COMMONWEALTH OF AUSTRALIA

Official Committee Hansard

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Reference: Aged Care

THURSDAY, 28 APRIL 2005

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BY AUTHORITY OF THE SENATE

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COMMUNITY AFFAIRS REFERENCES COMMITTEE

Thursday, 28 April 2005

Members: Senator Marshall *(Chair)*, Senator Knowles *(Deputy Chair)*, Senators Humphries, Hutchins, Lees and Moore

Substitute members: Senator Allison for Senator Lees

Participating members: Senators Abetz, Allison, Barnett, Bishop, George Campbell, Carr, Chapman, Colbeck, Coonan, Crossin, Denman, Eggleston, Chris Evans, Faulkner, Ferguson, Ferris, Forshaw, Greig, Harradine, Lees, Lightfoot, Ludwig, Mackay, Mason, McGauran, McLucas, Murray, Nettle, O'Brien, Payne, Watson and Webber

Senators in attendance: Senators Humphries, Hutchins, Knowles, Marshall, McLucas and Moore

Terms of reference for the inquiry:

To inquire into and report on:

the adequacy of current proposals, including those in the 2004 Budget, in overcoming aged care workforce shortages and training;

the performance and effectiveness of the Aged Care Standards and Accreditation Agency in:

(i) assessing and monitoring care, health and safety,

(ii) identifying best practice and providing information, education and training to aged care facilities, and

(iii) implementing and monitoring accreditation in a manner which reduces the administrative and paperwork demands on staff;

the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements;

the adequacy of Home and Community Care programs in meeting the current and projected needs of the elderly; and

the effectiveness of current arrangements for the transition of the elderly from acute hospital settings to aged care settings or back to the community.

WITNESSES

Committee met at 9.34 a.m.

BROWN, Ms Hilary Mary, Aged Care Advocate, Advocacy Tasmania Inc.

HARDAKER, Mr Kenneth John, Manager, Advocacy Tasmania Inc.

CHAIR—Welcome. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public, but evidence may also be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submission, and I now invite you to make an opening statement, to be followed by questions from the committee.

Mr Hardaker—I will start by commenting on something we said at the end of our written submission. In our experience at Advocacy Tasmania—and we have provided the aged care advocacy in Tasmania for about 12 years now—we have seen some real improvements in aged care in the last two years, particularly the last five years or so. We have seen a lot of positives occurring. Hilary, who prepared our submission and has been the aged care advocate for the state for—

Ms Brown—Four and a half years.

Mr Hardaker—four and a half years now, has had that continuity in the position needed to really get a good sense of what is happening around the state. We thought it was important to prepare a submission because, despite the improvements, we think there is still a way to go to have the sort of system that we would like to see, particularly with residents rights, which is the main focus of our work. We thought, if senators are happy with this, the best way to illustrate that may be not to speak specifically to our submission but to mention a couple of non-identifying cases that we are dealing with at the moment which tie together most of the things that are in the submission. If that is an acceptable way to approach it, I will hand over to Hilary to talk about these two cases that we are dealing with at the moment, one of which came in literally yesterday or the day before. The other one is probably a couple of weeks old.

Ms Brown—As Ken said, these two cases are extremely recent, from the last few weeks. They bring together a lot of the issues that I have raised in my submission. On Tuesday I had a phone call from a lady in a home in Tasmania who, in her opening words to me, said how difficult she was finding it to actually ring me. In her words, she felt ‘scared stiff’ about reprisals. She was not the only resident in the home who was not happy with certain things, but she had taken it upon herself, fairly reluctantly, to be a spokesperson for them. She gave me a list of things that she was not happy about. She said that the staff in the home were so busy and had so little time with the residents for showering that many residents were experiencing scouring and chafing in their groin and under their breasts because the staff did not have enough time to spend drying them properly. She also said that many residents were being put to bed very early because of rostering issues and staffing shortages and that they had no choice about that. The residents did not seem to be given any explanations. The home was about to undergo an expansion and she had been told by the staff on the floor that they had been told that there would be no staff increases, despite the fact that there was going to be a 12-bed increase in the home. The staff were already stressed and overworked, and that was only going to increase as the numbers increased.

She then went on to tell me that the meals were not fit to eat. She said it was really very bad. She told me that tomorrow she would be having processed turkey and how sick of processed meats and things like that the residents were. A group of residents had joined together to buy a fridge so that they could buy fresh food and keep it. I find that very sad. She also went on to say that one resident had spent two days on just mashed potatoes. There was little consideration given to residents on special diets who had conditions like diverticulitis or diabetes. Meetings had been organised with the chef to discuss these issues but he had continued not to turn up. Very few alternatives were ever offered for her meals. She also told me she had paid $98,000 to be in the home and she wanted to know where her money was going. That is the first case, and that came in on Tuesday. We will be speaking with her and giving her some opportunities to decide what she would like to do with her concerns. Are there any questions about that case or would you like me to continue with the next?

CHAIR—I have some questions about how you move on to deal with that, but it is probably appropriate that you finish both cases and we will talk about them generally.

Ms Brown—All right. Last week I had a phone call in relation to a 60-year old man with muscular dystrophy who is cared for at home full-time by his partner. He requires a PEG feed through a stoma site. His wife does a wonderful job caring for him, seven days a week, 24 hours a day—I am sure you have heard it all before. Last year in October she decided to book some residential respite care for her partner. They had organised respite previously and it had worked quite successfully. She thought she would plan ahead, as people know they must, and made a booking then for May this year. Three weeks ago she decided to do as she had done with the previous respite and go and see the staff in the home, prepared with the detailed care plan for her partner with all his needs in it so she could inform the home about his special requirements in relation to his PEG feed. It all went well; they were well received, although originally when she made contact they had said, ‘We’re not sure that you need to come in and talk to us, but if you would like to that’s fine.’ So off they both went and were speaking to the staff who seemed to give them every indication that things were fine. The staff asked them to take the initial forms on their way out and said, ‘We’ll see you in a few weeks time.’

She had barely got through the door at home when she received a phone call from the care and respite centre that had made her booking to tell her that they had had a phone call from the home to say that they could no longer take her partner for the respite that was planned. She had a four-week holiday in Queensland booked to visit her daughter who was unwell. All the bookings were made. She went into a state of almost breakdown she was so stressed. Attempts were made to look for some alternative respite for him. The GP tried to book him into hospital for a social admission because he does have some private health coverage, but that was not successful. Attempts were made, but at such short notice there was no other respite available for him. She has had to cancel half of her break; she was going to cancel her whole break, but the care and respite centre has been able to come to the party and put some full-time care into his home. The concern in that case is the ability of the home to pick and choose who comes in. They informed me that there was quite a deal of discussion about the cost of things for him in the respite, his special food. They told me it worked out to be about $120 for the four weeks. It was negligible. You would expect that that is what it would cost a home to feed any resident.

Mr Hardaker—Did they see that as excessive?

Ms Brown—Yes. They expected her to sort out his food and bring it with her. That is almost like asking someone on respite to bring their picnic lunches with them. It seemed quite unreasonable. We were expecting the care and respite centre to meet that cost.

Mr Hardaker—Overall their issue was that they felt this person was going to be too high care for their facility, even though they do have high care residents. Getting access to high care respite is a real problem that we continually come up against and is mentioned in our submission.

Ms Brown—Obviously he is now suffering a great sense of rejection. He is quite ambulant. He is quite articulate. He is also very angry, as you would expect him to be. He wanted to know the consequences of taking some action about their concerns. He said, ‘I will have to go into a home soon,’ because of the deterioration of his condition. He understands that. He said, ‘People will know that I have complained or spoken up about what’s happened.’ It is very difficult for people. Hobart is a small place. He knows that most of the homes do know each other. Someone who has made an issue of something may not be acceptable. That is just this week. That is on top of many other cases that we deal with at Advocacy. I would like to give you the opportunity to ask questions.

CHAIR—Thank you. Just following on from those examples, your submission indicates your view that the accreditation agency is fairly ineffective. When people complain to you instead of going through the accreditation agency, what do you do in terms of formalising those complaints? Do you have a relationship with the accreditation agency where you can raise things about homes in particular? Will they then respond by doing spot checks or reviewing their accreditation process for the home?

Mr Hardaker—The process for us is more to do with our relationship with the complaints resolution scheme that the Department of Health and Ageing operate. We work fairly closely with them. A proportion of all the cases that Hilary deals with are involved in the complaints resolution scheme—handling it as a formal complaint. We also meet four times a year with the CRS and talk about some of the cases that we have dealt with where the complainant did not necessarily want it formalised, so that they get an understanding of the others sorts of things that we are dealing with. We have a relationship with the accreditation agency as well. It is a less formal one. There were industry liaison meetings happening. I do not know whether they are happening so much any more.

Ms Brown—They still are.

Mr Hardaker—The process is more for the department, through the CRS, to decide whether or not it needs to then go to the agency rather than to us.

Ms Brown—There have been instances where I have contacted the agency directly. I had an instance last year where there had been a number of things concerning one particular home. Sometimes we bring up things that appear to be fairly minor to some people—talking about the food or small things that residents have got concerns with. If you add them all together over time they do present a picture of things not being right. When I brought up some issues around a particular home, one of the comments that was made to me from someone at the agency was: ‘Has there been anything serious?’ I had indicated some of the things around poor management and a few other things and the way that things had been dealt with for residents that I thought were pretty bad. Obviously there were some serious rights issues for residents. But there just happened to be a very serious issue that was also happening. I wonder what would had happened if I had not brought that into the picture. That serious issue was actually with the complaints resolution scheme. Sometimes they do not always get connected up.

I then have to ask: where is my role in this? As an advocate, we often feel as though we are stirring pots—and we do at times because that is our role, that is what we are here for. But we tread a fine line with the industry also in doing that. It is happening much more often these days, thank goodness, that they have a much better understanding of our role in the whole system. Many in the industry do contact Advocacy or inform their residents about Advocacy if they have issues that are not specifically related to a complaint with the home. It will be a wonderful day when residents have complaints with the home and they tell them to go to Advocacy. It does happen, because they often see our role as supporting the resident. The outcome may not necessarily be different, but the people's sense of justice will often be much greater if we are involved.

We need to have a reasonable relationship for acceptance by the industry. I get invited by them to speak to residents—I cannot force myself on them—and that is often a very good opportunity for residents to get a picture of what we do. Having a charter of rights does not necessarily mean a lot to many of our frail residents in homes because, as you would be aware, rights are very abstract. When I speak to groups of residents and tell them stories, I get comments such as: 'Does that mean we do not have to get up and have our shower at six o'clock in the morning if we do not want to?' and I say, 'That is right; you should have a choice in that sort of thing.' So you can have an abstract right to choose, but when you are living in a situation where you are dependent on the care and this is the routine, it is very difficult to relate that to your own needs.

CHAIR—You obviously have not just described an isolated incident to us, because the whole tone of your submission is one of inadequacy, really. Regardless of what Mr Hardaker said about improvements over the last five years, you say this:

> In many instances complaints made to the Aged Care Complaints Resolution Scheme (ACCRS) have not been accepted because documentation and staff reports have not been available to substantiate a breach of standards. However, this doesn't mean a breach has not occurred.

Are you saying that, effectively, unless the home acknowledges the breach, there is no way to prove that the breach has occurred so therefore it is ignored?

Ms Brown—Yes. If you take the example that I used in the submission about residents being told to urinate in their incontinence pads, that is not an isolated incident. If somebody then wishes to make a complaint about that, they can come to me and I can go through the process with them. Sometimes people are very angry, because they have tried to raise things with the home and the result has not been to their satisfaction. It may be only one instance in several, so they choose for me to assist them to go straight to the Aged Care Complaints Resolution Scheme. The process is that they will then take that complaint to the home and there will be an investigation. Because there is an allegation, there is not automatically a complaint in the technical sense. That whole thing does not make any sense to consumers—if you have a complaint, it is a complaint—and it is very difficult sometimes to explain that technicality to people. So they go along and investigate what has been said. Of course they go to the home and ask about the incident and they look in the documentation. Who is going to write in the documentation that they told Mrs Jones to urinate in her incontinence pants? It just does not happen, and it will not happen in discussions with the home. They will then go away and say, ‘We cannot accept this as a complaint.’ Then I can write an appeal on the basis that it is inappropriate that they should do that, but it is a very difficult thing and so no complaint gets formally registered and there are no statistics about that complaint.

Mr Hardaker—It boils down to one person’s word against another, and because nothing in the documentation seems to suggest that this happened then there is no complaint. The complainer is told, ‘Sorry, your complaint is not accepted.’

Senator McLUCAS—I would like to pick up on that. The other issue that has been brought to my attention is consumers’ dissatisfaction with the mediation process. In some cases, mediation can be a clearing house for putting the views on the table, but in many other cases—I would say most cases that have been brought to my attention—the mediation is an unsatisfactory point in the process and people feel intimidated at that point. Do you have any views about the process of mediation after the complaint has been recognised as a complaint?

Mr Hardaker—We have not had too many. I have had one or two.

Ms Brown—I have had several incidents of mediation. I believe that you cannot mediate about some things. It depends on the actual incident that has happened. I can think of one very serious complaint that I was involved in last year, where a resident was asked to leave a respite situation because their needs were too high and the home was not managing. There were so many issues in that complaint around security of tenure and the treatment that she had been given in the home and the fact that she almost died in the five days that she was there. What is there to mediate in a situation like that? They are asked to consider that as a step in a process in which they really want some answers about what has occurred over that time. Mediation is fine if there has been some behaviour—you can go back to the example of someone being nasty. Ideally it should be recognised that that did happen and there should be some acknowledgment of the fact that it happened. When a complaint does not get accepted, people then automatically assume that the person who made the complaint has been mischievous and has not told the truth. You and I would both feel the same if we were telling people about what happened and we were told, ‘We can’t accept that’ and, ‘No breach happened.’ They automatically feel that. I guess mediation is not always satisfactory, and unless people are supported it can be extremely intimidating.

CHAIR—There is one last question from me. The tone of your submission was really painting a picture of the industry. I know you are not painting every home as failing to meet the standards, but it is obviously more than isolated incidents, as I said before. Can you give us a picture of the industry in Tasmania and where you think it is falling down, so that we can get something to take away with us. Also, can you tell us whether it is the not-for-profit or the profit-making side of the industry or whether it is evenly distributed?

Ms Brown—As Ken said earlier, generally I am finding that, although complaints about care and about homes in general are never going to go away, there are periods when they come and go. One of the things that I hope came across in my submission was that I am really keen for there to be much more accountability to residents. The industry is an industry, and it has quite a strong voice. It is a very strong lobby. And I do not believe it is as accountable to the people who receive the care. The level of accountability is that they have to meet the accreditation standards. As I have tried to indicate in the submission, there can be quite a deal of up and down, as far as I can see, in the standard of care across the accreditation cycle.

As I speak to residents groups throughout the state, my sense is that the majority of residents throughout the state are very happy with their care. I like nothing more than going in and talking to a group of residents who tell me: ‘This is the best time. We’re very happy here. The staff do a wonderful job. We’ve got nothing to complain about.’ And then I start talking about how it is quite difficult to speak up. I am constantly encouraging residents to speak up, despite the fact that, in the process of my discussion with them, they will all admit how difficult it is to do that. So, yes, we really try to unpack what it means to find it difficult to speak up. And then they will often come out with: ‘Oh, well, we don’t really like sharing bathrooms.’ They want to understand the process of why there are still certain facilities where they are sharing a bathroom. I deal with groups of residents who will then start saying, ‘The food here’s not the best.’ We start to deal with all of those things and their thoughts come out.

I would like to see more of that degree of the sense of what it is really like for residents experiencing their care, because we hear a lot from the industry—they are very strong. But I feel that the residents’ voices are not strong. They are a very vulnerable group. Most families are also reluctant to speak up because they know that they need to have their family members in care. I think we need to do a lot more to try and strengthen the voices of the residents themselves and find out more about how they are truly experiencing life in care. As I said, when I speak to them I get all these good things, but there are 4½ thousand or more people in care in Tasmania—or perhaps that might include the CACPs. The majority of them are very happy with their care, but I believe, because of evidence to me from them, that it does vary. Also, I do not think we have any fully privatised homes in Tasmania—do we?

Senator McLUCAS—No? I am surprised.

CHAIR—I am surprised too.

Ms Brown—Is that right?

Mr Hardaker—Yes, we do.

Ms Brown—We do; sorry. But they do still have government funding.

CHAIR—They all have government funding!

Mr Hardaker—Just in terms of independently owned, yes. Correct me if I am wrong, but in the Tasmanian picture, it is very difficult to say, ‘These are the problem homes and these are the ones that are always good.’ It seems to fluctuate. So you can understand our submission and where we are coming from, we deal with problems all the time. We dealt with 170-odd complaints, or cases, last year. Probably half of those were to do with problems with the nursing home and the care and services. The other half were personal issues that we assist residents with where their rights are being abused in some way. Often it is financial abuse by family members and those sorts of things. So we are dealing with the unpleasant side of things on a day-to-day basis.

CHAIR—Do not think that I have taken it the wrong way. I have not seen it as painting a terrible picture of the industry. I think it is a good submission because it breaks down into many points what is wrong with the accreditation process—the problems you see with it and how it interacts with the consumers and family groups. From that point of view it is a very good submission.

Mr Hardaker—A theme that runs through all our work at Advocacy Tasmania—and we have other programs as well in mental health, disability and home and community care—is dealing with people in institutional settings or group settings. The culture of those settings is critical. In aged care, what seems to dictate whether from our point of view a home is providing a strong rights environment for residents is the leadership at the time. I can think of a couple of homes where the leadership in our opinion was very poor, very antirights, antiresident, and often antistaff as well. That has changed in recent times. When that happens, suddenly a whole place, its tone and culture, changes. Leadership is a critical issue.

Senator KNOWLES—That is the same in any industry.

Mr Hardaker—I realise that. To paint the picture of what Tasmania is like at the moment, we see homes where the leadership has changed for the better and things are improving and we see other homes where we previously felt there was quite a positive, strong culture that appear to be deteriorating because the leadership has changed and they do not have that rights focus that they had previously. So it is very hard at any given time to say, ‘These are the good guys and these are the bad guys.’ It is not like that.

Some of the issues that we have tried to highlight here are those around staffing and the difficulty in recruiting people who are properly trained and have a strong rights understanding, which is what we try to refer to as the rights based care approach. We are not convinced that the training that most people go through has a strong element of that. They might have done the certificate III or IV training. That might be a little component of what they have done, but it does not necessarily give them a strong basis for moving into residential care if the culture they are moving into is not particularly strong on that either.

Another theme that we have picked up on in terms of the culture is this notion of fear of retribution. We want to see some sort of antibullying approach used in residential care, as it has been used in places like the school system and other workplaces, to try and strengthen all of the people in an environment who are trying to do the right thing. Often it only takes a few people who have a negative attitude to make residents’ lives very difficult. If that is combined with a leadership that is very weak on rights and focuses on other things, an environment is created that makes it very easy for people to be intimidated and to feel that they cannot speak up. It is a jigsaw. We recognise that it is not an easy exercise.

Senator KNOWLES—Something you said a moment ago really bothers me. You said the majority of residents are happy with their care. Then you went on to say, ‘Then I go in there and I ask them about this, this and this.’ The way I perceived the evidence that you have just given to the committee is that you go in and make happy residents unhappy residents.

Ms Brown—Goodness me, I hope not.

