one of the issues in the community that reflects the lack of understanding, particularly of families, is that very few families who have cared for a young person with a severe intellectual disability all their lives—when they turn 18, a minority actually go through the process of becoming legal guardian.

The reason for that is that they will tell you, “I have cared for this person all his life. Why should I go and get a piece of paper and go to the court and become their guardian? I am his mother.” The reality is that out there in the real world that is no protection for that young person with an intellectual disability who can be extremely vulnerable in the community.

Even in that area, we do community education. We did many sessions of community education to over 1,000 people in the last year. We always encourage people to either take out enduring powers of attorney when people are still competent or if they have the care of somebody. Even for their elderly mother for whom they are carer, we say that they should go and get a guardianship protection.

We are yet another step along the way. I think I have to agree with you that people in general are overwhelmed often with the 24/7 care of people with disabilities, whether they are their children, their partner or their elderly relatives. They really do not know about all of the services that are out there.

MS BRESNAN: I want to follow up on what Mr Doszpot was saying earlier in his question about the level of standards, about there being no minimum standards, about compliance and all those issues. In terms of how that would be addressed, obviously there are the national disability service standards. In terms of looking at what more can be done—the qualifications and those issues—do you think it could possibly be dealt with with contracts that are between services and departments? Is it something that requires something stronger, whether it is a code of practice for the industry as such? That is not the right word. Perhaps it could be a code of practice that is mandatory within the respite sector or within those organisations. Would either of those means be adequate? Would legislation possibly be required? That is more of the stick approach. Could it be dealt with in those other better ways?

Ms Phillips: Certainly, I agree very much that to have a mandatory code of practice is something that nationally the disability services are keen to instigate. But it is hard to implement and to monitor. If you do have something that is mandatory or is legislated, then you do have a very substantial stick approach. We are always hearing about backyard operators almost that families use because of their desperation. I do not know how we wipe them out.

I am not being overcritical of the very hardworking and very good services that exist. I am just really trying to bring it to government's attention that they need more support, that parents and families in general out there need more options and more choice so that the services are improved even further and increased in number. Those services generally speaking do not need severe stick. But they, I am sure, would be happy to adhere to standards that were more rigorous than they are now.

MS BRESNAN: I was going to ask another question, but it has escaped my mind. Sorry, it might come back to my memory. Thank you.

CHAIR: Ms Porter.

MS PORTER: Thank you, chair. You talk on page 3 about the lack of early intervention supports, and you also mention on page 2 the reluctance of some families to accept or maybe even contemplate respite care, because it is seen as a way of saying, perhaps, "I am not coping." I know, in my own father's case, when my mother was suffering from confusion and a form of dementia, I think, he would not sing out for help, because he had always been the person who had been able to cope. So, given those two things, the lack of what you say are early intervention supports and the fact that people possibly will not sing out for help until a crisis actually occurs, or when someone else steps in perhaps, have you any suggestions?

Ms Phillips: I suppose, in having a whole of government, more holistic approach, it is possible then—for example, in the case you gave of an elderly partner—for people to be slowly introduced to the supports that are available, at an earlier time. This thing, as I said, goes for young people or for anybody. So that the first time somebody goes to the doctor and is given a diagnosis and is then given some treatment possibilities, the treating doctor at that time can also inform them of the kinds of support services that are available.

Sometimes it is just about, if, say, somebody is diagnosed with Alzheimer's disease, giving them contact with Alzheimers Australia. That might involve a telephone call—

and then they might say, “Oh yes, we have all of these services, we can do this, we have support groups, we have other things.” Often the response is, “I don’t need all of that,” but sometimes they put that at the back of their mind and when things get really hard they know where to go back to.

So it is giving people the service contacts and the information about support at a really early stage, so that they can access it then. If people access it then, we have found, for example, with families with people with challenging behaviours, they do not get to the desperate stage that we know families can get to, because they have been encouraged to use the facilities earlier.

But, for those who do not, at least we can intervene at an earlier stage by giving them the information. And then all of the people who are providing the services are all singing from the same sheet, in terms of telling people that, if they are not coping, the services are there and they are there for their help. So, wherever the person goes, they get the same message, and that is not seen as a failure but just part of the process: “We are giving you medication for your partner and we are giving you services that are there.”

MS PORTER: You talk about the language—that you believe that possibly we should be changing the language and talking about short breaks. You say overseas they are looking at this. Have you any information about how that is being received overseas and whether people are starting to change their language or—

Ms Phillips: Certainly, in terms of government and agencies, the language is changing. Whether, in fact, users are changing or whether they still see it as respite, that is just a matter of time. But I think you are right in pointing that out. That is consistent with this approach that all of the services are there, so why don’t you just take a short break, instead of having to put the person into a facility because you are not coping. So it is a more positively oriented way of saying, “We are all working in this, it is going to be a long road, it is going to be difficult, this is what we need to do now instead of waiting until there is a crisis.”

THE CHAIR: Ms Phillips, time is running away from us, but I have just a couple more questions. You mentioned, I think, that there is no official visitors scheme for disability and aged care services in the ACT and legislation would be required to bring that in. Has there been any previous request to the government to rectify this situation? I am just trying to get a time line as to whether this has been on the backburner for a number of years or whether there is a sudden emergence of this issue now.

Ms Phillips: No. As far as I am aware it is just something that has been discussed. I certainly have pursued it for the five years I have been in the position. It is something that we need and should have, so I cannot say categorically that I have put in a report that has not been positively responded to by government. I am optimistic enough—

THE CHAIR: But it is fair to say that it has not been positively responded to, because nothing has happened?

Ms Phillips: I cannot say that it has been knocked back by government at all, no. And

I really do feel quite optimistic about us maybe in this venue being able to really have this achieved. I cannot say that I have ever had a negative response to it, no.

And can I just clarify. The commonwealth have very sophisticated monitoring services for aged care facilities, so that is quite a separate service that is delivered by the commonwealth. It visits and monitors and audits services that are available to people in aged care facilities that are funded by the commonwealth, as opposed to our facilities within the ACT government.

THE CHAIR: Thank you. We will certainly be highlighting these issues as well. Hopefully, with our recommendations to the government, maybe we can see some action coming soon.

Ms Phillips: Wonderful. That would be great.

THE CHAIR: Just a side question: are ACT children's visitors able to visit children's respite services?

Ms Phillips: When you are talking about respite services, there are some respite services for young people but, generally speaking, if we are talking about respite services that are for children with a disability then they come under the disability services and so the children's official visitors would not be visiting services that are predominantly for people with a disability, albeit for children with a disability. So the children's official visitors visit Marlow and other refuges and similar facilities such as that for young people, where there may be some young people taking a short break.

THE CHAIR: Thank you for that. Ms Bresnan, have you remembered your question?

MS BRESNAN: No, it is okay, because we are out of time. I did remember it, but we are out of time, so that is fine.

THE CHAIR: Okay. We would like to thank all three of you for coming and presenting your submission and thank you for the great work that is being carried out by your organisation and for coming here this afternoon.

Incidentally, a complete transcript of what has been said here will be provided to you and, if anything else occurs to you as a result of further thought that may come along on any of the issues we have discussed, we are very happy to receive further information from you. We are concluding the inquiry in the next couple of weeks so, if you do have any further suggestions, could we get them sooner rather than later.

Ms Phillips: Thank you very much.

The committee adjourned at 1 pm.