REPORT OF PROCEEDINGS BEFORE

STANDING COMMITTEE ON LAW AND JUSTICE

SECOND REVIEW OF THE LIFETIME CARE AND SUPPORT AUTHORITY [LTCSA]

At Sydney on Friday 26 June 2009

The Committee met at 9.30 a.m.

PRESENT

The Hon. C. M. Robertson (Chair)
The Hon. J. G. Ajaka
The Hon. D. J. Clarke
The Hon. G. J. Donnelly

CHAIR: Good morning everyone. Welcome to the public hearing of the Standing Committee on Law and Justice's second review of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council. Today we will be hearing from witnesses from the authority and the advisory council as well as from representatives of the Greater Metropolitan Clinical Taskforce, the New South Wales Bar Association, the department of rehabilitation at the Children's Hospital at Westmead and the New South Wales branch of the Australian Association of Social Workers. Later today the Committee is pleased that it will be hearing from a participant in the scheme and carers of participants to aid the Committee in its understanding of how the scheme is operating from the perspective of participants.

Before we commence, I would like to make some comments about aspects of the hearing. There are broadcasting guidelines, which are available in the room. Media representatives who use this facility understand those. In relation to the delivery of messages and documents tendered to the Committee, witnesses, members and their staff are advised that any message should be delivered through the attendants or the Committee clerks. I also advise that under the standing orders of the Legislative Council, any documents presented to the Committee that have not yet been presented to the Committee may not, except with the permission of the Committee, be disclosed or published by any member of such Committee or by any other person.

Committee hearings are not intended to provide a forum for people to make adverse reflections about others. The protection afforded to Committee witnesses under parliamentary privilege should not be abused during these hearings. I therefore request that witnesses avoid the mention of other individuals unless it is absolutely essential to address the terms of reference. I ask everyone to turn off their mobile phones for the duration of the hearing, including mobile phones that are on silent mode, because they interfere with Hansard equipment.

I very much welcome witnesses appearing this morning: Mr David Bowen, chief executive officer, Mr Richard Grellman, AM, chairman of the LTCS Advisory Board, Mr Dougie Herd, chairman of the LTCS Advisory Council, Mr Stephen Payne, chief financial officer of the LTCSA, Ms Suzanne Lulham, director of service delivery for the LTCSA, and Mr Neil Mackinnon, manager of service coordination of the LTCSA. I do recognise the busyness of your lives and how much work you put into this program. Thank you very much for expending your time with us.

STEPHEN ALLEN PAYNE, Chief Financial Officer, Lifetime Care and Support Authority, Level 24, 580 George Street, Sydney, and

RICHARD JOHN GRELLMAN, Chairman, Lifetime Care and Support Authority Advisory Board, 67 Bancroft Avenue, Roseville, 2069, and

SUZANNE MARGARET LULHAM, Director—Service Delivery, Lifetime Care and Support Authority, Level 24, 580 George Street, Sydney, and

NEIL JAMES MACKINNON, Manager—Service Coordination, Lifetime Care and Support Authority, Level 24, 580 George Street, Sydney, sworn and examined:

DOUGLAS DUGGAN HERD, Chair, Lifetime Care and Support Authority Advisory Council, Level 24, 580 George Street, Sydney, and

DAVID BOWEN, Chief Executive Officer, Lifetime Care and Support Authority, Level 24, 580 George Street, Sydney, affirmed and examined:

CHAIR: Do you know the terms of reference?

Mr PAYNE: Yes.

Mr HERD: I do.

Mr BOWEN: Yes.

Mr GRELLMAN: I do.

Ms LULHAM: Yes, I do.

Mr MACKINNON: Yes.

CHAIR: If witnesses should consider at any stage that certain evidence they wish to give or documents they may wish to tender should be heard and seen only by the Committee, please indicate that fact and the Committee will consider your request. We would like replies to questions on notice by Friday 17 July. We will prepare the report fairly quickly after the hearing date. I thank you for the detail of your answers to questions on notice. That was excellent work, and thank you very much indeed. By reading quickly, I do not mean to imply that you are in any way unimportant, but just so that we have more time to do our work.