Senator KNOWLES—I am going purely on the evidence you have just given to the committee. You ask, ‘Are you getting showered at the right time, are you doing this or are you doing that?’ I used to be in marketing and I used to have a very big sales team. I used to insist that they went and saw their clients repeatedly after every sale and I used to have more successful ones than others, and I would find out why. Some people would go in and say, ‘How’s everything going? Is everything okay?’ The answer would be, ‘Yes, everything’s fine.’ The others would go in and say, ‘Have you got any problems?’ and the client, asked that specific question, would then feel honour bound to say, ‘Now, what problems have I got? Let me think up a problem, because you’ve asked me if I’ve got a problem—I’d better have one.’ From what you are saying, you are going in to see people who have declared themselves happy and saying, ‘Well, how about this and how about that and how about something else?’

Ms Brown—I could say I resent that observation—

Senator KNOWLES—I do not want you to resent anything; I am just going on what you said.

Ms Brown—When I go in for my information sessions with residents, the main purpose is to let them know that I exist, should there be any issues, and also to discuss with them the recognition that sometimes speaking up in a situation where you are receiving care is a difficult thing. In the main, they acknowledge it. I do not start my talks by asking them if they are happy or not; I start my talks by explaining who I am and what I do. Then, within the talk, they will give me information about what it is like in the home, because I also tell them stories about what their rights really mean. Taking the instance of the lady who is getting up every morning at six o’clock to have her shower on a cold Hobart morning, many people are very accepting of their situation within the home.

I would love some of you to come and witness my sessions with the residents. I ask them to discuss what it was like for them to come into the home, what the process was, because what I have found is that, if people go through a reasonable process of accepting the fact that they do need to go into care, they are much more likely to have a positive experience of that care. So we discuss all of those things, such as, ‘Yes, we’d all like to be at home but we know we can’t manage anymore.’ They have accepted that. They enjoy the stimulation of the home, but what often happens in the home is that they are told, ‘We don’t want to talk about negative things; we want you all to be happy’—but they would quite like to discuss what it was like for them to have to come into the home.

Senator KNOWLES—But I am talking about the self-declared ‘we are happy’ residents that you told the committee about. Can I get onto another thing, because we are going over and over the same spot at the moment.

Ms Brown—Okay.

Senator KNOWLES—Can you provide to the committee the number of residents in nursing homes in Tasmania?

Mr Hardaker—The number?

Senator KNOWLES—Yes. How many people are residents of nursing homes in Tasmania?

Mr Hardaker—I think there are about 3½ thousand.

Senator KNOWLES—Mr Hardaker, you said that last year you received 170 complaints, half of which were directed at the facilities—

Mr Hardaker—Roughly half would have been about that, I would have thought. That is how many cases we dealt with last year.

Senator KNOWLES—Your initial statement, Mr Hardaker, was that things had improved dramatically in the last five years. Then we get Ms Brown saying that everything is crook in the kitchen, metaphorically speaking; the number of complaints is—

Ms Brown—I think—

CHAIR—I am not sure that that is—

Senator KNOWLES—Excuse me, Chair; this is my opportunity to question the witness. Ms Brown said that everything is crook, people are unhappy and it is fairly widespread. Then we get the situation where Mr Hardaker says, ‘We have 170 complaints out of 3½ thousand residents, but only half of those 170 complaints are actually against the facilities.’ I am getting a very mixed message here.

Mr Hardaker—The referrals we get each year have been increasing for a number of reasons.

Senator HUTCHINS—Excuse me, I do not want to interrupt Senator Knowles’s line of questioning but does your definition of the 170 investigations refer to a telephone inquiry where someone rings up and asks, ‘What are my rights?’

Mr Hardaker—No, there is a separate figure for that side of it.

Senator HUTCHINS—Can you fill me in? Senator Knowles will not be backward in telling me to butt out, but how does it get to a complaint situation? Is it a major thing?

Mr Hardaker—We define what we do in terms of cases. Our advocates in each of our different program areas handle a certain number of cases each year, and in those cases they are representing the person as an advocate. We do not investigate complaints as such; the facility or the complaints scheme looks at the complaint. We support a person through a complaints process as their advocate speaking on their behalf or on behalf of the family. In the aged care program last year, Hilary and one other part-time advocate assisted about 170 cases. A case can range from something that might be dealt with in a day to something that might take literally years. We have had a couple that have taken a couple of years to resolve. They are on a continuum of involvement, if you like, with us from those two ends of the spectrum.

We have had an increase every year in the number of referrals we have received, and that is because we think there is an increased awareness about who we are and what we do. There is more understanding about advocacy and the mechanisms that exist for people to have complaints dealt with. As I said, probably about half of those 170 cases were to do with facility related matters; the other half were to do with other issues in a person’s life where their lives are at threat. The examples we have given are examples of things that are fairly terrible, and that is why we have given them. They are examples of things that we think should not be happening and need to be addressed.

Senator KNOWLES—They are not necessarily systemic.

Mr Hardaker—They can be systemic to a facility. We are not saying they are systemic to the whole industry in Tasmania. We have said that we think things have improved overall. If we had had this meeting five years ago we would have had a lot more of those examples than we have today. We also have a lot more facilities coming to us to ask our advice about situations: ‘What should we do about this?’ There may be residents’ rights, family issues or complaints and they ask us how to deal with them. We have tried to develop relationships with industry and from our point of view that has paid off. It is a difficult line to walk. On the one hand you are trying to develop relationships and work alongside and in collaboration with nursing home managers and directors of nursing. On the other hand, when a problem is brought to you on behalf of a resident or a family member who is unhappy you have to go into bat for that person. It is a difficult line to walk.

Our overall theme is that things are better but there are still some fairly terrible examples out there. The facility Hilary mentioned first is one that we felt was improving. They had some problems a few years ago. Something seems to have happened there to set it back a bit. That is the changing nature of things. The leadership can change or a decision can be made about extending a facility which suddenly puts a lot more pressure on them and they take their eye off the issues around residents’ care, and things deteriorate. Systemically it is about a facility or sometimes an organisation, but not about the whole industry overall.

We have an education information role. That is part of what we are there to do—to inform residents, families and staff about who we are and what we do. We have only one advocate for 3,500 people, so she is spread fairly thinly. We have to take the opportunities when we are asked to go into the facility and talk to residents, staff and family about who we are and what we do, and that sits within a context of their rights. Do you understand what rights you have? Have you heard of the charter of rights? Many people have not. Those discussions will sometimes raise issues about things that people had previously put up with and now they realise they do not have to put up with them.

Another part of the discussion is around: what do you do in your facility and what mechanisms exist to raise issues if you are not happy? That is an important part of the discussion as well. Does this facility have systems in place to deal with this? Does it have residents groups? We did a major project 18 months ago on residents groups across the entire state, surveying them all and looking at providing each of them with a kit on best practice for residents groups. We are trying to help them to strengthen their own processes so that when we have these sessions people will say to us, ‘Things weren’t as good but now we have a well-functioning residents committee, we have a suggestion box and we actually feel the suggestions are listened to.' Those sorts of things are happening.

Senator KNOWLES—What you are saying now is vastly different from what I gleaned from Ms Brown's contribution to the committee this morning. Mr Hardaker, you were talking about the positives as well as the negatives. Ms Brown, I perceived that you were talking solely about negatives; you were trying to hone in on the negatives and were drawing those negatives out of self-declared happy residents.

Ms Brown—No.

Senator KNOWLES—I would have thought that it is important for you as part of your role to go in there and enhance a happy situation instead of trying to pull it down.

Ms Brown—I do—very much so—and I say to residents that nothing pleases me more than to go into a home and hear that the residents are very happy and that the culture is very positive in that home. I think you have tried to twist what I have been saying in terms of what actually happens.

Senator KNOWLES—No, I am not trying to twist anything. That is not my job.

Ms Brown—It is very complex when I am talking to residents and getting a sense of how they feel, because they do have mixed feelings. I actually go out of my way to try not to do what you say I am doing—to make them all feel unhappy—because that is far from what I would want to do. But I do want to draw your attention to a really important part of my submission in relation to people in homes. We have a very high number of people in residential care who have cognitive difficulties. The level of dementia is extremely high, and those particular people are very vulnerable unless they have families who see them often. There are many people with dementia in our residential care facilities today who do not have regular contact from family and they are extremely vulnerable. Who is speaking up for them? They can be in situations where the care is not always perfect and they cannot speak up about it. That is a really difficult situation. I say, on many occasions when I give education sessions to staff, that it is pleasing to see the changes in culture that are taking place and that it is good. But the essence of my submission is that we are looking to try to give the residents a strong voice in the accountability system. I do not believe that the way it happens at the moment through accreditation really does that for the residents.

Senator KNOWLES—Ms Brown, how long have you been dealing with the aged care industry?

Senator McLUCAS—This is not an inquiry into the Advocacy organisation; this is an inquiry into aged care.

Ms Brown—Fifteen years—not just in residential care but in community care as well.

Senator KNOWLES—How long have you been dealing with aged care facilities?

Ms Brown—Four and a half years.

Senator McLUCAS—I go to your comments about the process of dealing with the aged care complaints resolution service. Do you have any data on the number of issues that have come to your attention and which have not turned into an investigable complaint by the CRS?

Mr Hardaker—No. The CRS would have a record of that. Do you mean complaints that were rejected, refused or not accepted?

Senator McLUCAS—Yes, issues that you have brought to their attention which they have not been able to substantiate and which, therefore, cannot be progressed down the resolution pathway.

Ms Brown—Probably a half to one-third will be rejected initially.

Senator McLUCAS—We are going back to the data that you are putting to us? Is that half of 170?

Mr Hardaker—No, that would be half of the cases where we are involved with the CRS, which, in any given year, may be a dozen cases. So on the occasions when we have supported people to go to the CRS, which is probably about a dozen in a year, maybe half to one-third are rejected initially.

Senator McLUCAS—Because they cannot be substantiated?

Mr Hardaker—Yes.

Ms Brown—Yes. When an issue is brought to my attention when I speak to a residents group—and it may be about the food or the routine—most of the time we go through the complaints process within the home. I have a group of residents that I am working with at the moment who have brought the food issue to my attention. We have had two meetings. They met with me and we met with the CEO of the home. He has met directly with a small group of residents. That is the way that we usually try to resolve problems. When an individual resident brings an issue to me it is very rare, unless they have a supportive family, for them to choose to go through the complaints resolution scheme. Generally they are too frightened to do it alone.

Senator McLUCAS—Essentially you are telling us that the role of Advocacy Tasmania is to do some of the work of the CRS. Your agency is able to resolve these issues locally with the resident.

Ms Brown—That is the majority of cases.

Mr Hardaker—It gives people the choice, because a lot of people do not want to make a formal complaint or they do not want to take it to a formal body outside the facility. They find that too intimidating and too complicated. So if an advocate can help them resolve things quickly and easily at the local level, which is what happens in the majority of our cases, it is better for everybody. That is why we liaise regularly: four times a year we liaise with the CRS so we can compare notes. In Tasmania we have written joint papers for the industry group here for the last three years in a row, where we have sat down together and asked, ‘Did you experience this here?’ because we are both dealing with complaints. It is useful to have that dialogue in order to get a fuller picture. Our joint papers have been presented to the industry group here each year, saying, ‘These themes are common to advocacy in the CRS over the last year: failure to communicate with complainants, issues to do with dealing with families poorly and ranges of things like that.’ In the last year I think security of tenure issues came up as well. That will be available to the committee if you would like a copy of the last paper.

Senator McLUCAS—That would be useful, thank you. That goes to my next question, which is: what is the nature of those issues you take to the CRS that cannot be substantiated? Food is a common issue.

Ms Brown—Yes.

Senator McLUCAS—It is a fairly universal complaint. You can understand why: you come from your home, where you particularly liked to have spaghetti bolognaise on Friday night, and you do not have it in the nursing home. That is just the way it is.

Ms Brown—The interesting thing is that when you ask residents to talk about that, and most residents do not, they are not necessarily happy with the routine, but they are very—

Senator McLUCAS—Accommodating.

Ms Brown—They understand the staff. The most important thing to most residents is the staff. This is backed up by research; it is not something I have pulled out of my head. It is something that I discuss with staff at their information sessions. Having a wonderful room and all of the other things is extremely important but, as I have pointed out at the end of my submission, when it really comes down to the quality of life for residents in care the vital thing is the relationship with the staff and it is the reason that they are happy generally. If there is a good culture in the home and the staff are happy, research also bears out the fact that residents are generally happy. This requires keeping the staff happy and that is very difficult but it has a marked impact on residents’ quality of life. The complaints that come to us are often because family members have been unhappy with aspects of residents’ care. I sometimes go and talk to residents and I will often find that, yes, certain things have happened but they are reluctant to make a formal complaint about them. Nevertheless, the family members still wish to do that.

Getting back to your question, I do not have many complaints that go that far that relate to food. They are much more likely to be about things that have happened in relation to care, such as falls. I generally find that at the centre of a major complaint is the issue of communication and how things were dealt with. When issues are raised with homes, if they are dealt with in a very accepting manner and the issue is acknowledged and looked into, the family member will generally be happy with that. A bad culture is when somebody raises something that they are concerned about and it gets denied.

I have had this happen to me. I have gone to directors of nursing and told them that residents have raised an issue with me and I have actually been told that it is not true. In our dealings with the scheme with combined complaints we all keeping registering the notion of communication and the way things are dealt with. We all know that when you are dealing with the care of this number of people things are going to happen and you cannot meet the needs of 150 people in residential care. You cannot expect everybody to be happy with the food choices and all of the other things. Accidents are going to happen and there will always be incidents. But it is actually how those are dealt with that really seems to count.

Senator McLUCAS—Yesterday we took evidence from COTA National Seniors. They agree with your submission essentially that as an advocate group they do not feel as if they are part of the accreditation process. They gave us some advice about how that could be improved. Have you got any advice to the committee about how consumers—that is, families or residents themselves—can be more involved in the accreditation process, given that it specifically states that residents and residents' families should be involved in accreditation?

Mr Hardaker—About three years ago we were one of the advocacy services that hosted forums for residents and families on accreditation. Five states did this and the process was called, 'The lessons that can be learned from the accreditation process'. It was from the resident-family perspective. In that exercise we found that most residents and families did not know very much about accreditation until they were told after the event that it had happened. The 50-odd residents and family members from around the state who attended the forum wanted to know more and they did want to be involved. So the notion that people are not interested was not true.

Certainly every nursing home and every hostel has a proportion of people in it who are interested and families who are interested. I guess the underlying theme of the bullet points we have put in the submission is that they are still not finding out about it. They still do not know that that opportunity exists. So a lot of it is around communicating with people beforehand so that they know it is there—they know it can happen and they know they can be part of it—and providing a range of opportunities to do that. A small proportion of people will want to have a confidential discussion with an assessor about their experiences; others will be happy to come along to focus groups and have interviews with assessors where it is quite publicly known. It seems to us that not enough of those sorts of opportunities are being presented to people at this stage. I guess some sort of strategy from the agency as to how they are going to draw out the most input and feedback possible from residents and families should be attached to each accreditation process.

Senator McLUCAS—COTA National Seniors said yesterday that the word 'accreditation' is confronting and that it does not encourage residents or residents' families to be involved. It sounds like a very bureaucratic, legalistic thing that is not very welcoming. I do not know what the alternative word is, but if you can come up with something I am sure the committee would be interested in knowing about it.

Ms Brown—Yes, I think that is very true also. As I pointed out in the submission, there is this apparent accreditation cycle where conditions and staffing levels seem to vary. I guess it is similar to election cycles, really, when you look at what happens with budgets and throwing money around. I believe a similar thing happens. It is certainly reported. Residents are not silly. They see it happening and they talk about it, and families do too. And then they experience the cutbacks in hours and diversional therapy—the things that really influence their quality of life. I have put forward the possibility—and I have said it many times—of some form of survey directly to residents and families that captures the mid-cycle dip, if you like, because when the accreditors come into homes and the accreditation is happening, you have to get over this sense of 'Who is going to come forward and speak up?' People feel they have to be articulate; they have to have their arguments ready. Also, they think: 'I'm being critical. My dad lives here. Yes, most of it’s good, but I really need to have a bit of a whinge.’ And they think: ‘No, it doesn’t matter.’ That is what it is like for residents: ‘Look, it’s generally pretty fine, and we’re okay, but we’re not sure if this is how it should be.’

Senator McLUCAS—I think the other thing is that, yes, generally experience is reasonable, good, or however you want to describe it. I think people feel a bit embarrassed about raising something which may seem rather trivial in the scheme of things but which for that resident is significant.

Senator HUMPHRIES—Can I go back to that issue you raised about the bullying of residents. Allegations of that nature have been raised with us by another group similar to yours. Of those 170 or so complaints that you deal with each year, how many relate to allegations of or perceptions of bullying by operators or providers of residents who make complaints? Just a guesstimate would be fine. Do you get one of those each year or, say, 10?

Ms Brown—I have had some significant examples of the bullying of residents in homes but, again, a lot of it comes down to definitions. I do not think I have received any complaint, when it relates directly to a home, where the person involved does not at some point mention their fear about bringing it up as an issue. Only in cases where people are very angry do they not have that fear.

Senator HUMPHRIES—The issue I am raising is not about that. It is more about the number of people who come to you and say: ‘I complained and I’ve been victimised by the home. They’ve given me cold food and they won’t answer my buzzer because I made a complaint the other day.’ How many of those cases do you get in a year?

Ms Brown—Few.

Mr Hardaker—A handful—of actual retribution?

Ms Brown—A handful of actual instances of retribution. But it is not the same as the number of people who fear retribution.

Senator HUMPHRIES—That fear, though, might be exaggerated or unfounded. It is hard to know.

Ms Brown—Absolutely.

Mr Hardaker—And some people will say, ‘I am fearful about speaking up because when old Bill complained everyone labelled him as a pain, and I do not want to end up being seen the same way as old Bill.’

Senator HUMPHRIES—And other residents might be responsible for that just as much as the management of the home.

Mr Hardaker—It could be.

Ms Brown—Or they say, ‘I don’t want to complain because I saw how Mrs So-and-So was spoken to by one of the nurses because she had spoken up and I don’t want that to happen to me.’ Sometimes residents have witnessed other people being picked on.

Mr Hardaker—That is right. In a discussion last year with a public advocate in the north of the state, a resident said, ‘I don’t want to be blackballed. That is what happens here when you speak up.’

Senator HUMPHRIES—The thing that disturbs me about allegations that there are such incidents in nursing homes is that, when we have asked that question of other umbrella groups representing the interests of people in nursing homes, they have almost invariably said they are not aware of such incidents occurring. It has only been the publicly funding advocacy groups such as yours that have made those allegations. Can you explain why that would be the case? Why don’t bodies such as the Council on the Ageing—

Mr Hardaker—That is not entirely true. In his annual report of the year before last, the Commissioner for Complaints, Rob Knowles, spoke about this issue.

Senator HUMPHRIES—I concede that that is true. In a sense, your issues feed up to a body such as his. I am talking about umbrella groups representing residents, or their interests, in these homes. None that I can recall—having asked that question—commented that they are aware of those sorts of issues being prevalent.

Mr Hardaker—I believe there was something recently on this matter from the ANF. I could be mistaken, but I have some recollection of hearing a radio report about the release of a study by the ANF into this issue.

CHAIR—I thought we asked the ANF about that.

Senator HUMPHRIES—We did ask the ANF, and they said they have not done a study.

Mr Hardaker—I cannot answer why those other groups have not mentioned it. I guess the difference is that we and the complaints resolution officers whom Rob Knowles oversees are working directly at the coalface with these people, and they will tell us stuff that they would not necessarily tell others. I guess it comes back to the culture, which is the theme we are talking about here, and what we believe is a need to understand this better through research directly with residents and their families about their experiences. It is a difficult thing to get a firm grip on. It can be quite subtle. The more explicit forms of actual retribution are relatively few—the ones reported to us. But then, as I said, we only have one advocate in the whole state for 100-odd facilities. I guess we see ourselves a bit like a canary in the coal mine. We become aware of things, because of our independent position and the role we play, that others in the industry do not necessarily get an opportunity to see and hear.

Ms Brown—Sometimes it is not the residents themselves who suffer the retribution; it is often their families. Only the other day, I was told by a family member, ‘The staff always look the other way now, and don’t acknowledge me any more.’ It is not always the resident, because the family member often does the speaking.

Mr Hardaker—Ostracism, yes.

Senator HUMPHRIES—In a sense that is human nature though, isn’t it. You make a complaint about somebody. They are under pressure because of the complaint. They are not going to feel happy about it. That is hardly victimisation, is it, if someone turns away from the person talking to them?

Mr Hardaker—What happens is that the person will then feel uncomfortable about visiting their own relative. They do not feel welcome in that facility. It may be more than one staff member who takes that attitude.

Senator HUMPHRIES—But you cannot change that. You could not sack a person because they got browned off because they were complained about.

Mr Hardaker—No, and it is not necessarily about sacking people. It comes back to the issue of leadership and how you set a culture within a facility so that that sort of behaviour is not acceptable. All of the language around complaints handling is about continuous quality improvement and opportunities to learn from complaints. Some have taken that message and actually understand it and value it. Others still react in a more gut instinctive way, but we are trying to move towards that continuous improvement and positive way of looking at things. I think that is where we need to keep heading.

Senator HUMPHRIES—Can I clarify something you said earlier about the complaint resolution service. Did you say that allegations that were made and investigated by the service which were not proven or substantiated did not appear in the statistics of the service?

Mr Hardaker—Of the complaints service?

Senator HUMPHRIES—Yes.

Mr Hardaker—I am not quite sure. I would have thought they would have kept those statistics.

Senator HUMPHRIES—I thought you said earlier that they do not become a complaint, and therefore do not go in their records or statistics, unless they are substantiated in some way by looking at the records of the service. Ms Brown, you referred to that situation of the people who were told to pee in their incontinence pads. If someone makes a complaint—say, you complain that your mother has been left in her bed for 24 hours or something like that—are you saying that, if they cannot substantiate it, it does not appear in the CRS’s statistics?

Mr Hardaker—I believe not—that is, that it is listed that the complaint was assessed but not accepted.

Senator HUMPHRIES—But it is still recorded as a complaint?

Mr Hardaker—No. I do not believe it is, because it was not accepted as a complaint because it boiled down to one person’s word against another, so there was supposedly no action that could be taken. A lot of families and residents find that very confusing. They make a complaint and then they are informed, ‘Sorry, your complaint has not been accepted’.

Senator HUMPHRIES—I can understand why they might not treat it as a substantiated complaint, but my understanding of the way that the service works is that they will record all complaints that are made.

Mr Hardaker—I am not sure.

Senator HUMPHRIES—They will even record anonymous ones—they have the capacity to receive anonymous complaints—but they will not necessarily categorise them as substantiated claims.

Mr Hardaker—I am not sure. You would need to take it up with the CRS as to how they record that. In our dealings with them what we are mostly doing is comparing those issues that we have worked on where there are common themes.

CHAIR—Thank you for your submission. Ms Brown, you did suggest that it would be terrific if we had an opportunity to come and experience one of your discussions with the groups. I am not sure about everyone else but I will be back in Hobart in early June and I might communicate with you. If there is an opportunity to do that, I would like to take that up before we finish the inquiry. That is what you get for making such rash offers during submissions to Senate inquiries! Thank you for your submission and your presentation today.

Ms Brown—Thank you. I would like to say that I would love you to come along, but please do not make it in June. You will have to make it later in the year because I will be away on some leave.

CHAIR—All right. Thank you.

Proceedings suspended from 10.49 a.m. to 11.05 a.m.

SADEK, Mr Richard Anthony, Chief Executive Officer, Southern Cross Care (Tasmania) Inc.

SAVELL, Mrs Jillian Ann, Director of Community Care, Southern Cross Care (Tasmania) Inc.

WALLACE, Ms Carolyn Jane, Director of Nursing, Rosary Gardens, Southern Cross Care (Tasmania) Inc.

HARDY, Ms Jo Anne Cressey, Chief Executive Officer, The Mary Ogilvy Homes Society

CHAIR—Welcome. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public, but evidence may also be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submissions, and I now invite you to make an opening statement, to be followed by questions from the committee.

Mr Sadek—Thank you very much for the opportunity for Southern Cross Care to make a submission. I believe our submission covers the fact that we believe aged care services—at least up until the last budget, when some corrective measures were made with an injection of $2.2 billion and the recommendations from the Hogan inquiry appeared—are overregulated, underfunded and underresourced, certainly in terms of the availability of nursing staff, and there is still poor access to residential accommodation services and opportunities within aged care. Our paper focuses on those key issues, and my colleagues will identify a number of aspects, particularly in relation to residential and community care services, which have been emphasised within our report.

In respect of the underfunding situation, Southern Cross Care, albeit in 1998, as an initiative to correct the inappropriate funding from being provided—and we are not complaining generally; we try to live within our means—suggested in an EQOLL paper that the government consider introducing an aged care levy. We believe that the majority of the community, being taxpayers, have contributed to the provision of aged care services and the availability of aged care services in their twilight years. If difficulties were being experienced in terms of providing sufficient funding to provide proper access, quality of care et cetera, in order to correct the imbalance of funding that is available the government could consider the introduction of an aged care levy, and perhaps reconsideration of that initiative could occur.

In relation to our comments regarding the Aged Care Standards and Accreditation Agency, we believe that in the last two accreditation terms there has been a strong focus on compliance, checking of outcomes et cetera, and perhaps there should now be a refocus on partnering with the industry to ensure better practice is achieved in terms of quality service provision. I would be delighted to expand on that. Also, the recommendations made by Catholic Health Australia in that regard—there were eight or nine recommendations in relation to that—could be considered. We certainly support the recommendations made in terms of the change in focus and direction of the agency. Carolyn Wallace will now talk about a couple of the salient points regarding residential services, then Jill Savell will talk about community care.

Ms Wallace—I will talk about what I see as the two main issues with residential care. One issue is a direct consequence of the policy shift to assist maintaining people in their homes—which in itself is what should be done, but it has had a consequence for residential care. That consequence has changed the type of individual who now comes to residential care and at what point they come to residential care. Those coming now have much more complex care needs, are much frailer, have a much higher acuity level, have a lot more medical issues and stay a much shorter time than people did five to 10 years ago. That issue is compounded by the work force issues. Currently, the number of professional nurses is reducing, which is forcing providers to look at differing models of care that are perhaps more reliant on the non-professional staff—and by that I mean non-professional nurses. However, the people who are coming into the beds are actually in more need of those more qualified professional staff. Therein lies the issue.

Some statistics from the school of nursing at the University of Tasmania indicate that last year they had 197 new graduates and over the past five years they have had an average of about 150 new graduate RNs. However, the Nursing Board of Tasmania’s 2003-04 annual report states that there were 53 new graduates registered in Tasmania. So the question is: where did those other 100 or so new grads go? Most of them went interstate or overseas, because there is just as big a shortage there as here and, while the fairly generous and extensive budget initiatives go some way to retaining nurses in Tasmania, I do not think they are going to meet the anticipated demand. Also, bear in mind that it takes seven to 10 years to grow an RN through education and experience to take on a lot of the roles that we are expecting them to undertake in residential care.

Mrs Savell—I think it is important to recognise that we all endorse the initiatives which are outlined in *A New Strategy for Community Care: The Way Forward*, with its tiered models of care which allow clients to slip in and out of different tiers as their care needs change. However, it is really disappointing to see that there were no time lines available to go with this. The document is fantastic, but it is not definitive. The first step in this process has resulted in a very competitive tendering process for all the programs funded under the National Respite for Carers Program. In line with this document and the initiatives, it sought to ensure fewer entry points for clients. Unfortunately, there were no contingency plans for ensuring continuity of care for those clients so, when the new system comes in as of 1 July, the clients, who have become very dependant on and secure with the care that they already have, are not sure whether they are going to have the same provider. In addition to that, some of the service providers who have staff employed on contracts or leases on equipment or buildings are unsure of their certainty for the future.

Something else that is important is the introduction of the quality reporting mechanism, and we all welcome that. It is long overdue. That will commence in July 2005. Unfortunately, the Tasmanian sessions will not be held until 30 and 31 May and 1 June, which allows little time for service providers who do not have a formal system in place to develop a sustainable system before July. In fact, because we do not know what is really required, it is probably quite difficult to develop a system.

In the last budget there was an increase in the ratio of community aged care packages from 10 to 15 places per 1,000 people aged over 70. That was certainly a welcome decision, because the waiting list in the Hobart area is currently 179 people. Some clients have been on that list, waiting for a package, for almost a year. One client in Kingston, which is a suburb of Hobart, has actually been on the list for 602 days. By the time a client is admitted to a community aged care package, their care needs are very often beyond the limitations of that package, and I suspect that is why that one client has been on the list for so long. This has become an increasing problem due to the reduction in the numbers of low-level care beds. Service providers find that they simply cannot sustain financially disadvantaged residents who require low care.

But the biggest problem that we find working in the community with our many clients is with the client whose care needs exceed the level of care that is able to be provided by a community aged care package, which is generally recognised to be about seven hours of care a week. The next level of support is the EACH, or extended aged care at home, package, where the care level starts at about 14 hours a week. What is going to happen to the client who falls in the gap? Of necessity, and out of our duty of care, the care is of course continued to be given to that client, but it is probably continued at the expense of some of the other community aged care package recipients. That gap is something that has not yet been addressed, and it is a huge problem for us.

These people want to stay in their own home and they deserve to stay in their own home, but there needs to be a means of keeping them there. One model that has been proposed on many occasions before and I think probably needs consideration again relates to who should actually own the package of care. I would like to pose the question: should the funds for the delivery of care be directed to the client or their broker so that they may purchase services on their own behalf? Thank you for the opportunity to talk with you.

Ms Hardy—I would like to make a fairly short address. I think a lot of the points have been covered, particularly with regard to funding and residential care work force issues. I would like to make a couple of points from the submission. With regard to funding, several of the other members have mentioned the budget initiatives and, while they are very welcome, the issue in attracting staff is also a wage parity issue, because the aged care sector is unable, because of funding, to match public health sector salaries.

In a recent award here that has been agreed to by a majority of aged care providers in this state there was an increase of 18.75 per cent over the next three years. In this calendar year alone, registered nurses will be eligible for an eight per cent increase in salary—five per cent I believe in January and then another three per cent or so in July. The Australian government has agreed to indexation for this year, totalling about 3.75 per cent, and that is a combination of the conditional adjustment payment, which was a budget initiative, and the indexation figure that was set at two per cent. So, already, just for this year alone, you can see that there is a gap of five per cent in RN wages, which is very difficult for us to meet.

Aged care is not alone, and the health sector is not alone, in having these work force issues. We are aware of that, but there are some issues that are funding related and certainly the wage parity issue is one. The funding is federal, as you are aware—they are moving towards an equal federal funding arrangement—and yet wages are a state issue, so we always seem to be chasing that gap in attracting staff. There is also the issue of medication legislation, which varies from state to state, and that makes it very difficult. It puts very strong legal parameters around any change of models of care, as I think Carolyn mentioned. That is not always going to be a possibility.

I want to talk a little about dementia, which is something that the inquiry was looking at. Although the Commonwealth government is very well aware of and has agreed to look at the funding instrument with regard to commencing a component for dementia care, that is only recurrent funding. Dementia care is very specific. The majority of the industry would agree that it needs to be carried out in what is known as a segregated model, and that requires a capital funding stream to build buildings that are architecturally appropriate for residents with dementia.

The situation for many dementia residents in Australia currently, certainly in Tasmania, is that they are in integrated models so that someone like me, who manages 74 beds and another 22 transition beds, is trying to manage people with wandering and sometimes gross behavioural disorders in with residents who are cognitively capable. That is totally unfair to both those with dementia and those without dementia. Although we welcome the government's acknowledgment that dementia funding needs to be increased, it is not just the recurrent funding. We need the capital funding to build those buildings.

I would argue—a lot would not agree with me—that there are two sorts of care: aged care and dementia care. Dementia care is a very different sort of care, requiring a very different staff ratio and very highly trained staff. That is just not happening. Given the demographics around dementia that are being projected for Australia, it is a serious issue and it really requires being looked at in depth. Our organisation, along with Southern Cross and another of our colleagues here in Hobart, did a very small pilot study some years ago that we presented at an international gerontology conference in Vancouver in July 2001. Our pilot study—and it was only very small; it was unfunded and we just did it out of academic interest to see what the result was—showed that for every resident with dementia, all else being equal so that they had the same RCS level, there was at least a 45 minutes a day difference in care. Someone with dementia takes more time than someone without dementia to have their medications. They take more time to be toileted and to have their meals. They are by their very nature going to take more time to put to bed, get dressed et cetera. Under the current funding instrument none of these things are recognised, so I think that is something we need to make a very strong point about.

I would like to go back to some of the information from Advocacy. As well as being Chief Executive Officer of the Mary Ogilvy Homes Society, I am an external assessor with the aged care agency. I have been very active in that role in Tasmania for about 5½ years. With accreditation visits—certainly the ones that I have been involved in; and it is my understanding that it is the same for all of them in this state and indeed Australia—residents and relatives are notified at least a fortnight prior to a visit. On the visits that I have undertaken there are always flyers out in the facility advertising that fact and there are always appointments booked for relatives and residents to talk to auditors. My understanding, and I may be a bit rusty, is that at least 10 per cent of residents and relatives have to be spoken with. There has to be documentation around that, and we are always well above that. So I want to reassure you on that point. I think Hilary talked about the mid-cycle slump. I would like to point out that fortunately or unfortunately—whichever way you like to look at it—the agency is very active in spot checks and also in what are called support visits. It is not as if we lay fallow for three years. I just wanted to make those points.

Senator KNOWLES—The first thing I would like to come to is what you were suggesting about an aged care levy. You are very brave.

CHAIR—Braver than we are going to be, I am sure.

Senator KNOWLES—You will recall that back in the late nineties we talked about bonds, and the political and family outcry on the notion of bonds was deafening. In more recent times we have had evidence to this committee—and there have even been people in political parties who have been talking about it—about the introduction of bonds. Why would you opt for a levy instead of a bond, and at what level would you put a levy? Who would pay the levy? For how long would one pay the levy? Generally, what is your notion about a levy versus a bond?

Mr Sadek—Thanks very much for that question. It was our view in 1998—and, when I say it was our view, it was the collective view of Southern Cross Care organisations across Australia—to look at how aged care could be better financed. The thrust of it was: the government were finding difficulty in providing adequate funding, so as an initiative we engaged Professor John McCallum, of the University of Sydney at the time, and we held a number of forums and he developed a paper, which was endorsed and submitted. To answer the question: it was proposed at that time that a 1.1 per cent levy be imposed on the taxpayers—that was the suggestion—and that that be part of the taxable income. That was captured on the thrust that it would ensure quality of later life and provide the best possible care for people in their twilight years, as part of the contribution of society, I suppose. Why would that be preferred to accommodation bonds? Good question. We find it very difficult in Tasmania, particularly, to attract appropriate accommodation bonds to assist with our capital development program. The level of bonds is not the same as in the other states. That is from my limited research, but it is quite apparent that the level of bonds that we get is not consistently at the same level.

Senator KNOWLES—This is into low-care facilities?

Mr Sadek—Yes. If you are suggesting that perhaps accommodation bonds be introduced right across the sector, I believe that is an option available to assist with capital development. We talk about the lead time in terms of building facilities—the number of places being made available—but the lead time for being able to develop the facilities and finance the facilities is not there. Can I go back to the suggestion of an aged care levy. If the levy were imposed on the taxpayers, it would be—in my mind; I am not quite sure what the position of Southern Cross Care Australia would be—a fairer system of being able to identify adequate funding for the provision of aged care services generally.

Senator KNOWLES—It would not necessarily be more immediate, would it?

Mr Sadek—More immediate?

Senator KNOWLES—Where you would actually get the money.

Mr Sadek—No.

Senator KNOWLES—The more immediate process, I would have thought, would be bonds.

Mr Sadek—Yes. This is an alternative assistance. Is it politically acceptable to introduce accommodation bonds? Both governments of today are saying it is not. Is it politically acceptable to introduce an addition to the Medicare levy? Perhaps.

Senator KNOWLES—Perhaps! I am not laughing at your suggestion, because it is the first time we have had such a suggestion and that is why I want to explore it with you. I am just thinking that, as I said, it is very brave. I am concerned at the lack of immediacy about it and I have no doubt that there would be huge public outcry over it, but let us just come back to the bond issue. The biggest problem that we had—other than our political opponents—back in 1998 with the introduction of bonds was the families who somehow thought they were going to be dudded when mum or dad croaked. That is still going to be a problem today, even though they get the majority of the money back. I am still interested to know why the industry here in Tasmania thinks that a levy would be better than a bond.

Mr Sadek—Can I interject there straightaway and say it is not the position of the industry. It was the position of Southern Cross Care Australia. We submitted the proposal prepared by Professor John McCallum; it did not see the light of day. What I am saying is: perhaps it could be resurrected and considered as an option. It is not the position of the industry in Tasmania.

Senator KNOWLES—What do you think about that from your position, Ms Hardy?

Ms Hardy—It is not the first time I have heard about it as an option. I think that, again, whether it is politically palatable is going to be the issue. The issue that you raise about bonds is an interesting one. I believe the last outcry was really around education, education of relatives. People did not actually understand. Certainly, with the residents that we see and chat to, once it is really laid out for them, it is not an issue because they do understand that we would keep very little of it.

Senator KNOWLES—The other element of that argument back in the late nineties was that it removed the flexibility of mum or dad to go home if they chose to do so. The reality is that very few go back to their home after they go to a nursing home.

Ms Hardy—Absolutely.

Senator KNOWLES—They might have a greater chance of going home from a low-care residential facility, but the argument was never raised from that perspective. It is an interesting one. I thank you for that.

Mr Sadek—Can I just add to that? I will read a little excerpt from the paper, and I would be delighted to provide you with a copy of it if you have an interest in this subject.

Senator KNOWLES—Thank you. That would be useful.

Mr Sadek—I will just mention the definition of how the levy would apply, because I think it is important. Under the model proposed at that stage:

> … all Australians would be able to afford high quality residential aged care, home and community care—

we would include community care within this levy—

> and a full range of health services designed for senior citizens. Under the EQOLL model—

and I explained what that was—

> all Australians aged over 25 and earning more than $15,000p.a. would be required to set aside 1.1%—

that was suggested because of the financing modelling that occurred—

> of their taxable income per annum from 2000-2011 in one of four forms—

and this is the important point—

> of aged care insurance in order to be eligible for …

And so it goes on. I am only suggesting that, if there is difficulty in funding aged care services, perhaps this could be revisited and considered. I am delighted to make the paper available. If you need to get further explanation, I think Professor McCallum would be only too pleased—I do not think he has changed his position—to expand.

Senator KNOWLES—Can I move on to young people with disabilities. You were talking about demands on beds in your facilities. Can both of you indicate how many young people with disabilities you have got in your homes at the moment who should realistically be placed elsewhere?