The Committee notes that the Motor Accidents (Lifetime Care and Support) Amendment Bill 2009 has been passed by both Houses. Can you please advise the Committee on the development of legislative change in relation to injured people buying into the scheme and how this will impact of the scheme? A submission from the Children's Hospital at Westmead suggests that interim participation should carry on until the child is eight years old compared with the legislated change to five years. What is the authority's view of that suggestion?

Mr BOWEN: I will answer the first part of that question and will refer the second part to my colleague Ms Lulham. Prior to doing so, if I could table one additional document. An attachment to our answers to the questions on notice provided a five-year projection on the scheme. Subsequent to that attachment being prepared, the board of the authority has met and determined to reduce the levies from 15 August by 3.5 per cent, so we have recalculated that projection taking into account that reduction in the levy. I table that document today.

In terms of the implementation of the first amendment to the Act allowing buy-in, the process of establishing the base of setting the buy-in price is really quite critical to this; it requires the authority to make guidelines to give effect to it. We have met with the Bar Association, the Law Society and the Australian Lawyers Alliance over this issue, because we recognise quite critically, with buy-in being voluntary, that people who may wish to take it up will be seeking the advice of their lawyers on the matter and the legal profession collectively have submissions on it. I think we had a very good, fruitful meeting with them. The upshot of that is that as a preliminary step to establishing the guidelines we have engaged an experienced personal injuries lawyer to undertake a case review of 12 finalised matters in either the Supreme Court or the District Court, looking at the verdicts and looking at the allocation as to heads of damage. We will then use the medical information from those files, and if necessary get the insurers' files to support, that to calculate the purchase price using our life cost calculator, to see how close we are in the ballpark between the buy-in price and the amount of the award of damages.

I expect that that process will take a couple of months, and at that point we can start to construct the guidelines. At the suggestion of the legal profession, I have agreed with their suggestion that the purchase should be supplemented in effect by way of a contract whereby the Authority sets out what will be the terms of the care and support that is provided. That will be in accordance with the Act—what that will mean in terms of the immediate care and support, plus the transition points that may alter that over time. So the persons buying in will have some assurance as to exactly what they are getting for handing the money over to the Authority. I am quite happy, obviously, to keep the Committee advised of that. Of course, the guidelines, once they are in place and have been through the Advisory Council, will be tabled in Parliament. I will now hand over to Ms Lulham on the children's issue.

Ms LULHAM: I guess it is fair to say that the older a child is, the more reliable the estimate would be made about their lifetime needs and the more certain one can be about their prognosis. The age of five was chosen on the recommendation of the clinicians from both children's hospitals, so that is where it is now. One of the reasons why you do not want to extend the period too long is not so much in terms of making that decision from our point of view but from the insurers' point of view in terms of keeping claims open for periods of time. At the moment we have extended that period for five years—of them not knowing whether the child is going to be theirs or not. If you put it up to eight years, that could extend that period of time to eight years.

CHAIR: Resulting in a perceived impost on the insurers themselves?

Ms LULHAM: It is that uncertainty about knowing whether that claim will return to them. But certainly the older a child is, the easier it would be to assess him or her.

CHAIR: Given that there was some obstruction and representation before the Lifetime Care and Support Program came in about it being preferable for people to get the big payout rather than the lifetime care and support, why do people think that the increase is happening in the request for buy-in to the program?

Mr BOWEN: The buy-in is just giving an additional option to a person who had received an award, to manage their care. It is a very difficult circumstance to contemplate what might be your lifetime needs if you are personally injured or, for example, for the parents the needs of a child who is injured will continue to be met. The reality is—and I am sure the Committee is aware of this because a lot of work was done in preparation for this legislation—that most awards of damage run out well before the person dies. There are some exceptions to that, but on average awards of damage run out in about 17 or 18 years. There is a lot of research to that effect. There are a variety of reasons for that, one of which is that it is very difficult to give a young person a large sum of money and say to them, "You will need to invest this. And you will need to set aside a lot of it because your care needs will increase as you age and you need to make provision for that at the moment." This scheme gives the person an assurance that upon having bought in, they will have it for life and they will get all their needs met. As those needs change over life, it is very hard for someone to predict what their future needs will be.

The Hon. DAVID CLARKE: I guess you would be seen as a body that has expertise, so those coming to you would have faith that by buying in they are getting the best expertise they can get in this situation?