Ms Hardy—I guess it depends on the definition of young.

Senator KNOWLES—I am reliably informed the definition of young is ‘under 65’.

Ms Hardy—Is that correct? Great! Excellent! I am really pleased about that.

Senator KNOWLES—So am I. You have no idea how pleased I am about that!

Ms Hardy—I have to inform you that we have no-one under 65. That is fairly much a deliberate policy by our organisation.

Ms Wallace—Southern Cross Care have a couple of people under 65 at one of our Launceston facilities, as we have six facilities in the state. However, Southern Cross Care also have a deliberate policy of providing care to those aged over 65.

Senator KNOWLES—So where do young people with disabilities go in Tasmania?

Ms Wallace—Some facilities choose to provide those services. Southern Cross Care feel that our expertise is in providing care to the aged and that we do not have the necessary skills to cover the wide range, so we confine ourselves to what we consider is our area of expertise.

Ms Hardy—I agree. It is not just the expertise; it is also very disruptive to have young disabled people in an environment where you have elderly infirm people. The two are almost juxtaposed.

Senator KNOWLES—None of us would disagree with that proposition but we have had evidence in every state that we have visited that there are thousands of young people inappropriately placed in nursing homes, and the ramification of that is not only an implication on their wellbeing but also tying up beds that should properly be used for aged people.

Ms Hardy—Absolutely.

Senator KNOWLES—Therefore I am interested to know what the situation is with young people with acquired brain injury or whatever here in Tasmania. Where do they go and are they adequately provided for in alternative facilities?

Ms Wallace—I cannot answer that. I see on your program that a number of people from organisations that provide services to younger disabled people will appear later in the day.

Senator KNOWLES—That is right. I am only asking you in the context that most homes have been able to say, 'Yes, we have people whom, in an ideal setting, we would prefer not to have.' Mr Sadek, you mentioned being overregulated, underfunded and underresourced. What would you change about the overregulation, given that we have a responsibility to ensure that the public and those who are in facilities are confident that everything is satisfactory? We talked about spot checks and everything else. People are now complaining about spot checks although there was much community and political pressure that such checks should be made. What would you change?

Mr Sadek—Where would you like me to start? There is paperwork absolutely everywhere. You talk about the resident coming into the facility first of all, the extensive amount of documentation—I hope my colleagues here will be able to support me in this—and the time taken by registered nurses. We highlighted the unavailability of registered nurses doing the assessment through to providing details to the Commonwealth on the claiming procedures. We talk about the time and resource—

Senator KNOWLES—We know what the problems are. What would you change? How would you ensure that there is perceived community satisfaction with the quality of homes if those sorts of requirements are changed? How would you change them? What would you do to make it different?

Mr Sadek—There needs to be some sort of validation process in place—perhaps a system of adopting the acute system of negotiating agreements with the Commonwealth government in terms of financing and then reporting on the outcomes that have been specified or agreed. We have Medicare agreements with the acute sector, I understand, and I cannot talk about the detail of them. There are agreements that are entered into, there are specifications that are formulated and there are outcomes that are supposed to be delivered. Perhaps that approach could be one alternative.

Senator KNOWLES—I put it to you that in 1994 the Gregory report found that 13 per cent of nursing homes failed to meet the relevant fire authority standards, 11 per cent did not meet the relevant health authority standards, 70 per cent did not meet the relevant outcome standards, and 51 per cent of nursing home residents were living in rooms with three or more beds. There is no way that we want to go back to that situation. Therefore the accreditation process is a very important part of ensuring that we do not slip back into a situation where 70 per cent do not even meet relevant outcome standards. I ask both of you: if you are unhappy with the way in which those standards have been pulled up and are now continually monitored, how would you change that process to simplify it?

Ms Hardy—As an external auditor I suppose I am a little bit biased and I have a depth of knowledge about the system that perhaps my colleague does not. People are always going to whinge about any auditing process—end of story. Yes, it may well be perceived to be subjective by some in the industry. But, as I think Mr Brandon said at the Sydney hearings, the facts of the matter are that about 68 per cent of homes were fully compliant at the end of round 1 and now, just over three years later, the figure is in the nineties. Like it or not, those figures speak for themselves. It is also very reassuring for elderly people and their relatives in Australia that we do have over 90 per cent of homes compliant with those standards and those outcomes.

Senator KNOWLES—But that does not stop them grizzling about the process—that is what I am getting at. It is terrific that we now have over 90 per cent that have got full three-year accreditation, but wherever we go we get people grizzling.

Ms Hardy—My answer would be that if it is the industry grizzling then they should do what I do and get with the program.

Senator KNOWLES—Get on with it?

Ms Hardy—Just get with the program. There is ample opportunity for people to be external auditors. In that way you get to see other homes. It is terrific for networking. It is terrific for all sorts of things. Yes, it is a bit of a time imposition, but I personally think it is an improvement on the outcome standards monitoring process. The only other way to go would be—as in some other industries—a much more prescriptive style of auditing. That is very difficult when you are dealing with a service industry and when you are dealing with a whole lot of small providers. Obviously there are larger providers in the Australian industry but there are still a number of very small providers, and those providers like to be individual, so I would not have thought that a prescriptive style of methodology is going to be acceptable.

Mr Sadek—I would like to add to that. You asked what we would change. It was remiss of me not to say—I think I referred to it in my brief opening address—that we endorse the Catholic Health Australia recommendations in terms of accreditation. What we have found—and I am not sure whether it is the right feeling—is that it is a bit like a ‘police check’. The support visits are much more like a validation. There needs to be accountability in the system—I understand all that—but there needs to be a refocus on a partnership role to improve best practice. There needs to be some sort of partnership between the accreditation agency and us to ensure that we are continuing to provide for continuous improvement. How do you do that? I suppose the role of the agency could be changed to ensure that there is a focus on care services and let the operators look at other accreditation models for the other business activities of the industry. That is one suggestion that perhaps could be explored.

Ms Hardy—Richard is talking about partnership. What better way to be in a partnership than to actually be in it and have some of your staff be external auditors. That way there is that peer review process. Personally, I would much rather be audited by people who are in the industry, who know the difficulties, who know the resourcing issues, who know the game.

Senator KNOWLES—Can I have your comments on this national aged care workforce strategy? What do you think of that?

Senator MOORE—It only came out last week.

Senator KNOWLES—That is right. It is not a trick question.

Senator MOORE—We have just been so excited about getting it that we keep asking about it.

Ms Hardy—I have had the opportunity to have a quick glance at it. I think there is some terrific work that has been done, without a doubt. There is a lot of information and data in there that we have not seen previously and that in fact has not even been gathered previously. So that is wonderful. There is one thing I did wonder about—and I am not alone in this. Although we are all recognising work force shortages as a problem, to my knowledge and in this document there does not seem to have been any formal sort of gap analysis. We must be in a position to say: ‘The policy is to have this many places, either community or residential, in the next five years. We know how many FTEs it takes to run each residential place currently’—and let’s presume everything else stays equal—‘we know how many FTEs it takes to run a community package and therefore this is the number we are going to need,’ and then ‘How are we going to get them?’ At the moment there does not seem to have been that sort of structure put to it. That is all I would say about that. Other than that, I think it is great that it is out there, and I suppose we should remember that we in the aged-care work force are not alone in the difficulties we experience. There are a lot of work forces suffering those difficulties.

Senator KNOWLES—Do Southern Cross Care have any comments?

Ms Wallace—I actually have not seen it.

Senator McLUCAS—Can I just go back to the levy proposal, Mr Sadek. What is in the proposal to stop any government, once the levy is collected, from simply reducing their contribution to aged care through consolidated revenue, shifting the point of receipt of those funds out of consolidated revenue and into the levy?

Mr Sadek—I cannot really answer that.

Senator McLUCAS—That is what I think may be the falling down of the proposal. Yes, we will have another point of collection of money, but we are just moving it. You get the same amount in the end, but less of it is coming out of consolidated revenue.

CHAIR—Was the levy meant to cover all the costs of aged care—

Mr Sadek—Yes.

CHAIR—or to cover what we perceive as a shortage in what is spent now and the growing need?

Mr Sadek—It was proposed that there would be a contribution through your lifetime towards ensuring a properly accessed, properly resourced and quality service in your twilight years. That was the thrust of the proposal.

Senator McLUCAS—So the costings of the 1.1 per cent—

Mr Sadek—At that time.

Senator McLUCAS—At that point in time—were for the full cost?

Mr Sadek—Yes.

Senator McLUCAS—The current moneys expended into aged care plus some growth, I would imagine.

Mr Sadek—It is identified as the provision of aged care services, yes.

Senator McLUCAS—You could quarantine it in that way, I suppose, given it was a total allocation.

Mr Sadek—Yes.

Senator McLUCAS—In terms of the work force, the issues both of you have raised with us have been raised in every state. I was wondering if there are any particular Tasmanian realities. Thanks, Ms Wallace, for giving us that data on graduates from UTas and what has happened to them, but do you have any particular challenges in Tasmania that are slightly different or that the committee needs to understand so as to understand the Tasmanian experience?

Ms Wallace—I think the average age of a registered nurse in Tasmania is heading towards the late 40s rather than the early 40s as it is in some of the other states. Very shortly, according to the demographics, Tasmania will be the oldest aged state—I think we will overtake South Australia very soon. Another issue facing Tasmania is that it does not attract younger people.

Senator McLUCAS—I think you have a net migration of younger people at the moment.

Ms Hardy—Like Ireland; they are our best export!

Ms Wallace—As the nurses are getting older, there are not other nurses coming in—and nurses come with families who also need work. There is not much happening there. Education opportunities for nurses, particularly in the area of postgraduate education, are very limited.

Senator McLUCAS—Where do you have postgraduate training in Tasmania?

Ms Wallace—UTas has very limited postgraduate programs. I think they have programs for mental health and midwifery. There is no capacity for gerontology, there are very limited health-specific management postgraduate studies and I do not think there are any specific community care or primary care based postgraduate education opportunities available. If you are a Tasmanian nurse and you want to go into that field and you want postgraduate education—which you ought to want if you actually want to make that a career choice—you need to either move interstate or do the very difficult, long, hard road of distance education, which is very difficult. You are very isolated. So those are a few of the issues. Nurses in Sydney and Melbourne and the other big metropolitan centres also have more variety of choice. The pay rates are a little higher, I believe, than in Tasmania in the acute sector.

Senator McLUCAS—I think Tasmania recently had a decision around your acute sector that would put your acute sector in parity with the rest of the nation. Whether that has flowed on to aged care I am not sure.

Ms Hardy—It hasn't. There is still a gap.

Ms Wallace—So there are those things that would be a disincentive. When I have the figures from the University of Tasmania they have about 200 in each year undergraduate year, but, when you look at the figures from the nursing board, two-thirds to three-quarters are choosing to go elsewhere. Tasmania is really one large rural and remote population. Hobart really is not the same as other capital cities.

Senator McLUCAS—In terms of training for care workers as opposed to nurses, what opportunities for training does Tasmania have?

Mrs Savell—We have very good opportunities. There are lots of registered training organisations and our organisation actually has one of its own as well. So all the field staff working in community care have their level III certificate as a mandatory condition of employment.

Senator McLUCAS—And that is not a blockage?

Mrs Savell—No.

Senator McLUCAS—That is good.

Mrs Savell—As for registered nurses, I agree with Carolyn. Our staff have acquired qualifications by distance education from universities in Melbourne.

Senator McLUCAS—Have you talked about it with UTas?

Ms Wallace—There have been a lot of discussions over the years. It was raised at the last Senate committee into nurse education.

Senator McLUCAS—They are basically saying there is just not the number?

Ms Hardy—It is too small.

Senator McLUCAS—We had that with Medicare and training doctors as well.

Ms Hardy—It is important to note that the industry itself in Tasmania has taken quite a lot of initiatives in trying to encourage registered nurses into aged care. Our organisation offers an honours scholarship for an honours student to work with us. I know that Southern Cross Care recently have had a PhD. So the onus is on the organisations themselves to try to encourage that. I go up to the university about three times a year and lecture to undergraduate students, trying desperately to encourage them into aged care. I do not know that we have much success. So there is quite a lot of activity that we undertake ourselves in that regard. There were some preceptorship programs, weren't there?

Ms Wallace—Rosary Gardens had undergraduates for the first time last year. We had first year undergraduates coming to aged care facilities and it was the first time that first year undergraduates from the Tasmanian school of nursing had done any clinical placements. Prior to that they did not do them until their second year. We are happy to have any other clinical speciality placement. We are happy to have anyone who wants to do aged care as a placement. There are not very many.

The biggest, I guess, input is those undergraduate students who work as care assistants to finance their studies. We have as many of those as choose to apply to work with us. Once they have finished their training we offer them some supported practice in those two months between registering and commencing their graduate year, which they need to do. But mostly those are people who have worked with us as carers to support their studies.

A few of those eventually go off and do a grad year. They go and work somewhere else for a year or two in the acute sector. That is experience they need to have, because in aged care there is not the support network for the RN that there is in the acute sector. You are the one who will decide if the doctor needs to come in or does not need to come in. There is no junior doctor or very many other staff members of whom you can ask an opinion. So a new graduate in residential care is going to struggle because you cannot afford to have enough staff to have those supports for them. They need to go off and grow for several years and then choose to come back to aged care. It is very difficult to do that.

Senator McLUCAS—It has been put to us, during both the nursing inquiry and a range of inquiries, that if you lose them at that point it is very hard to get them back. But you have to do it so that they are qualified.

Ms Hardy—Yes.

Ms Wallace—They need that other experience.

Ms Hardy—The other point too is just the total number of hours focused on gerontology within the undergraduate nursing course itself. I do not know the exact statistics, and I am sorry that I do not, but I do know it is a minimal number of hours. It is very hard to attract people to a stream of nursing if they do not actually know about it.

Senator McLUCAS—Or understand it. The government has required that all courses have some gerontology but the question is: how much? Ms Hardy, in terms of your role as an external assessor, does that happen all over Australia?

Ms Hardy—No, my role is just in Tasmania.

Senator McLUCAS—How many external assessors are there? Why do we have them in Tasmania and not anywhere else?

Ms Hardy—We have them everywhere else.

Senator McLUCAS—We do?

Ms Hardy—Yes. It is a work force that the agency draws upon. They have their own internal assessors who are their employees. But due to the number of audits, particularly because it does come in cycles, rather than putting on more employees they will draw on the expertise. They are not necessarily coming from the sector. A lot of those external auditors are people who have done the auditing course, which is quite extensive. Then they undertake an interview and they are out there. But there does not seem to be much take-up by the industry. I am just trying to think how many external auditors there are in Tassie. I do not have the latest figures but I think there are only about seven. To my knowledge, currently only two of those—I am one of them—are directors of nursing who are attached to organisations.

Senator HUTCHINS—Ms Hardy, you are going in and assessing other nursing homes—people in the same industry as you.

Ms Hardy—Yes, that is right. It is, I guess, a peer review process.

Senator HUTCHINS—Why wouldn't we come to the conclusion that it is like Caesar judging Caesar?

Ms Hardy—You could come to that conclusion if you like, except that I am not judging; I am assessing against 44 outcomes. So regardless of what I may do at my facility—

Senator HUTCHINS—But presumably someone in that same industry is coming in and assessing your home too, aren't they?

Ms Hardy—No. I am sorry; could you say that again?

Senator HUTCHINS—Isn't someone else from the nursing home group coming in and assessing your home?

Ms Hardy—Not always, no.

Senator HUTCHINS—But there is someone out there who potentially could do that.

Ms Hardy—Yes, of course. As I said earlier, my preference would be—

Senator HUTCHINS—So you could go and assess their home and they could assess yours.

Ms Hardy—They have to be accredited.

Senator HUTCHINS—I am just asking that; I am not making any judgment on that. I am just asking if that could happen.

Ms Hardy—If they were accredited assessors and if they were on the register of external assessors with the accreditation agency, yes, that could happen. I did say earlier that my preference would be, when our home is audited, that I have someone from the industry as well as an internal auditor.

Mrs Savell—It is not just one single person.

Ms Hardy—Thank you, Jillian. Yes, that is important.

Mrs Savell—It is a team effort.

Senator McLUCAS—That is the model that is used in child care. All assessments in child care are peer assessments. I think it is quite a robust system.

Senator HUTCHINS—The team is not from the Mary Ogilvy Homes Society, is it?

Ms Hardy—No.

Ms Wallace—The team that assesses any particular facility will be made up of at least one internal agency employee plus one to two people—depending on the size of the facility—who were approved and accredited to be auditors. So the ideal team would have people from several other organisations and the agency.

Senator McLUCAS—Mrs Savell, you have made some comments about *The way forward* and generally are supportive of that document. I find it hard to find someone who can be critical of it because it is a very generalist document. It does not have specifics. But you also talked about the competitive tendering that has come out of that.

Mrs Savell—Yes.

Senator McLUCAS—The theme that is coming to me from people who are involved in community care is that there was a bit of surprise that the first practical response was the introduction of a competitive tendering model. I would like your comments on the suitability of competitive tendering in human services and also some specifics about the number of services in Tasmania under the National Respite for Carers Program—what has it meant to the notion of collaboration across the sector? If you could just explain what has happened in Tasmania as a result of that policy.

Mrs Savell—This competitive tendering process came as a great surprise to everybody. The time frame for getting the submission together was extraordinarily short; from memory, it was something like 17 working days. The submission that we put in consisted of more than 7,000 words. The guidelines were fairly sparse and, because Tasmania is small, there were negotiations with many different organisations to see if small programs could all join together to try and reduce the fragmentation of the systems. We had been funded for an in-home diversional therapy program, which is a unique program to care for people with dementia who live in their own homes. It is a respite service centred on very meaningful activities that have been identified as making a difference to their quality of life and preserving the skills that they do have. We tried to fit that in with other service providers so that there could be collaboration between us, and in the end we simply could not.

Senator McLUCAS—Why not?

Mrs Savell—Because ours was so different to anybody else's. There was another provider that had a respite service, but ours was a different respite service. We had lengthy negotiations with them to see if we could join together, but in the end they said: 'No, yours is just far too different from ours. You'll have to go on your own.'

Senator McLUCAS—Was that previously funded as a stand-alone program, and you were looking at developing collaboration with another program instead?

Mrs Savell—Yes. Both of them were stand-alone, but they had other strings to their bow as well, through this same program—and they were a larger HACC provider. We at this stage do not have any home and community care. For us it just was not possible, so that was a problem. They were also looking for people to have programs including the continence aid service, information service and carer respite service. I really feel that the idea of that was excellent, but I will be very interested to see the actual outcome and we will not know that for quite some time.

Senator McLUCAS—When you say 'the outcome', I understand it has to be in place by 1 July.

Mrs Savell—Yes. We will not know until then. It will be interesting to see what changes have occurred under the new streamlining of the National Respite for Carers Program.

Senator McLUCAS—I am interested that you used the word 'streamlining', because that was the language in *The way forward*. It has been put to this committee that it is not actually streamlining to go through a competitive tendering process; that due to the opportunities to collapse programs together, given you are in a competitive environment, it is working against streamlining.

Mrs Savell—Perhaps it is because I am passionate about community care and I look at things from the client perspective—and I do not apologise for that.

Senator McLUCAS—No.

Mrs Savell—When I use the word 'streamlining' I mean streamlining for the client, because one of the very real problems that we have is that the clients do not know where to go. Unless there is somebody there to act as an advocate for them, which we do in the case management role, they very often miss out on the services that they should be entitled to. They struggle away without knowing what is available.

Senator McLUCAS—What I am getting to is that introducing competitive tendering does not actually support the client negotiating the myriad services, because we are now in a competitive situation. Providers who previously would have collaborated to serve that client need are now competitive, so their desire to collaborate is diminished.

Mrs Savell—I quite see your point. The notion that I suggested of the client being the one who is in control of purchasing the services could perhaps be investigated.

Senator McLUCAS—I have used up far too much time. I would like to talk about that if we have got a minute, but I have been too greedy.

CHAIR—If we have time after Senator Humphries's questions then we will come back to it.

Senator HUMPHRIES—There have been criticisms from other aged care providers that the extra money provided in last year's federal budget to improve liquidity of homes is not enough. You have repeated today the concern that there is not enough there to cover the projected wage increases. Can I take it, then, that both your organisations will be fully expending your share of that $877 million on meeting extra wage demands or dealing with wage disparities in your organisations, and not—as I think the Australian Nurses Federation suggested might be the case for some organisations—doing some profit taking from that money? You shook your head, Mr Sadek; that will not come out in *Hansard*.

Mr Sadek—We find it very hard, as not-for-profit organisations, to break even. Of the amount of revenue that we receive, 80 per cent is spent on salaries and wages. About 12 months ago Aged and Community Services Tasmania did a survey of the financial situations of all organisations and found that there were only six operators that were breaking even or making a slight surplus. In fact, it said that 99.5 per cent of moneys available through subsidies were spent on direct resident care.

Senator HUMPHRIES—Can I take it from that that the extra CAP money is fully committed in your organisation to extra pay for workers in your organisation?

Mr Sadek—Yes.

Senator HUMPHRIES—Is the same true for Mary Ogilvy Homes?

Ms Hardy—Yes, and I would suggest it would be true of most operators. Wouldn't you, Richard?

Mr Sadek—Absolutely.

Ms Hardy—To be more specific, given that most of us have signed off on the recent aged care award agreement, which is 18.75 per cent or whatever it is over the next three years—

Senator McLucas interjecting—

Ms Hardy—Yes—that speaks for itself. There is eight per cent in this year alone for registered nurses alone.

Senator HUMPHRIES—Sure.

Mr Sadek—I want to reinforce what I said. In the survey that was undertaken by Aged and Community Services Tasmania, they list the response: 99.5c out of every dollar of subsidy received was spent. I do not see that situation changing with the CAP.

Senator HUMPHRIES—Okay; that is good. I do not think any of you were present when we had our first set of witnesses today from Advocacy Tasmania. I do not know whether any of you have read their submission to the inquiry or not.

Ms Hardy—I was present for a very short period right at the end. I have read their submission, but it was some time ago.

Senator HUMPHRIES—Besides what they had to say orally, in their submission there was some very distressing evidence about things that are happening in Tasmanian nursing homes. Because you are the only representatives we have seen of Tasmanian nursing homes, I want to give you a chance to respond to the issues they raised. You might like to do that now, if you feel confident in doing so, or you might like to take that on notice. I think it is fair to give you a chance to respond to the issues they were raising. Possibly, of course, they were not raising it about any of the institutions that your organisations run, but presumably—particularly you, Ms Hardy, as you are an assessor—you will have some idea of whether the picture that they paint of what is happening in Tasmanian homes is a fair picture or whether there are other perspectives that we should look at.

Ms Wallace—It would be useful to know what sort of comments we would be responding to.

Ms Hardy—Examples, details et cetera.

Senator HUMPHRIES—There are quite a few and there is probably not time to go through them now, but they raise questions about victimisation of people who make complaints by management or staff in nursing homes and a problem of nursing homes, for example, having the power to choose who enters those homes. There was a suggestion that that power gives them the capacity to avoid meeting the needs of people with a particular acuity of care needs. There is an idea, which you have addressed, Ms Hardy, that resources are being pushed into homes just before inspections and then pulled out again afterwards—things like that.

Ms Hardy—I was here for some of those comments. I suppose my only response at this early stage would be that a lot of that is anecdotal. A lot of that is simply someone saying something, and I am not denigrating people who came forward as witnesses, but there did not seem to be today, certainly verbally, much in the way of hard data, such as X number of submissions et cetera.

Senator HUMPHRIES—I suppose that is partly their point—that since they are very rarely present when these things occur they would say it is very hard to prove them. The question I am asking you is whether you feel that the tenor of the problems in certain parts of the industry in Tasmania is a fair description or whether what they are describing is very much an extreme and atypical experience in Tasmania.

Ms Wallace—If you look at the reports on Tasmanian facilities from the Aged Care Standards and Accreditation Agency that are available, I do not think there are any facilities that have been found to have a substantial or even serious risk. So you would have to ask yourself about where the evidence is to support those statements, and whether such a comment has been made once in one circumstance. You would need to know the background behind that statement to see whether it was from someone who was momentarily angry about something that they perceived to have happened or whether it is a systemic issue. You would need to know that information.

Ms Hardy—I was just thinking to myself that there are issues of degree around these things as well. A lost sock, a shrunken jumper or another laundry process et cetera, for example—and I am not being flippant—may be an extremely serious issue to someone. I think this goes back to something I think you, Senator McLucas, said earlier: that, with meal services, one person may be very happy with baked beans on toast and another person may not. It is simply a matter of services identifying resident needs and responding to them. When you are talking about victimisation, I think I would agree with Carolyn—you would need to have a look at the degree and have some pretty hard evidence around what is termed victimisation, because that is about feelings, isn't it? That is a very difficult thing to define.

Senator HUMPHRIES—The point I am getting at is that this evidence has now been put before this parliamentary committee and it is open to us to use that evidence in compiling our report and to refer to it and say, 'These things are said about nursing homes in Tasmania.'

Senator MOORE—Some nursing homes in Tasmania.

Senator HUMPHRIES—Yes, obviously some nursing homes in Tasmania. In fairness, we really do not have a sense of the extent of that problem. I do not think even the people from Advocacy Tasmania do either, in a sense. But, having had those things put to us and having the capacity now to reflect that in our report, I think it would be fair for us to invite you, as representatives of the industry, to respond if you want to—in writing if you like—to the issues that were raised by Advocacy Tasmania.

Ms Wallace—I think we would be happy to respond. However, we really would like the opportunity or the time to read the submission and to see what was actually put to you. I do not see how we can respond without that, but I think we would be happy to give a response.

Senator HUMPHRIES—That is fine. One last question: we heard some comments yesterday from ACAS in Victoria, the body that represents the teams that do the ACAT assessments, about the reforms to the system which have now allowed the nursing homes to self-assess the appropriate classification of their residents. They were sounding warnings about that idea of the homes being able to do that for themselves and said that it was better in some circumstances to have someone external doing that. What do you feel about that criticism?

Ms Wallace—I do not see that an external person is necessarily better placed than a facility which has perhaps in some cases been providing care for that individual for some time. There needs to be a process in place to check the accuracy of those assessments, both those made by the ACAS and those made by facilities. I do not see that either is better placed than the other to make those assessments, but there certainly needs to be some process whereby the accuracy can be checked.

Senator HUMPHRIES—Is that process there with these reforms, in your opinion?

Ms Wallace—I am not sure.

Ms Hardy—Senator Humphries, I presume you are talking about changes to the funding instrument that are being mooted as a result of the Hogan review and about the use of external assessors for that. Is that what the reference is to?

Senator HUMPHRIES—No. One of the reforms announced was that there would be a capacity for nursing homes themselves to determine within the home what classification a resident might be at, rather than having to do that through an ACAT coming in and making an assessment.

Ms Hardy—So from low to high.

Ms Wallace—That is if someone comes in as low and the facility thinks they are high.

Senator HUMPHRIES—That is right.

Ms Wallace—My comments still stand. Possibly neither is better placed than the other, provided there is a proper system in place to check that both are accurate.

Ms Hardy—I was confused there for a moment, but now I see what you are talking about. All aged care organisations currently have the capacity to do their own assessments about the RCS levels within their homes. All that changed was that if somebody was going from low care to high care we used to have to call on the ACAT and, because of resourcing, it used to be some time in some cases before they were able to respond. The change that was made that we have the RCS instrument. Presumably it is valid, because you are doing all the other RCS assessments, and so you may also do this one from low to high. That is what has changed.

I think there are two issues there. If it is a valid instrument, then it ought to be valid whether you are changing from category 1 to 2 or 2 to 3—and indeed from 4 to 5; that ought to be just as valid. There is also an issue around resourcing for the ACATs, and there was very much an issue in some rural and remote areas around the timeliness of the ACAT capacity to respond to those requests and the funding lost in that time gap. Take these hypothetical time frames. You may assess the person as becoming high in March. ACAT, for whatever reason, may not be able to get to your facility for six weeks and then there is the two weeks, and so that is eight weeks. The decision was made that it was not the date on which you applied for the ACAT to reassess but rather the date on which they came. There was a very big funding issue there for facilities and that is what was changed. In terms of who is better able to do that, I do not think we really want a system where it has been so duplicated. If facilities were doing every other assessment adequately, correctly and with credibility, then why would suddenly the assessment from a level 5 to a level 4 not be able to be done effectively?

Senator HUMPHRIES—So you support the changes?

Ms Hardy—Absolutely. Let me add that, with the Hogan review, a change to the funding instrument is about to be piloted. There is some discussion around external assessors for that. I would probably make the same point with regard to that. The home have to do their own assessments in any event in order to effectively care for the resident, so although it is not yet very clear what the system will look like a lot of industry are fairly uncertain about that for those reasons. Why have ACAT doing assessments when we then have to do a whole lot of assessments ourselves? It is about the duplication, which goes back to Richard’s initial point about paperwork and regulation.

Senator McLUCAS—We have gone over time; I apologise. I was going to ask you, Mrs Savell, about the funds travelling with the recipient rather than going to the provider. We might communicate with you and have a discussion about that in a different way because I think it is a longer conversation than we have time for. Have either of the two residential aged care providers heard of an assessment method called Interai? Do you have a view about whether or not the adoption of that checklist—I think that is probably not the right descriptor—as a method of reducing paperwork?

Ms Hardy—I am familiar with it. I am on the minister’s implementation team for the Hogan review and I have actually seen that instrument in detail. Having looked at it, I think it will effectively reduce paperwork. Currently, in order to substantiate our funding, we are required to generate very text-driven documentation over 21 days, which is very time-consuming for registered nurse staff, professional staff and, indeed, carers. What is being proposed is more or less as you have suggested. It is almost like a tick system, I guess. It is a very prescriptive set of assessment documents. Currently, what happens is that each facility develops its own assessment documents. I believe, although it is untested as yet—it is about to be piloted—that it will in large part address that. The industry has been moaning about that for some time. This is the instrument I was talking about, though, that was going to be externally assessed. The industry is not quite so certain about that being a positive.

Senator McLUCAS—It is going to be externally assessed?

Ms Hardy—That is what is being discussed.

Senator McLUCAS—But I thought that, on admission, that instrument is applied—that sounds terrible—by the staff at your residential aged care facility.

Ms Hardy—That is one model. The other model that is also going to be piloted is where an external person, that is, an ACAT person, will actually fill the form in. That is what I was talking about in terms of duplication. They may well do that at the person’s home three months prior to admission, during which time all sorts of things may have occurred. Then they come to us and we are going to have to do it in any event. But, certainly, I believe the instrument itself, regardless of how it is proposed that it be applied, will in large part reduce a lot of the text documentation.

CHAIR—Thank you all very much for your submissions and your presentation today.

Proceedings suspended from 12.22 p.m. to 1.07 p.m.

ROWELL, Mr Mathew Christopher, Chief Executive Officer, Tasmanian Council of Social Service

CHAIR—Welcome. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public, but evidence may also be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submission and I now invite you to make an opening statement to be followed by questions from the committee.

Mr Rowell—Firstly, thank you for the opportunity to make a verbal presentation to the committee. I would like to highlight some of the key areas in our written submission. It is important to note that, in the time that has passed since we provided that written submission in August, our consultation project has consulted with a large number of consumers and potential consumers of aged care services and has produced quite a lot more valuable material. This material is not so much additional or new material but supporting material that is more current than what was in the original submission.

Given the scope of our organisation, TasCOSS chose in the written submission to focus only on the two points in the terms of reference that we felt we had the experience and the knowledge to comment on with some accuracy. Those two terms of reference, as you have seen in the submission, are (d) which relates to the adequacy of the Home and Community Care program, and (e) which relates to the effectiveness of arrangements in relation to transition.

TasCOSS, as you know, is the peak industry body for the community services industry in this state. The sector in Tasmania is made up of over 250 non-government community service organisations that provide a range of services to vulnerable and disadvantaged Tasmanians, and they are the organisations that we use to gain access to vulnerable consumers in this area. For over four years we have consulted directly with consumers and potential consumers of home and community care services and provided a report to the state government, which provides funding for that particular project in order to assist them in their planning process to deliver growth fund services across the state.

As we state in the submission, it is important to note the uniqueness of Tasmania in relation to our demographics. In particular we point out that Tasmania is the most regionalised state in the country, with almost 60 per cent of our population living outside our major urban centres. We have the lowest weekly average earnings, the highest proportion of any state of people with disabilities and a higher proportion than other states of people who are 65 and over. TasCOSS is of the view that the Home and Community Care program is currently not adequately meeting the needs of the elderly. We believe that the program is not provided with gross funds at the appropriate rate to enable the future needs of the elderly to be met in particular programs. That is on top of what we hear from services in relation to the quantum and the quality of the service delivery that is currently provided.

Some of the key elements of the Home and Community Care program that we allude to in the submission and which I will flesh out a bit for you now include the widely reported epidemic of social isolation or loneliness of older people in Tasmania. As I said, we have a higher incidence of older people living in rural and remote communities without access to HACC services or family supports. Individuals consulted also believe that in Tasmania there is a higher incidence of their children, particularly adult children, moving out of the state and therefore reducing the family support systems that exist for older people. We also have an increase in social isolation for Tasmanians because our transport system is inadequate to meet their needs, particularly in rural areas.

In terms of general services under the HACC program, elderly people that we have consulted are really only seeking minimum care, including things like domestic help, transport and help with cleaning—in particular, spring cleaning—and gardening. These are some of the areas that we understand from consulting with older people in Tasmania are of particular concern to them. People often report insufficient and inadequate domestic services. An example that was provided to me from a consultation that was conducted last month involved an elderly woman who was living at home with some mobility barriers. Her son normally cared for her but was away on business for the week. She dropped a bowl of soup in her kitchen and because her domestic assistance was only weekly that sat on the floor for a week because there was no-one to clean it up, which caused her great distress and discomfort.

As I said, the transport barriers in this state are particularly high and people find it very difficult to live independently, particularly in rural and remote communities where there is no access to transport. You all know the impact being stuck at home has on people who do not have access to transport services—and the impact of lacking basic access to medical appointments. If someone with mobility issues has to get onto a bus to get to a town that is 10 minutes away and that bus does not return to their home town that evening, they have to stay in another town overnight. People’s access to medical appointments and social activities, which are also really important for this target group, are limited because of those transport barriers. Community bus services are either non-existent or inflexible in their timetables and when cheaper taxi fares are available they are still often prohibitive, particularly when travelling between smaller rural townships.

An area that older people report to us directly as of particular concern to them is gardening. We have heard stories in the last months of older people seeking to relocate because their garden cannot be maintained. There is a sense of pride for older people in their home being maintained at a certain level, but there is also a sense of vulnerability and safety for older people. They report to us that the less tidy their garden looks, the more vulnerable they feel to break-ins and vandalism.

The other major area of concern for us in the HACC arena is that of information. Something like 90 per cent of the people we consulted had never heard of the Carelink Centres or services so were unclear on how they could get access to services that may have been available to them. That is particularly important for people living in rural and remote communities where a mainstream service may not exist. Accessibility and visibility of services in terms of people providing information to their neighbours or their friends is important. We know that information about Home and Community Care services is often provided by word of mouth, through a vertical dissemination route. We continue to recommend to the state in our report that information dissemination is an area that needs particular attention.

In the last six months we focused our consultations on the migrant communities in Tasmania and found that they are grossly underrepresented in HACC services. There are fewer migrants than Australians accessing HACC services. It is clear that the smaller migrant communities in particular, which are ageing rapidly, do not have access to some of the ethno-specific services that some of the larger migrant communities have—they do not have the critical mass that would have allowed them to set up their own HACC services to provide services to their ageing communities. There are particularly high levels of language and cultural attrition out of care as migrants get older. We are hearing reports of clients not being able to communicate with HACC workers if they have them, because as they get older they often slip back to their first language or their language of origin. We are also hearing a large number of stories of migrants who have had World War II experiences or unhappy settlement experiences in Australia suffering from delayed post-traumatic stress disorder that exhibits in physical symptoms as well.

The other thing to point out about the HACC arena in Tasmania is the reliance on volunteers. We have about 13,000 people who are currently HACC clients or registered HACC service users in this state, with an estimated 5,000 volunteers providing critical HACC services. Some organisations run with volunteer based services because that is the way they have been set up and that is the service model they have chosen to adopt. However, in a range of services it is reported that volunteers are being used because the services do not have funds to employ the staff they need. One of the concerns is that the volunteer demographic is also rapidly ageing and decreasing because as volunteers get older there is a fine line between whether they are volunteering for service delivery or are actually eligible for services themselves.

In relation to point (e) in the terms of reference regarding transition services, we know that Tasmania’s acute health care system is at capacity; that there are a number of people who are aged care patients in Tasmanian hospitals who are unable to access aged care facilities or Home and Community Care services; and that there is a strong need for protocols to be developed between HACC services and hospitals to ensure that we do not have inappropriate discharges being undertaken. We continue to hear anecdotal evidence of elderly people being discharged in the evenings or at weekends without referrals having been made to HACC services and without supports being put in place, so people are being discharged at times when there is not the capacity to set up care for them immediately. They are going home to no support at all. Indeed, there are examples of clients being discharged from hospitals but with no transport to get home.

We have also heard some examples of carers of clients who also need assistance—for example, people who are over 65 caring for their parents. HACC services are provided to the parent as a primary client, but often the physical and emotional toll of being a full-time carer means that by the time that parent is deceased the carer themselves needs to be eligible for HACC services. That is not being acknowledged in the services provided at the moment.

In summary, the key findings of our consultations between 2001 and the present day are that there is little or no knowledge in rural and regional areas of HACC services and of which HACC services are available; that the services that are currently provided are grossly insufficient to meet their needs; that community transport, home and garden maintenance and domestic assistance are of particular concern to the clients themselves; that generally people do not have sufficient care to ensure that they will not be prematurely forced into either an aged care facility or the acute system; that any attempt to assess unmet need by looking at waiting list figures will consistently understate the level of unmet need because people are not even applying for assessment of services; and that the need for seamless transition for HACC consumers between acute and community care is essential for the maintenance of independent living and is recognised by the non-government community services industry as a reform that is long overdue. In closing, it is important to state that TasCOSS and its members fully support the general direction and aims of *The Way Forward* document that has recently been released.

Senator HUMPHRIES—On that last point you made about the range of organisations available to assist in the community and the lack of transition—you referred to gaps between systems—is it your experience that in Tasmania most of the providers of residential aged care services tend not to be in community services and vice versa, or are there many organisations that overlap between those two sectors?

Mr Rowell—My understanding is limited because we do not have a strong membership base in the aged care facilities in the residential aged care sector, but I do understand that there are more and more aged care facilities of a residential nature which are also now providing CACP or HACC programs. I understand there is an increasing number of those organisations that are delivering both.