Mr BOWEN: Yes. I think also we can get some efficiencies in service delivery. We are able to purchase care at a price that would be unavailable to most individuals purchasing it. In addition, working in conjunction with the Attendant Care Industry Association, we are putting in place appropriate competencies and standards for service delivery. The industry itself has been very supportive of that. In fact, we have been supporting the industry putting it in place. People who buy into the scheme have the assurance that the care delivery is at the highest level possible.

The Hon. DAVID CLARKE: Have any other desirable legislative changes to the scheme been identified? If so, what would you see them as being?

Mr BOWEN: We are still in the development stage. I am very conscious of that. We have all the infrastructure in place around the critical issues of care and support. As would be obvious from our replies here, we are still grappling with issues like recreational support and we still have to address how we will deliver vocational and employment support. I imagine that issues will come out of that. We have not been able to identify them up front.

There are some minor bits and pieces. I think it will be appropriate as the scheme develops and we build up a body of participants. We have been talking about how we can empower other participants, not only to manage their own affairs but as a group to give some feedback. I think having a participant representative on the Advisory Council would be a desirable thing to achieve in the future. But nothing comes to mind at this stage.

The Hon. DAVID CLARKE: We simply finetune it as we go along?

Mr BOWEN: Yes.

The Hon. JOHN AJAKA: Mr Bowen, I still do not understand how you calculate the buy-in for a claimant who has received their award of damages.

Mr BOWEN: We are in the process of constructing a program, in effect, that is a life cost calculator in which we can put in the person's age, their injury, the severity of the injury, and, critically, the assessment of their care and needs using the care-and-needs scales that clinicians produced for us. At the moment it uses actuarial averages to say what that person’s needs will be over life, recognising two things: first, that care needs often escalate, so the present value of the aggregated amount would be much greater than the person may be receiving at a young age; and, second, that there are significant transition points in a person's life which might cause their care needs to escalate. That delivers us a present value. We are using that for the purpose of both cash flow projection and one to five year cash flow. Mr Payne can talk about that if you like.

We are also using it to try to provide, in insurance terms, a central estimate of our liabilities that will match to our actuarial liabilities. At the moment that is primarily designed around projected information, but as we get more and more actual information into it and feed that into the calculator we get a better and better estimate. For example, we have also noticed that the rehabilitation costs we are incurring are higher than we expected but that has been offset because the utilisation of care has been lower than we expected. All of that will become more sophisticated as time goes on.

The Hon. JOHN AJAKA: Let us take an individual who had a claim 10 or 15 years ago. The claim was settled, the person received a substantial amount of money that was poorly managed—if I can use that term—financially, and they want to buy into the scheme. You calculate a figure. If they do not have that money left over from their award the reality is that they are not buying in?

Mr BOWEN: I think that is probably the reality. We would like to explore—and I put this on the table—options to allow people perhaps to use something like equity in a home that they may have purchased with their award to buy into the scheme so that they get the assurance of the lifetime care. The asset is then dealt with at the end of their life. But if they do not have the funds, no, there is no option to buy in.

The Hon. JOHN AJAKA: At the end of the day—I do not mean this in a derogatory way so please do not take it that way—it is no different than any other insurance-type purchase of a product. If you have the money to purchase it, hopefully it will take care of you if the need arises.

Mr BOWEN: The alternative would be a structured settlement or an annuity. What makes this different is that a structured settlement or an annuity has a term on it and that term is calculated using life expectancy tables but if you live longer than that term—

The Hon. JOHN AJAKA: It cuts you out.

Mr BOWEN: —the money runs out. By providing for a cohort of people, we are able to say, "If everyone buys in we have a swings and roundabout effect on life expectancy" and that will deliver the care for the person however long they live.

The Hon. DAVID CLARKE: By what percentage are these medical and support costs escalating, are you finding, in the industry as a whole?

Mr BOWEN: Recently for the purpose of the board meeting we had some analysis provided by Access Economics. I had a concern that health and care costs may have an inflation greater than average weekly earnings. Certainly if you look at the ABS statistics, health employment costs are escalating slightly above AWE but the work from Access Economics suggested to us that over a long period of time it will be within the reasonable ball park. However, we recognise that an area of personal care, going into somebody's home and providing them with personal care in the home, is unlikely to be able to achieve the sorts of productivity savings that you may get in other areas of the economy, including hospital care and institutional care. So we are very careful to factor those into our economic assumptions going forward.