Senator HUMPHRIES—Do you think organisations which have a multiplicity of roles like that are part of the answer to that problem you raised of gaps between services or lack of smooth transition between services as people’s needs change?

Mr Rowell—Particularly in the rural and remote communities around Tasmania, which are not far out of our three major cities, that kind of flexible service delivery is really important, and we recommended in our last two reports that funding models and service type models, particularly for those communities, need to be innovative and flexible to be able to accommodate that. In some of those communities there could be some benefits from that particular service type.

Senator HUMPHRIES—If there was a funding model which was based on a case management type of approach so that a variety of a person’s needs could be addressed, presumably that would be better for the person concerned, arguably, and it would mean that there was more encouragement for organisations to deal with more of the facets of a person’s problems or needs. It might encourage organisations to think about diversifying the things they do and the services they provide. Otherwise, it is hard to see what role we can play in stimulating organisations to look at that problem. We cannot very well recommend that service providers amalgamate—I suppose we could but I am not sure that would be very useful—but if the funding model were to change then that would encourage them to think about that. Would you regard that as a good thing?

Mr Rowell—Case management type packages of care are useful in particular situations for clients. In the non-government community services sector in Tasmania they are not as useful in terms of organisational capacity. We have organisations that are reporting that 20-hour a week staff members are carrying case loads of 90 to 100 clients. That equates to not being able to get around to many of those clients very often. We are hearing stories of those organisations not being able to keep up with demand or reporting requirements. A range of organisational capacity issues exist that apply not just to the home and community care sector but to the non-government community services industry in general. Those sorts of packages of care provide limitations to organisations being able to plan to recruit and retain staff well. It lends itself to uncertainty of organisational capacity.

Senator HUMPHRIES—You mentioned the problem of lack of knowledge in rural and remote areas of what, for example, is available by way of HACC funding. How do you fix that problem?

Mr Rowell—We need to be a bit smarter about how we disseminate information. What we hear from HACC consumers or potential HACC consumers is that most of them hear about whether they are eligible or whether they should be applying for HACC services either through friends and family or through social networks who are already receiving it or already know of people who are receiving it. GPs are crucial in rural communities. Tasmanians have a distinct lack of access to GPs in rural communities but if we can get around that then I think GPs will have a very key role in disseminating appropriate information. Things like Carelink centres and Centrelink offices and some of those human services one-stop shops that are being talked about at the moment do not apply necessarily in our rural communities because we often do not have any of those offices in smaller townships and you have to travel to a larger semi-urban centre to get that information.

I am not sure what the definitive answer is but we need to be a bit more innovative about how we get information out there—publicity and promotion through the media and through bowling clubs and other social clubs and things like that that occur in particular communities. Rural communities have particular elements that are unique to them and their social hub. If we can tap into accessing whatever the heart of that community is—where older people congregate or where people most use services—then I think that we need to be providing a greater level of information through those avenues, rather than just through traditional methods.

Senator HUMPHRIES—You talk a lot about HACC and how well it is addressing needs. The HACC funding base has been expanded by at least 73 per cent in the last nine or so years in terms of Commonwealth contribution. I assume that means the states must have matched that funding, so it has had a pretty sizeable increase in capacity in that time. But I do not sense any sort of slackening off of demand or that demand is being satiated by this process. You talked before about there being unmet need and that people only come out of the woodwork in certain circumstances. Do you think that is happening with respect to HACC funding? If so, how do we measure what the total unmet need actually is in a sector like your own?

Mr Rowell—As we said in the submission and in the report that was attached to the submission, it is really difficult to measure unmet need accurately. But we know that in Tasmania approximately 28 per cent of people aged over 65 receive HACC services. If you made some assumptions that perhaps 50 per cent of people over 65 needed or required HACC services then we would still be left with quite a large proportion of people not accessing them. If you think about people who are HACC eligible in Tasmania, over 70 per cent of people over 65 are not accessing HACC services, which is quite a large number of people.

Senator HUMPHRIES—I take your point. It does not give us much that we can recommend specifically in terms of improvement. Perhaps you would like to have a think about whether there is anything you can specifically recommend in that respect. You mentioned on page 2 of your submission that you made a recommendation to the Tasmanian Department of Health and

Human Services to have a ‘review of funding and service delivery models to isolated regional areas to ascertain if consumer access to service provision can be improved’. I assume that is a facet of the issue that you raised before about information. What was the response of the department? Do you think there is a role for Commonwealth agencies to piggyback on that kind of work?

Mr Rowell—I think so. We provide that report to the state Department of Health and Human Services, who are seen as our funding body, but acknowledge that it also goes to the Commonwealth Department of Health and Ageing, as it is the matching funder in that particular program. While we make the recommendation directly to the state, we also expect that the Commonwealth will engage in a conversation with the state. There is quite a strong, close working relationship between DOHA and DHHS in Tasmania. I think that the state picked the recommendation up within the limits of its ability, with the growth funds that were available. We know that some further funds were directed in the growth round towards some of the rural and isolated communities that we recommended in that particular round. But, in terms of systemic change to the HACC program in general in its funding model, I think that the state has not picked that up yet.

Senator HUMPHRIES—Finally—you do not mention this in your submission but obviously you would be aware of it—there is the concern that has been expressed about the lack of alternative facilities to aged care facilities for young disabled people. Have TasCOSS or constituent organisations of TasCOSS taken a case up to the state government for there to be better facilities for those sorts of people?

Mr Rowell—We have. We have made strong submissions to the state government in recent weeks for the state budget in May to deliver increased group homes and support services to young people with disabilities.

Senator HUMPHRIES—Would you accept the premise that those sorts of campaigns, which I understand are being pursued to varying degrees in other states as well, are only going to be successful if it is possible for organisations like yours to raise the public profile of that issue? I suspect most people in the street, here or elsewhere in Australia, would not be aware that there are significant numbers of young people in aged care facilities. Do you need to work on building up that understanding in order to get more political traction on that issue? Is that fair?

Mr Rowell—It is fair. Any campaign work we do involves engaging in a public debate and raising the public profile of a particular issue, whether it is disability or homelessness. That is part of our campaign strategy.

Senator McLUCAS—Like Senator Humphries, I was a bit concerned about the point you made about people in regional and rural areas having limited knowledge of HACC services. In the work that you have done, did you see that there was a contrast between urban based Tasmanians and rural based Tasmanians?

Mr Rowell—Absolutely. I think that is about visibility of services. I think that people in urban areas do see on the street that services exist. They see a building and they see a sign, and I think there is an increased visibility through that. There is also much greater access to GPs, for example, and health care services in urban areas. Therefore health care professionals have information at their fingertips. So I think there is definitely a contrast.

Senator McLUCAS—And referrals are recurring. Could you give the committee a bit of an understanding of how HACC is delivered in Tasmania?

Mr Rowell—I think there are 59 organisations across the state who deliver HACC services. Some of those are state government funded services. I think there are a couple of private organisations as well and then a range of non-government community services organisations who deliver HACC services.

Senator McLUCAS—Are they broadly geographically based? What is the structure of delivery?

Mr Rowell—I would have to go back to the data, which I do not have with me. They have been broadly geographically based. There are a number of statewide organisations and there are a number of organisations that are unique to the south, north and north-west. Tasmania is often divided up in terms of service delivery or programs by those three regions. That is my understanding of how those organisations have been set up over the years. In the last two years we have seen much greater attention to some of the smaller and more isolated regional communities as well in terms of the unique needs that they have.

Senator McLUCAS—You said 90 per cent of people who you interview had no knowledge of Carelink. How is Carelink delivered in Tasmania?

Mr Rowell—My understanding is that Carelink is delivered through offices in the major urban centres. Certainly we see advertisements in the regional newspapers about how Carelink had been the gateway to community care services of various kinds. But I think that has been the extent of the promotion of how that office actually works at this point.

Senator McLUCAS—Have you interviewed Carelink providers or talked to them at all?

Mr Rowell—No, we have not done that.

Senator McLUCAS—Just finally, you said TasCOSS supports the intent of *The Way Forward*. Are you aware, though, that the first strategy that has come out of that document has been the competitive tendering of the national respite for carers program?

Mr Rowell—No, I was not aware of that.

Senator McLUCAS—I will not pursue that. Thank you very much.

Senator MOORE—The communication issue is a longstanding issue in Tasmania. When we ask questions about these programs at Senate estimates, the response we get is that one of the main ways of communicating to this group is through the *Aged Pension News*, a social security product, which has been around a long time. Has your group done any work about the effectiveness of that as a tool? Certainly in the communication strategies around any of these processes, the fact that just about all of the aged care population are recipients of that document means that that is one of the streams the department relies on. In terms of the communications process in Tassie, has there been any work about the effectiveness of that document and its distribution?

Mr Rowell—We have not done any specific work about the effectiveness of that document but we have had some anecdotal evidence from the consumers we have consulted with. There are often literacy issues for older people. People are not as literate in those generations as other generations. For those from non-English-speaking background, there are particular issues about understanding some of those documents, but not in relation to that specific publication.

Senator KNOWLES—You mentioned the difficulty of some aged people being able to access medical appointments in other towns and not being able to get transport back to home, necessitating overnight stays. What is the solution to that problem?

Mr Rowell—One of the things we have been calling for in our reports in previous years has been for community transport services to be expanded in their scope and to be expanded in their delivery across the state but also to be used flexibly. So one of the things that we hear quite often is that there are community transport buses which organisations are not able to access volunteer drivers for because of the demographic of the particular community or school buses that get used for an hour either side of the day and then sit vacant for the rest of the day. We have tried to make some recommendations to the state government about how they might look at some more innovative ways of providing transport assistance to people in this particular target group, An increase in the number of disability taxis, for example, has just been achieved with the state releasing a number of new licences in that area.

Senator KNOWLES—I saw a very flash one out here a little while ago.

Mr Rowell—There are some new vehicles around. People with disabilities whom we work with are reporting a greater ability to access those. Again, those taxis are mostly based in urban centres, not in regional or rural areas. We have been wanting the state government to engage the private sector with the community transport providers in some conversations about how they might be able to best make use of the vehicles that are currently on the road and that exist in those communities but are not being utilised appropriately.

Senator KNOWLES—With what response?

Mr Rowell—It is fair to say that it has been difficult to engage the private sector in those conversations.

Senator KNOWLES—If we just specifically look at, say, the school bus issue, has there been any positive response about the wider utilisation of that?

Mr Rowell—In rural and regional communities, most of the providers are private, not in the state government system. My understanding is that the state government has attempted to engaged the private sector in conversations without much success.

Senator KNOWLES—Do you know what the barrier has been?

Mr Rowell—I am not sure. I could not answer that question.

CHAIR—Thank you very much for your submission and your presentation today.

Proceedings suspended from 1.36 p.m. to 2.06 p.m.

HODGSON, Mrs Susan Mary, Vice President, Housing Options Providing Extra Support Inc.

PEARCE, Mr David, President, Housing Options Providing Extra Support Inc.

NEILSON, Ms Carolyn Annette, Member, Housing Options Providing Extra Support Inc.

ACTING CHAIR (Senator Knowles)—Welcome. I understand you have another commitment which you need to attend to. Therefore, we are going to speak to you first. I thank the representatives of the Brain Injury Association of Tasmania and the MS Society of Tasmania for their acceptance of having a short delay before their presentations. Do you have any comments to make on the capacity in which you appear?

Mrs Hodgson—I was responsible for the submission that was sent to you earlier. At that stage I was president of HOPES.

ACTING CHAIR—I think you have been provided with the information about parliamentary privilege. The committee prefers all evidence to be given in public. However, if you wish to give any in camera evidence the committee can certainly consider that request. We have before us your submission. If you would like to make any comments I am sure we would love to hear them. The senators will ask you some questions, no doubt, after your comments.

Mrs Hodgson—Perhaps I could just start by saying that we do not have a supplementary submission. We just thought it would be good to come and speak from a personal point of view about some of the issues that we have raised in the submission. For that reason, you need to know a little bit about our backgrounds. I am the mother of a daughter with an acquired brain injury who has fairly high support needs and who has been living at home with me for 19 years now. Obviously, as you can tell by the colour of my hair, my concern is about what happens when I cannot support her. I have had added complications in recent years in that she got married very unexpectedly three years ago so I have inherited a son-in-law with an acquired brain injury too. This has led me into a lot of issues in terms of respite and support and what is and is not available currently for my daughter.

Obviously my colleagues will introduce themselves but Carolyn is living in the community managing on her own. She was sharing her life and home with somebody who has now been moved into a nursing home. David is managing in the community with support but still needs a lot of support from his parents. So I guess we can offer three perspectives of some of the issues that we have raised in our submission. Would you prefer to ask us questions and work from there, or would you like us to speak further?

ACTING CHAIR—We are flexible as to whether Ms Neilson or Mr Pearce would like to make any additional comments before questions.

Mr Pearce—As Susan has said, I have a unit. I currently have an individual support package of approximately 35 hours a week. That support package equates to approximately 4½ hours each day to allow me to cater for my personal care needs, the provision of meals, assistance with my personal hygiene requirements and my involvement in the community. I am a member of 15 different committees, representing many organisations across the human services area. I am also a former elected member of the Glenorchy City Council, and I served from 1999 until 2002. The package that I receive allows me the flexibility to bank up to and including 50 hours on an annual basis. If I need a support worker to come in at different times of the day or the evening, and if I need the support worker for three hours to assist me with things like extra housework or gardening or assistance with the many organisations that I represent, that enables me to do that.

However, having said that, I must tell you that my parents, who are now in their late 60s and their 70s, still provide me with in my estimation about 35 hours a week. They still assist me with things like cooking meals or if there is an emergency with my personal care needs and there is not enough time for a support worker to get to may place then they assist me with that. As I said, my mother will often prepare meals for me and put them in my freezer so my support worker can just get them out of the freezer and thaw them out. Also, the extra hours that my parents put in to assist me include things like paperwork, because, as you can appreciate, when you are on 15 different committees there is an awful lot of paperwork to get through on a weekly basis. So my parents assist me with paperwork and filing and the necessary things required with that. It is those sorts of things that the support package that I receive does not take into account. For example, under the personal support guidelines shopping is not counted as a personal care requirement. So I cannot receive hours to do that, and so my parents or my friend assist me with my weekly grocery shopping. So without the extra hours that my parents provide there is a huge possibility that I might not function as well in the community as I do today.

One of my major fears is about what will happen to me as my parents age and acquire health problems and disabilities themselves, as they are now doing, if the support package that I get does not provide me with enough flexibility or enough hours to do what I need to do to assist my community. One of my biggest fears is that I may end up in a nursing home myself. Although the staff there do their very best, nursing homes should not be for young people with disabilities.

One of my previous positions was as a member of the National Disability Advisory Council, on which I served from 1996 until 2001. One of the committees I served on in that role was made up of members of the council and it worked on closing down major state run institutions. I am pleased to say that many of those institutions have now closed, yet across Australia we still put young people with disabilities into nursing homes, and that virtually sends a message to the community, from my perspective anyway, that they have become invisible citizens. My fear was that if I had to go into a nursing home I would lose access to many of the services I now receive. For example, I would not be eligible to receive assistance for equipment; I would not be eligible to receive any home and community care services; I would not have access to my general community, of which I am proud to say I am an active member; and the odds are that I would not be able to advocate for the many people in this community for whom I advocate, simply because I would not have access to the support services that enable me to do that.

CHAIR—Ms Neilson, do you have anything to add?

Ms Neilson—As I alluded to earlier, I was living with my partner in his home. He had a further fall and subsequently has ended up in a nursing home. Because of that, his parents sold his house and I had to find somewhere to live. I went to the housing department but, would you believe it, I earn too much and I have too much money in the bank. Their answer to my situation was, ‘You’ll have to go into a nursing home.’ I refused outwardly. Fortunately, at the place where I rent privately I was allowed to do the modifications required to enable me to live in the community.

Mrs Hodgson—The other side is that Carolyn has now been able to see her partner in the nursing home. Carolyn, would you like to comment on that?

Ms Neilson—He has set times for meals and you have to try and work around that. It costs about $11 by taxi. As you can imagine, in any partnership the dynamics change. So it is different.

Mrs Hodgson—Would you like to comment on the differences you have noticed in your partner while he has been in the nursing home?

Ms Neilson—Unfortunately, his parents are unable to care for him and, of course, it is too difficult for me. He is 52. You go along to the nursing home and he is playing bingo with a group of elderly ladies. I have nothing against elderly people, but he is 52. Also, there is his acceptance of the nursing home environment as, ‘Well, it’s better than nothing.’ Personally, I would loathe it. Mind you, I will probably end up in one myself in years to come, but not at this moment anyway.

Mrs Hodgson—We just wanted to be able to show you some of the problems that, in some instances, are not directly involved with living in a nursing home as a younger person. In Carolyn’s case it has made a change to her whole life. From a situation where two people were supporting each other, she now finds herself in isolation and it is difficult for her to see what is happening to her partner within the nursing home environment. In my case, prior to my daughter’s marriage, say 10 years ago, when I was looking for respite the only respite for her was in an aged care nursing home. The first time she went in was fine; on the second occasion she returned to the nursing time I was told it would have to be for three weeks and I fought that and said we only wanted one week. It actually turned out to be one night because, when we got there, to my horror I discovered that the respite bed was actually in a locked dementia unit.

I think this is quite common in nursing homes, too, because they have little choice. If they only have one respite bed, they have to be prepared for the person with the highest dementive needs. In my daughter’s case, she has no verbal speech and uses a computer to communicate and is wheelchair bound. So to be locked into a situation where you cannot get out, with 11 very elderly demented people around you, was not an option for her or for me. That is still a problem with nursing homes.

Mr Pearce—It is also the fact that young people in nursing homes, if they were given the correct community support that they and their families need, can still remain as productive, contributing citizens in their respective communities—particularly with the Commonwealth and state governments putting more emphasis on the fact that they need to get people with disabilities back into the work force as contributing citizens. I cannot understand why they still have the attitude that young people should be in nursing homes. It does not ring true with what they now want people with disabilities to do.

Mrs Hodgson—The other thing from HOPES’s point of view is that we have for several years, as intimated in the submission, been attempting to get a cooperative living unit up and running. We are currently in discussions with an aged care group and a co-housing group for the possible development of some land on the eastern shore of Hobart. The difficulty is that it is very hard to get the financial support for that sort of project and approval that what we are trying to do is workable.

In the last couple of days there has been some press coverage, which you have probably seen, of the innovative pool program funds from the Commonwealth. The difficulty with that is its inflexibility. The requirement is that it is for bringing younger people out of nursing homes, which is fine, but if you do that on its own it is really not a sustainable option, because you have a few people with very high level needs which are going to be very expensive to support on their own in the community. In the project that we are supporting, for example, we have a mixture of support needs and ways in which resources can be shared in a cooperative fashion, which we think is preferable. I am not saying that our option is the only option, but I think there are options out there which need to be trialled but are stifled by programs like the innovative pool. We would obviously like to see some closer working partnership between the Commonwealth and state to allow some of these things to happen and to perhaps enable additional support for younger people who are currently in aged care nursing homes.

Mr Pearce—From my perspective, with this idea of cooperation between state and Commonwealth governments, there needs to be more emphasis placed on the value of the Commonwealth State/Territory Disability Agreement. For many years, because of political ideology, there have been arguments between state and Commonwealth governments as to where the CSTDA should go. This has resulted in many of the services that people with disabilities need to be able to function in their communities not being funded sufficiently to enable them to do that.

Senator KNOWLES—Mr Pearce, what has been your negotiation with the state government in regard to the CSTDA? We have had evidence everywhere we have been that the sheer number of places available for young people with disabilities is not what it needs to be. I would be interested to know what the state government’s response to your lobbying has been.

Mr Pearce—For many years Sue, my other colleague and I have been negotiating with state governments. We have been on many working parties to work with state government departments on how best to consult with people with disabilities. We have been on working parties with state governments to work with them on how to identify what the issues are at the state base. As a joint member of several community based organisations, including HOPES, my colleagues and I have worked closely with state governments through the Commonwealth and state advisory bodies. As far as the Commonwealth State/Territory Disability Agreement goes, one of the major issues, as I have said previously, is the fact that there has been too much argument between the state and Commonwealth governments because of political ideologies. This has meant that the agreement itself has been held up. It has also meant that when community based organisations have applied for funding they have not been able to plan on a long-term basis because they do not know when the funding will be made available to them.

Senator KNOWLES—The Commonwealth State/Territory Disability Agreement has been negotiated across all different political parties. We are not just talking about the current agreement; we are talking about all the previous agreements and, needless to say, the ones to come. It is not just about politics that I am asking this question; it is about the practicalities of it.

I do not much care, quite frankly, what political colour either government is. The fact of the matter is that the agreement has been signed and certain undertakings have been made. What we have evidenced is that those undertakings are not being met. You say here in your submission ‘Tasmania has more than 150 people under the age of 65 in aged care nursing homes’. That is pretty unsatisfactory.

Mr Pearce—It is. Without knowing the exact number, per capita I would say that Tasmania has the highest proportion of young people in nursing homes.

Senator KNOWLES—Do you know how many young people with disabilities are placed in the community?

Mr Pearce—That is hard to say. It has been very difficult to tell because the department of disability services in Tasmania have figures they deal with but then there are a lot of small community based organisations which do not necessarily have direct contact with the department of disability services.

Mrs Hodgson—You can register with the Disability Services program for support, accommodation and your other needs but they have nowhere to put you. So people generally do not bother registering unless there is somewhere to go beyond that point.

Senator KNOWLES—Mrs Hodgson, what has happened in the situation of your daughter and son-in-law? Have you had talks with the state government to try to put them on a list or to see where they can go, whether they can live independently now or in the future?

Mrs Hodgson—I have had some discussions about that. At the moment I am getting some support hours for my daughter—some historical HACC funds from many years ago, six hours a week, and a few extra hours through independent options programs. As a result of that, she spends two nights a week at her husband’s home with a carer and the rest of the time they are both with us. In the discussions I have had with the department, part of the issue has been trying to get the HOPES project up, which, on three occasions, we almost received funding for through the community housing program, but each time Disability Services has been asked to sign off on that to say that there is adequate support for this project. There concern last time, which is now 2½ years ago, was that whilst there would be adequate support through the budget we had drawn up there was no guarantee that people would not have higher support needs in the future, which seems a little bit obvious and not really part of the current situation.

My basic concern is that Disability Services in this state—I would not like to comment on other states—have themselves in virtually a crisis situation. They cannot address the unmet need and they are very concerned about younger people going into nursing homes—genuinely concerned. Because families are not happy about their young people going into nursing homes, they are blocking up the hospital system by keeping people in hospital much longer than they should. Then when they are forced to take people out of that environment they are putting them inappropriately either into a group home where there is a vacancy—compatibility is somewhere down the list—or into a situation where one or two people may be in a house for behavioural issues, which is an extremely costly way of addressing the issue. What happens as a result is that the amount of money being used for a small number of people is considerably higher than it might be if pre-planning had gone on. Many organisations are saying that there needs to be pre-planning. They have themselves in such difficulty because of the unmet need that it is difficult to sort that out and to pre-plan without a quite heavy injection of funds.

Mr Pearce—We regret to say that the department of disability services has become reactive instead of proactive. As Sue just said, because the waiting lists are becoming so long, unfortunately there has to be an emergency before the department can get themselves into action.

Senator KNOWLES—We had evidence yesterday that a lot of it was all about cost shifting so that, if people with disabilities were placed in a nursing home, it would be the Commonwealth, as opposed to the state, that picked up the cost. But that also has a flow-on effect—as you say, Mrs Hodgson—because of the acute sector having to hold people in hospitals, and many of those people might be assessed to go into an aged care facility.

Mrs Hodgson—Yes.

Senator KNOWLES—So they cannot get into where they should be—

Mr Pearce—That is right.

Senator KNOWLES—because young people are in there. So it has a snowball effect. We are just trying to find our way through as to how best this can be solved.

Mrs Hodgson—We talked about 155 people under the age of 65 in aged care nursing homes. Many of them have been there for many years and, if you went and asked them—or particularly if you asked their families, where maybe they need that support—whether they would be happy to move out of the nursing home, many of them would say no, because it is an environment that they have come to know. They and particularly their families feel that they are safe there.

So there are myriad issues here, but they are issues that have been raised over and over again, to my knowledge, since the early nineties anyway. There have been various reports done. And this is another concern: when partnerships do officially occur between the state and the Commonwealth, they seem to go back to this researching of the problem and creating working parties, reference groups et cetera to go over the stuff that we all know. As far as I am concerned, the difficulty is that the problem is out there. If you spend a lot of time now getting numbers, by the time you move to the next step those numbers may have changed again anyway. I really think that we need some practical trials of something to try and work this out.

One thing that seemed fairly straightforward to me many years ago was that, if there were a closer tie between the Commonwealth and state in terms of the younger people in nursing homes which would allow top-up funds from the state to support those younger people and which would allow aged care nursing homes to have a younger person’s unit, there would not be much additional expense for an improved quality of life for those people.

Senator KNOWLES—There is no point having the CSTDA then, is there—getting money for nothing?

Mrs Hodgson—That is right. I agree. But those—from our point of view—bureaucratic tangles seem to bog down the whole process. From the consumers' point of view, the state obviously will blame the Commonwealth; the Commonwealth will blame the state.

Mr Pearce—And for many people it is not just when people with disabilities go into nursing homes. As the family members and primary carers age, they find themselves having to be accommodated in nursing homes—and then what happens to their family member with a disability? There is often no other alternative but to accommodate them in a nursing home as well.

Senator McLUCAS—Mrs Hodgson, you said you thought that accessing the innovative pool moneys was—I think you used these words—'inflexible' and 'non-sustainable'. Can you elaborate on those views please?

Mrs Hodgson—Yes. One problem with the innovative pool funds is that it is a short-term project, so it is funding for either a year or a maximum of three years—for example, in Victoria, where three young people were moved out as a result of those innovative pool funds.

Senator McLUCAS—We went there on Tuesday night.

Mrs Hodgson—Yes, and it is great, isn't it?

Senator McLUCAS—It is terrific.

Mrs Hodgson—Obviously the hope is that at the end of that three-year period the state will be pushed into a position where they are going to have to pick up the tab, because it is not going to be a self-sustainable project. I can see where the Commonwealth is coming from in terms of getting the ball rolling, but the difficulty is that for people like us, for example, if we wanted to try and tap into the innovative pool funds, unless we can get the state to sign off to say that they are prepared to pick up the tab at the end of the three years, we are in no-man's-land. I know that the three people involved in Victoria have said that three years is better than none, but I am not sure that we really have the right to encourage people in that way.

The other issue, as I mentioned before, is my concern that, while it focuses on bringing young people out of nursing homes, many of our young people currently in nursing homes would not want to come out; they would be scared of what they were coming out to, because it is an unknown. If there was something there for them to see, that might be different. But there are a large number of people, including my daughter and including David and possibly even Carolyn, who may be in the position of having to go into a nursing home. We would like the innovative pool funds to be able to broaden out to include that group of people, to stop other people having to go into a nursing home.

Senator McLUCAS—The model that you are proposing, that you describe in your submission, would have people with different levels of ability living together. Why have you selected that approach?

Mrs Hodgson—We talked to people within the HOPES membership—people with acquired brain injury predominantly, but also with cerebral palsy and MS—and asked, 'What is it you want?’ Basically, what people are telling us is, ‘We want our own space, but we know we need support.’ So we looked at models which would give them that. They also want to feel that they are in control, particularly people with acquired brain injury who have lived for 15, 20 or 30 years as independent beings. I am not saying it does not apply to people who have been born with the problem, but people who have lived as independent beings and who suddenly become dependent feel stricken by this loss of independence. They want to feel they have got some control over where they are living and the ownership of what they are doing. The model that we came up with is cluster units with a common house. It is similar to Pallatt Street that you visited in Melbourne.

Senator McLUCAS—No, we did not go to Pallatt Street.

Mrs Hodgson—Did you go to Beaumaris?

Senator McLUCAS—No. We went to Carnegie.

Mrs Hodgson—The intention is that you have a multipurpose house, which can be used for respite and transitional living and has an on-site caretaker, and then you have individual units where people can share with one other person or, if necessary, be on their own. But they are in a cluster where they can share support. The project that I mentioned before is a bigger version of that, in that we have linked in with the Association of Christian Homes for the Aged and southern cohousing groups. We are looking at being able to develop a total village where lot of things can be shared, but where people still have their independence.

Obviously, it is not easy finding a financially sustainable way of giving people independence when they have high support needs. There are major problems with the present system where people are linked together in a group home—this is if they are not going to a nursing home—based on their level of need. For instance, if the five of you have major behavioural issues—

Senator McLUCAS—And we do!

Mrs Hodgson—I will say, ‘Let’s put you in one house.’

Senator McLUCAS—No!

Mrs Hodgson—Exactly. This is the point that I do not think people really appreciate. While most of us do not have the choice of living in Buckingham Palace or on the Gold Coast, we do have some choices of our home and who we share that home with. For people with disabilities, those choices are often out the window. They are not choices; their options are developed according to their level of support need. If the five of you have high behavioural issues, then the likelihood is that, if you are put together, your behaviour issues are going to be even worse. That is why we have looked at trying to mix and match whilst giving people their own—

Mr Pearce—If you have multiple disabilities, a failure of the current system is that one government department will say, ‘I’m sorry; this client doesn’t fit into this category because he’s got XYZ and we only cater for ABC.’ Another government department might say, ‘Sorry; we don’t cater for this because he or she doesn’t fit into this category or into this little narrow box that people with disabilities are expected to fit into.’

Senator McLUCAS—You have some group homes operating in Tasmania, from what you are saying.

Mrs Hodgson—There are group homes, yes. There are group homes run by the department and there are group homes run by other organisations. One organisation which is a member of HOPES is Optia, which has a philosophy similar to ours and runs group homes and unit accommodation predominantly for people with intellectual disabilities. Optia is part of the reason we have developed our concept. It has not had the same concept but it has had cluster housing with some support, which it found to be a satisfactory way of supporting people.

Senator McLUCAS—Are those group homes funded directly by the state? I am trying to get to how they operate financially.

Mrs Hodgson—Yes, apart from the group homes that are run for the Motor Accidents Insurance Board. At one stage, going back 10 years, we had an agreement between the Motor Accidents Insurance Board and the state department, where the physical bricks and mortar were supplied by MAIB, and there were compensable and non-compensable people in that group home. However, economic rationalism and the core business focus have meant that in recent years the Motor Accidents Insurance Board have said they could no longer support the non-compensatable people within their homes, so they have had to move out.

Senator McLUCAS—How many of those group homes exist?

Mrs Hodgson—I am not sure.

Senator McLUCAS—The acquired brain injury people might be able to help us with that later.

Mrs Hodgson—Yes. The only homes specifically for people with acquired brain injuries are those run by the Motor Accidents Insurance Board. Another one of these non-compensable people has now moved into a home managed by the Eskleigh Foundation, which has a large younger person’s nursing home that you may be aware of in the north and which runs some group homes as well. But the majority of the group homes are for people with intellectual disabilities.

CHAIR—Thank you for your submission and your very valuable contributions to our inquiry today.

Mrs Hodgson—Thank you for your time.

[2.48 p.m.]

BYRNE, Mrs Deborah, Executive Officer, Brain Injury Association of Tasmania

DUNCAN, Mr Ross Lachlan, General Manager, Multiple Sclerosis Society of Tasmania

CHAIR—Welcome. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public, but evidence may also be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submissions and I now invite you to make an opening statement, to be followed by questions from the committee.

Mrs Byrne—With this inquiry, our perspective relates to the term of reference (c), which is to do with the appropriateness of young people with acquired brain injuries being accommodated in residential aged care facilities. I guess the short answer to that is that it is not appropriate for young people to be accommodated in residential aged care facilities. It was particularly pointed out that the Commonwealth Department of Health and Ageing acknowledges that the nursing home environment rarely, if ever, enhances the quality of life of young residents and should only be considered as a last resort. For us, given that there are over 6,000 young Australians in nursing care facilities, having 6,000 'last resorts' is a concern.

I should point out that it is probably a bit incestuous too. Sue Hodgson is on the BIAT committee of management and I am also on the HOPES committee, so we have had involvement in both of the submissions. As Sue has said, a lot of the issues have been covered. But it is not just about the issue of those that are currently inappropriately placed; it is also about those at risk of entering an aged care facility. As Sue pointed out, there is the fact that those young people that are already in nursing homes may choose to stay in the nursing homes, but it is also about looking for support for them, particularly as to their rehabilitation needs, social needs et cetera. As David said, there is also meeting their community needs. I should point out that the inappropriate placement of young people in nursing homes is a feature of the ABI services system in Tasmania, in that we do not have planned appropriate supported accommodation options for people that have non-compensable acquired brain injury. In Tasmania those needs are ignored, so they are inappropriately placed in nursing homes.

It is interesting to point out one of the comments that was made. This follows on from what Sue said. We had a meeting with the Premier not so long ago in which he made a comment about some funding that was available for housing that had not been allocated. I rang up for clarification of that, given that our budget was coming up. He said that we would be more likely to be successful with funding for one-off capital grants and that there would not be ongoing recurrent funding. So that would not be there for the people that you were talking about—those at Carnegie Street or those in the one that Sue referred to before. One of the reasons that they cited for having vacancies concerned access to the package of funds. I quote them:

> ... it has been impossible to acquire the necessary support packages for those considered compatible ... potentials have dropped off because Case Managers have feared that funding was never going to come through.

So we have that same situation in Tasmania whereby we can have the bricks and mortar but we do not have the recurrent support dollars for people to go into the accommodation facilities. So that would be something that would need to be addressed in terms of this issue. Another point that they made—and this is an issue for other people, particularly those with acquired brain injuries—is that another reason that they are nominated for those vacancies is to do with the allocation of funds to people who may not have a physical need but do have cognitive needs. It is very hard to convince the department that a person who is walking and talking is worthy of the required support dollars. So I think one of the other barriers is to do with an understanding of acquired brain injury. While people may not necessarily have physical needs, their cognitive impairments can be very debilitating. Those can require people to go into a nursing home because other people are not able to care for them.

Following on from some of the questions you asked of Sue, I made some additional notes. Disability Services in Tasmania are in crisis. That is one of the reasons why what you have said is quite right: the dollars have been made available but they are not being appropriately spent and those concerned are not meeting their responsibilities. One of the reasons is that the Disability Services body in Tasmania tends to look at that intellectual disability model, the historical model of funding for people in Tasmania with disabilities. The Tasmanian Disability Services Act does not actually incorporate cognitive impairment, something that all the other state acts do. We do not have cognitive impairment in the act. It is to do with physical, intellectual or sensory impairment. Once again, this gets back to an understanding of the differences for people with acquired brain injury, particularly with regard to rehabilitation. By operating on that intellectual disability model, there is obviously the assumption that people will need 24-hour care seven days a week for the rest of their lives. For people with acquired brain injury, the most important time is discharge from the acute care setting into the community. If you can put in intensive rehabilitation dollars early in that stage, then the chances are that they may not need long-term care further down the track. That is another issue that needs to be addressed.

Rehabilitation is a particularly big issue. Eighty per cent of the rehabilitation of a person with an acquired brain injury occurs following their return to the community. Obviously people who are in a nursing home environment do not get that rehabilitation. I recall a story—you may have even heard it—from the Brain Injury Australia committee. I was talking to one of my counterparts about a young person in a nursing home. He was basically without any rehabilitation and was unable to do any self-care—basically lying in a bed. They went through the back door, got him out of the nursing home facility. He is now able to live independently and does a lot of work within the community. Without the rehabilitation that he was not getting in the nursing home, he would not have been able to actually do that.

As Sue said, the other problem is the division in Tasmania between the compensable and the non-compensable cases. I think Sue covered your question earlier. We have the facilities and the homes for people who are compensable. For non-compensable people it is aged care facilities and our hospital system. There is one house that Sue discussed that has four clients in it currently at the moment. The department moved two clients with acquired brain injury into a government-run group home. I do not know whether you are up on our media recently, but they have been splashed across the front page of our media and had to be moved from the government-run organisation into a non-government organisation. There were some concerns about their health care. I guess another issue for us is the lack of specific training for people with acquired brain injuries in meeting their needs.

The other point that I made is the frustration in the number of reports and everything that has been done. A report was done in Queensland in 2002; there was the *Creating a Pathway from Aged Care to Appropriate Care* summit—a lot of action is required by government—and the 2004 report came out of that; there is the national alliance, which we are loosely a part of as well; there was the *Unlocking Potential* conference; and the 700 Out Campaign, which happened recently, and you have probably seen a lot of information on that.

It is interesting in Tasmania. I made a note about the duck-shoving which happens quite often. You meet with the state government—and this happened at the last meeting we had with the Premier—and you are told, ‘It’s the Commonwealth’s fault, it’s not our responsibility. It’s the Commonwealth that are letting the side down.’ We have had a community development committee inquiry into young people with acquired disabilities. The Democrats put out a press release. They were going to look at ways of moving young people out of aged care facilities. In October 2002, the department put a young people in nursing homes project together. Part of that included a forum, which was actually the closure of the project. Nothing has come out of that.

I have a note here about the icing on the cake, which is about the Disability Services draft strategic plan that has come out. One of the things in that was to convene a state-wide working group to discuss and develop service options for younger people with disabilities in nursing homes. That will have another look at the situation and go nowhere. The other thing that we talked about before was Disability Services in Tasmania and the fact that they are operating in crisis mode at the moment. They are constantly reactive. It was interesting that there was a response from the minister on that. He said, ‘There is no money for a proactive approach, and such would raise people’s expectations.’ As I said, you have some points that I made and you have my submission in front of you. Do you have any questions on that?

CHAIR—We will.

Mr Duncan—Thank you very much for allowing me the opportunity of coming here and talking with you today. I am probably referring to item (c) in relation to young people in nursing homes. Our organisation here has a great deal of passion for this. We provide case management services for the state government in relation to people with neurological conditions. We do not necessarily limit ourselves to people with MS; we extend our services to others with a need. We basically have people on the ground dealing with people in the community with conditions such as MS, which is a neurological decease. It is a progressive, degenerative disease as well. It has impacts in a number of ways. There is a lot of talk in relation to impairment and that sort of thing, but MS is slightly different to that. The instances of this are probably not as high in relation to the nursing home situation and the needs are not necessarily the same for the people concerned. That does not mean that there are not synergies in relation to that as well. We are realists in relation to this. It is not going to be a case of having everything fit with that, so we are realists in the outcomes associated with it.

For a young person with MS, normally someone between the ages of 20 and 40, needing to go into a nursing home is basically one of the last steps in their particular care needs. It is not a case of them choosing to do so. In the majority of situations it means that all the resources that are available within the community have been exhausted, as well as those within their family. MS is one of those diseases that does not affect just the individual; it affects their families as well.