The Hon. JOHN AJAKA: I understand why the whole concept of the Lifetime Care and Support Authority was created, but going back to the money running out in the past, was it mainly to do with either poor management of the money or was it a situation of claimants not having been seriously awarded sufficient moneys to meet their future expectations? Was there a shortfall on the part of the judges or the system in that respect?

Mr BOWEN: I think it is a combination of all of that. We are aware of research that has been undertaken looking at longitudinal studies of people with brain injury by Professor Robyn Tate at the rehabilitation studies unit at Sydney university. One of her findings, when she was making an assessment of whether or not their compensation was sufficient, was what were the variables in that. The biggest two variables that she thought impacted upon it was the level of family support, because you need quite a bit of family support to get through a litigation process, and the second was the quality of your lawyer, how well it was prepared and how well it was presented and argued. What she found was that there enormous disparity in the amount that a person might get for a very similar injury where the expectation would be that the award should have been the same. So first of all there is this huge disparity.

Secondly, the discount rate impacts quite a lot upon the amount that the person will get. So even though they are now getting allowances financial management, it is hard to achieve, particularly in the current climate, a sort of investment return that maintains the capital. Third—and this was somewhat surprising but we found this in our own research when we were looking at the eligibility for the scheme—awards of damages, including awards for future care, are treated as capital for tax purposes and for family law purposes. Unfortunately it is not uncommon for there to be a marriage breakdown following a severe injury, and the award of damages that person may get is treated as capital by the Family Court. So the spouse will get a proportion of that.

The Hon. JOHN AJAKA: Especially if the house is purchased with that money initially.

Mr BOWEN: Even if it is sitting aside, the Family Court does not accept an argument that this is money for the person's future care. It is treated as an asset of the marriage.

The Hon. DAVID CLARKE: That seems an anomaly, does it not?

Mr BOWEN: It does seem an anomaly. I have raised that with the legal profession, and I think that is something that they can look at as well.

The Hon. JOHN AJAKA: By having a system of lifetime care and support, where there is no one massive payment in the beginning but this continual payment, that eliminates a lot of those problems, does it not?

Mr BOWEN: That is right. The individual does not have to worry about how they will invest it to look after their own care needs, let along whether or not they can predict those care needs.

The Hon. JOHN AJAKA: In looking at the area of investment, were any studies done of those who were under the care, for example, of the Protective Commissioner as opposed to those who were either managing it themselves through family or friends?

Mr BOWEN: Not particularly. The people under the supervision of the Protective Commissioner pay fees to the Protective Commissioner. That is probably not that much different to the fees you are paying to a private trustee company.

The Hon. GREG DONNELLY: Thank you for coming along to speak to your submission and answer some additional questions. We understand that the case management system has been refined and developed and improved from the original arrangement. Can you explain how the case management system has evolved and developed and how that is benefiting the scheme, along with the service providers and participants?

Ms LULHAM: Case management, I just need to clarify, is used in two ways. The case management system that we are talking about in submissions is the IT system that we have introduced within the authority to manage the work flow and the claims and collect the information and that side of things. Case management is also a term that is used generally within Health about managing people and those sorts of things. The case management system's benefits will be mainly for the authority itself. It will provide us with a much better way of gathering and collecting information on the participants, their costs and their overall management. We will then be able to feed that information into the actuarial valuations. It will also provide us with a way of flagging things that we want to review into the future. It will probably not have that much impact on external service providers. Its main advantage will be for us in terms of time saving and freeing us up from a fair amount of paperwork. I guess the more electronically we can do things the easier it will be for us into the future.

One of the longer term things we want to do with our case management system is to actually have, I guess, portals into which our participants will be able to log and perhaps have a look at what services they have had approved, how much they have spent, what services they have still got to purchase, all those sorts of things so that there is information that will be available for them as well. We will probably also have a system for our service providers to log into this case management system as well and provide information directly in and to get information out. One of the aims we are hoping in the longer term is actually that our attendant care providers will be able to bill us electronically through this system. So we will be able to match it up with what services have been approved with them with the invoices that come in from that. So it is very much around an internal time saving.