You are looking at a demographic where the most common person with MS is between the ages of 20 and 40—27 is approximately the average age—and is a woman. To then place them in an aged care environment is extremely traumatic. In all of this there are medical and psychological or psychosocial considerations, and the system obstacles. For a young person with MS to go into a nursing home is an issue of care, not an issue of accommodation in a normal situation. It is not an instance where they go from a government-supported home situation into a nursing home; they go from their normal living arrangements into a nursing home.

When they go into a nursing home, they go in with very substantial needs. These needs are high care; they are acute. They have no mobility or very limited mobility—usually very limited mobility in the upper body. They usually cannot communicate in what we would consider normal terms. They are still functioning normally within their brain, but in their outward appearance sometimes they can be non-responsive or extremely frustrating. They have also been through a very big battle with their disease. It is very rare for someone to have MS for a short period of time and then go into a nursing home; this battle could go on for years and years. The other thing too is that, once they go into a nursing home, they are not there for a short time. It is normally for about 2½ years for an elderly person. The average for a person with MS is seven years before they pass on.

The other situation that we are striking, especially here in Tasmania, is that once they do enter into a nursing home, their access to a range of community services that they would have had access to when they were living in their own homes is either suddenly withdrawn or just not practical for the nursing home to support. We have also found—and this has really come through our case managers who are dealing with the staff of nursing homes—is that they do not have a very good understanding of access within the community to some of the services needed. There are resources available within the community that nursing homes can access, but the homes do not necessarily have the desire or the knowledge to enlist those services.

A lot of the time when people with MS have to go into a nursing home it has to do with the physical side of their disease. That is a very small part for the person. It is very much about their psychological condition—it is very common for a person with MS to develop advanced depression prior to going into a nursing home. It manifests when you take them out of their common environment and put them into a foreign environment.

One of the most frustrating things—and you have probably seen this in the case studies—concerns their ability to communicate. Speech is normally a major problem for them. Being able to swallow is normally a major problem. Being able to communicate their needs in a nursing home environment is normally extremely difficult. Of the other things, two have already been touched on. One concerns the social aspects of a nursing home environment. We have had discussions with nursing home proprietors about providing stimulation for young people with MS. The response that has come back is that they do their best but they have a much broader population of elderly people that normally takes precedence in relation to that. They say to provide suitable stimulation for one or two people, as against the rest, within their nursing home would become an unrealistic economic proposition for them.

The other thing to mention is something that case studies have borne out. Sometimes they are placed in situations where they just cannot respond. The example that I give is the young man in a nursing home who has no mobility with his legs, cannot lift his arms and cannot talk. He can groan, nod his head and shake his head, but that is about it. There was the inappropriate touching that was carried out by another person who was a resident in the nursing home. For the young person that was totally traumatic. He was not even able to communicate that in a form that we would normally expect, but we know that he was well aware of what was going on.

ACTING CHAIR—How did you know that had happened?

Mr Duncan—We actually had one of our case managers in the room at the time that this person entered the room and carried out the act. Our person responded as you would expect, but that still did not reduce the trauma in relation to that.

We know our clients are labelled as being difficult. They are difficult because they are high care. They are difficult because they cannot respond in normal ways. They are difficult because they need fairly constant care. In a nursing home environment that is not always possible. We have had situations where our clients have been left for hours in a chair out in a yard because the demands of the nursing home are such that staff have other people to care for and other duties to carry out. This is really another factor contributing to the psychological impact that these sorts of institutions have.

The other thing that happens to people with MS—and this is the same thing that happens to impaired people as well—is that they are lumped together in terms of what their assumed needs are with all of this. When you do that you are not catering for the individual needs of the person. This is grossly different from the philosophy that we try to impart through our case management services and current thinking in relation to the care needs of people with MS in the community. We seek to empower them. With all of this we seek to enable them to make decisions in relation to their care needs and to make decisions in relation to their lives. But when you place them in a nursing home situation that philosophy is not always carried through: they are within a system, they have to fit within that system and the decision-making capability is taken away from them. The effect is not only on the person that is in the nursing home; it is also on their family, because the family is taken out of its environment and placed in a systemic environment as well.

One of the other things that is quite apparent is to do with their sexuality and being able to express that. This has been a major concern for a lot of our clients who have moved into a nursing home, because they still have needs. They are young people. They are still going through that stage in their lives, yet the environment within a nursing home is not geared to assist them in any way, shape or form. We are not talking of major orgies or anything like that; we are talking of basic intimacy and things such as that.

The other thing too for a person with MS going into a nursing home is that it is almost reaching the stage of palliative care. One of the things that we have struck over the period of time is that nursing homes are quite able to deal with elderly people because they feel they have lived their lives and are progressing towards the end of their lives. One of the major problems we have is that a lot of the staff who are in these nursing homes are older or of the same age as the MS people going into them. They are seeing this person deteriorate over a period of time. It is not a case of being in a constant state; it is a case of deterioration. They are relating that to themselves. We have our staff going out there providing lectures and support. We have recently put on a counsellor, who we feel could probably spend the next 12 months going around nursing home facilities to assist people in dealing with this sort of situation. There is probably a whole range of other areas that I could go into in relation to that. Within the system itself there are real obstacles, but they are all covered in the submission.

From our perspective, we are raising awareness in relation to this situation. We are also a society that is about doing something. I have only been in the sector since October, but it has certainly become quite apparent to me that there has been a lot of talking going on over a number of years but very little action. The young people in nursing home concept that has been raised by HOPES before is another area that we are exploring as well. We are looking at models and having discussions with nursing homes on which are the best models that we can put forward. We are actually prepared to put our money where our mouths are. But we have also struck the same things, such as the issue of ongoings. We believe that the community itself can probably raise the funds to actually set up these things, but not the ongoing costs that are associated with them. That is where we are looking to governments, both state and federal, to step in to support these sorts of facilities.

MS is one of those things that is relatively small. We have in this state about 500 people that we know of who have MS. There are no specific records in relation to it. There are estimates ranging between 15,000 and 22,000 Australia wide. One thing that is quite certain with this is that, as they progress through their journey, this situation is going to increase. We also have, I believe, about a five to eight per cent increase in MS occurrences across Australia. It is not a situation that is going to go away. It is something that is actually going to increase. We feel it is time to progress that now.

Senator HUMPHRIES—I heard what you just said, Mr Duncan, about a partnership between the Commonwealth and state governments to fix this problem. In your submission, Mrs Byrne, you make the same point. Can I put to you an argument and have you respond to it: that may actually not be in the best interests of young disabled people presently in nursing homes. The decision was made quite a few years ago by the Commonwealth, no doubt at some point of crisis in the system, to allow young disabled people to be accommodated in nursing homes. Although that was obviously a compassionate decision at the time, with hindsight it has been a disaster for young disabled people. This has provided state governments, which clearly have the responsibility for that, with a very cheap alternative to discharging their own responsibilities.

Isn’t there the danger that, if we now make our new holy grail in this field the establishment of some kind of joint responsibility, we are going to provide a travelling circus that will go on for years, with buck-passing going on continuously about how that actually works? The people who lose out again in that are young disabled people who are presently in nursing homes. Isn’t it really time for advocates such as you, for those sorts of people, to sit down together and say to the state governments: ‘It is your responsibility. The Commonwealth is offering to chip in a substantial part of the initial set-up costs of these facilities. Come to the party and meet your responsibilities.’

Mr Duncan—It comes back to the accepting of responsibility. I am sure that, from our perspectives, we do not care whether it is state funded or federally funded, but there seems to be the buck-passing and talking in relation to that. We are looking for the answers, not necessarily what the problems will be going into the future. From the perspective of the MS Society and certainly from within the community itself, we would be looking at some logical answers coming out in relation to it. I do not really care where the money comes from and I am sure that people with MS do not care either. It is really a case of working together on this. This is a community issue; it is not a state or federal issue. Unfortunately our nursing home situation is governed within the federal sector, but our disability sector is governed within the states, and we are caught in the middle.

It is the last straw for someone with MS to go into a nursing home. They do not have another option. There are no options available at the moment. We can continue to say, ‘Yes, it should be state government funded,’ and ‘It should be federal government funded,’ but unless the goalposts change this will just continue.

Senator HUMPHRIES—A push has gone on for some time to get joint responsibility between the two sectors and it really has not produced any dividends, with the possible exception of the house in Melbourne. Do you foresee what you are suggesting to us being successful in the medium- to short-term future?

Mr Duncan—I do not think we have an option. I think it has to be successful, otherwise we are going to continue in a situation that is untenable for people with MS or impaired conditions. I do not think we can avoid the issue for too much longer—it is growing.

Senator HUMPHRIES—It has been tenable for at least 20 or 30 years, hasn’t it, in the sense that it has been a position that the governments concerned have lived with in that time, and it could go on for another 20 or 30 years.

Mr Duncan—This is the thing: we do not want it to go on for another 20 or 30 years.

Senator HUMPHRIES—None of us do.

Mr Duncan—Basically, we want results in relation to it. It is going to take a degree of cooperation from all parties within the community, but we need to address the issue, not say, ‘That’s your responsibility,’ and that sort of thing. It is really a case of actually addressing the problem with it.

Senator KNOWLES—Do you just scrap the CSTDA?

Mr Duncan—No. I think that is all part of the progression towards it.

Senator KNOWLES—But the partnership is already established.

Mr Duncan—Yes, but they are not achieving the outcomes in relation to it.

Senator KNOWLES—That is why I asked: do you just scrap the CSTDA—if someone is getting the money and they are not delivering the goods? If you said to me, ‘Balance a ball on the end of your nose and I’ll give you 100 bucks if you can do it for 30 minutes,’ and I did it for 29½ minutes, you are not going to give me 100 bucks.

Mr Duncan—But if you are in partnership with someone and they are not delivering on that partnership then you need to address that relationship—that is the thing. We, as the community, have the need. We have what is required. We can also put up models until they come home, but it is not necessarily achieving the outcomes. The relationship that you have is the partnership between you and the state government, and that needs to be addressed.

Mrs Byrne—From Tasmania’s perspective, part of the problem is that Disability Services in Tasmania are in such crisis. As I said, it is just so frustrating that they tend to operate in this crisis mode the whole time—it is react, react, react. They throw dollars at the situations. I do not know whether any of you ever had cuisenaire blocks as a child. I am tempted to go along and take the cuisenaire blocks and say: ‘Mr Premier, see this big orange one? This is what it costs when you react to a crisis. See these little ones here?’ We need to put in the services for people with acquired brain injuries in those early stages and not wait until they break down, until they are homeless, until they have made suicide attempts or until they have depression. We need to put those services in and find them accommodation or respite so the family does not break down and then need to either put them into a group home, which costs 10 times as much as respite, or put them into an aged care facility, because we do not have group homes for people with acquired brain injuries. We need to start to be proactive, to look at that forward planning and to look at the needs.

We have the statistics that say there is going to be this number of people who will have multiple sclerosis and this is what their needs will be. We have the statistics that say there is this number of people who are going to acquire a non-compensatable brain injury and we need to plan for that. But, as I said, our disability sector in Tasmania is in such a massive crisis that while we just continue to throw money at the problem—or not throw money—we are not going to resolve the issue. They are going to pass the buck and say it is a Commonwealth responsibility. As I said, the innovative pool program is not working in some circumstances because the states will not take on the responsibility of what happens at the end of three years. It is a massive issue.

Senator HUMPHRIES—And the broader public does not understand all of this. They just see that there is another argy-bargy between the states and the Commonwealth about some issue, and you can pick your winner or pick the victim and the aggressor in that situation—it is all up to whatever you happen to think personally. And the situation does not get solved.

Mrs Byrne—From my perspective, I was thinking before: ‘You lucky person—you’ve got all these people to work for you.’ The Brain Injury Association of Tasmania gets $50,000 of funding from Disability Services. They did a review of services for people with acquired brain injuries in 1989 and said: ‘Okay, you will set up a peak body and the peak body will be state-wide. You will provide professional support.’ So we go in and provide a training program on acquired brain injury for people who are working in aged care or in group homes. We give information and referrals. We have a very successful prevention program—prevention is the only cure for brain injury, and it is a particular passion of ours. We do that state-wide. We go into schools with police youth justice. We also have to do systemic advocacy and lobbying and be across all the issues. We do that on $50,000 from the government. So they effectively shut us down on the advocacy side of it and in lobbying because we are so busy in other areas, particularly that prevention area. So there are other ways that they stop us.

Senator McLUCAS—We know that there are 500 people with MS in Tasmania. Where do those people live?

Mr Duncan—At the moment, because MS is so different for each person, they live within the community in the majority of cases. They live with their families. Some are supported through government housing. It really does depend on the individual and their situation. Their preference, I believe, is to stay and be supported within the community. The reality of it is that, because this is a progressive disease, you do not know when you are going to need to have the high level of care.

The other thing is that a lot of people with MS can be incapacitated for a period of a week, three months or 12 months and require constant care during that particular period of time, but with relapsing and remitting MS they may well recover and go back to leading a relatively normal life. Our system does not cope with that; it just does not fit with that sort of situation. I heard a very good analogy in relation to that, and it was mental illness. It is a similar situation: someone can require a high level of care for a period of time and then go back into the community. Unfortunately with MS you tend to find that it will progress over a period of several years to a stage where you will start to deteriorate and you will need high care.

Senator McLUCAS—Do you have any group homes of the like that we saw in Melbourne and that we have seen in Western Australia?

Mr Duncan—We do not have any of those homes down here with that. One of the things with people with MS is that, when they need to have that high care, it is basically 24 hours a day, seven days a week. Group home concepts down here tend to be across the board rather than specific. Trying to fit people with MS into that particular sort of model is not necessarily always successful. Again it depends on the individual. The types of models that we are looking at are 24/7 situations where they can have independent living with that and they can have family access with that—those sorts of situations—but it is not the case that we can let carers go. They are required 24/7.

Senator McLUCAS—What opportunities do people caring have for respite?

Mr Duncan—It is very, very limited down here. It is within the normal system. There is no individualisation in relation to people with MS. There are no individual care systems. It is extremely limited right across the sector. Another thing is that nursing homes have said, ‘We can provide you with respite, but, in terms of long-term care needs, sorry, but you are not all that attractive for us.’ It is very limited in that sort of situation. You tend to find that people go without rather than go into a respite facility.

Mrs Byrne—Tasmania still tends to operate very much with the intellectual disability model. The intellectual disability out-of-home respite facilities are not appropriate for people with acquired brain injury or MS.

Senator McLUCAS—I went to MS in Brisbane. The MS Society actually operates a respite program. You do not have anything similar to that?

Mr Duncan—No. We do not have the funds to establish those sorts of things. Again, our aim, which is developed as part of the national model of service, is to support the person in their home—to provide the facilities from within the community to support the person within their home. Going into a respite situation is very difficult for a lot of people with MS. They can probably understand it, but they do not necessarily like it. They would prefer to be within their home. That is really about making decisions for themselves. That is the model that we use.

Senator McLUCAS—I come back to your comment, Mrs Byrne, about your department of disability being in crisis. Different states have departments of disability—they are called various things in different places—and they have different ways of supporting people with disabilities. Some states have disability packages. What happens in Tasmania?

Mrs Byrne—We have a variety of different packages that are available. One in particular is an individual support package. It used to be an individual options package. Currently we have a waiting list. I think there are well over 100 people on it. Even if respite were available and you got the support dollars for it, you are on a fairly significant waiting list. For people with acquired brain injury, actually getting in the door of Disability Services and having Disability Services recognising that they actually have a need is a battle—let alone finding the support dollars for them.

There is CSTDA funding available, but once again it is mainly using the intellectual disability model. We have people with intellectual disabilities who go into group homes, but if they are people with acquired brain injury then that funding just is not there; it is not available. They can go on a waiting list to access the individual support dollars. That is if Disability Services deems that they meet the criteria, but, as I said, one of the biggest barriers is the lack of awareness of the cognitive impairments with acquired brain injury. As I said, a person can walk in the door of Disability Services, clean and able to communicate their needs. They could walk out five minutes later and forget that they have ever been in there. We often joke about sending them in dirty and smelly and homeless because they may stand a better chance. That is one of the things that is a reality in Tasmania.

Senator McLUCAS—Is it just that the need is so high that someone with significant ABI does not fit the criteria?

Mrs Byrne—There is a need but, as I said before, it is that lack of awareness of the differences between acquired brain injury and intellectual disability that makes it so difficult for people to access services. We need to look at that funding model. You may have a person with acquired brain injury or someone who has episodes. The most critical point is at discharge into the community. If we can deal with the intensive support needs in those early stages, what it may mean is that further down the track they are not going to need those long-term ongoing dollars. Once again, it is looking at the resources.

But we are not putting those dollars in at the early stages. What that means down the track is that we then have a bigger drain on disability services dollars when the person is no longer able to work, when their family has broken down, when you have the homelessness and when you have the challenging behaviours such as obsessive compulsive behaviours, alcohol abuse, drug abuse, gambling et cetera—all those ongoing things. There have been a number of reports that acquired brain injury is overrepresented in the criminal justice system. We are looking at all those preventative and proactive things. If we could put those dollars in earlier, that then would free up those dollars so that we could look at appropriate accommodation for people with acquired brain injury. We tend to operate in a reactive crisis mode that does not look at infrastructure or at being proactive.

Mr Duncan—Going on from that, the other thing, too, is that there is a system down here and it is not flexible. There is no flexibility built into it. The skill of the case managers who we have working for us is in being able to manoeuvre through the system. Their skill is being able to make the right telephone call at the right time and that sort of thing. We could have a really good week where we have some really good outcomes for one of our clients. We will have the duplicate situation occur the next week and we will have terrible outcomes for our client in relation to it. There is no consistency associated with it; there is no rationale that goes along with it. It is really a case of trying to negotiate your way through the system.

Senator McLUCAS—You may not be able to help us with this. Both of your submissions talk about 155 young people being in nursing homes. Do you have any breakdown of that by age or by disability? We have asked those same questions in various states to try to get an understanding of what the nature of those people's disabilities actually is.

Mrs Byrne—There was a breakdown that was available. I did not bring it with me but FaCS had that breakdown. They provided it to us as part of the Tasmanian report. It gave a breakdown in ages but I do not think it actually gave a breakdown in disability. It is very difficult to try and get that information from the nursing homes.

Senator McLUCAS—That is what we have heard everywhere else.

Mrs Byrne—We have tried to get that information. But you can get the breakdown of ages.

Senator McLUCAS—You said that was from FaCS?

Mrs Byrne—Peter Limb at FaCS had that information.

Senator McLUCAS—FaCS or DOHA?

Mrs Byrne—I am sorry?

Senator McLUCAS—FaCS or the Department of Health and Ageing?

Mrs Byrne—I thought we got it from FaCS but it might have been the Department of Health and Ageing. I know I had it. I can get a copy of it for you.

Senator McLUCAS—I am sure we can get it from the department. We have been advised that the department does not collect information around the nature of the disability of individuals; it simply collects their ages.

Mrs Byrne—Just the age, yes.

Senator McLUCAS—There is a broader question than age. Age tells you something but the nature of the disability is also important in order to understand the level of inappropriateness of that placement.

Mr Duncan—I would say from the MS perspective that in terms of people within nursing homes the average age is probably about 35 or 36. There can be up to 20 people in nursing homes across the state but because some go and some do not it is not a constant figure.

Senator McLUCAS—Thank you both.

CHAIR—Thank you for your submissions and your presentation to the committee today.

Committee adjourned at 3.34 p.m.