CHAIR: What chance is there that this collection of data assists best practice information for the future?

Ms LULHAM: Quite high. We will have an amount of information that will look at an assessment of the needs of people, and what their functions are. It will actually look at what services have been provided to those people, and we will be collecting, as time goes on, various outcome measures on people. It will actually provide within 5 or 10 years' time information that probably is very rare, I guess, for New South Wales but even for Australia.

CHAIR: Is it worth getting someone to look at the questions you are asking? When epidemiological quality information is being collected someone needs to look at what you are collecting to ensure that it is able to be put together for that purpose? Is that worthwhile?

Ms LULHAM: At the moment we are getting a fair bit of advice in this area. The system that we are building is very much based on a system that the Transport Accident Commission in Victoria as well as the Accident Compensation Corporation in New Zealand use. We have also over time had discussions with some academics about some of the information and when is the best time to collect this information into the future. From an information point of view it is quite an exciting development.

The Hon. GREG DONNELLY: What is the number, nature and more broadly the content of the education programs run by the scheme in the past 12 months?

Ms LULHAM: I have a list of the programs we have run in the past 12 months. We have run sessions on what we call our scheme introductory training, which is for all service providers. It is a one-day workshop that starts about general information about the Lifetime Care and Support Scheme and then how to request services and our processes. We run three or four of those each year and we are continuing to do that. We ran one yesterday. We also run ongoing training in FIM, which is the eligibility assessment tool, and the WeeFIM. We run about two of those workshops each year for the FIM and then two for the WeeFIM.

The Hon. GREG DONNELLY: For Hansard what are those acronyms?

Ms LULHAM: FIM is the functional independence measure and it is a crucial measure for anyone with a brain injury in terms of eligibility into the scheme. WeeFIM is the children's version of FIM. The CANs, the care and needs assessment tool, we use very much to help with our costings and our review of people. Training on that is run two or three times a year for all service providers. We have also run three training sessions for our approved assessors—they are the assessors that do our assessment in the scheme in the last four, five months. In the next week we are about to run training for our disputes assessors which is specifically around that decision making and their role within our scheme. We have also run training sessions, and general information sessions, with a number of insurers and about their relationship with us. We have been out to the public hospitals social work departments and some of the neurological wards to run training sessions. We have been up to the Hunter occupational therapy group and run training sessions with them, the Brain Injury Association, the spinal cord injuries nurses' course and then there are other specialist interest groups like the occupational therapy spinal special interest group, their brain injury group, the physio spinal group and those sorts of ones as well. Some of it is planned and some of it is more on an ad hoc basis.

The Hon. GREG DONNELLY: Do the education programs involve presenting, or making information available, to people in the community who have had very serious accidents? Are they made aware of the scheme and what it can offer them? Obviously your advertising budget does not allow you to take out half pages in the *Sydney Morning Herald* and the way in which you present your programs is targeted and in a niche market. How do you interface with the broader community, particularly those who need to know about the scheme and what it offers?

Ms LULHAM: We have not run any specific education or information sessions for people with injuries. The way we usually do it is rely on the service providers in the hospitals, the brain and spinal units in particular, to let us know. We would then send a coordinator out who would talk with the family and that person on a one-on-one basis. If that is not possible we have information prepared that they can read about it as well. Also now that we have been going for a little longer the social work department people also know more about us as well. That information would be much more on a one-to-one basis than in an information group.

The Hon. GREG DONNELLY: The critical people and organisations in the hospitals who interface with individuals who are injured, do they have a good general understanding of what the scheme is and what it offers?

Ms LULHAM: There is a reasonable understanding of what the scheme is and what it offers. I think that where there is some uncertainty is more around those issues of what is a motor accident and that sort of criteria. Our suggestion to them has been for them to really refer those questions to us and let us answer them. So if anyone has been injured on a road with something that looks like a motor accident or a vehicle then refer that to us and we will do the investigations about whether it is a motor accident. That seems to be the hardest thing for people too.

The Hon. GREG DONNELLY: When you say "refer it to us" in practice does that mean to ring?

Ms LULHAM: To ring us is fine. We ask that they actually send a consent form which means that we can then get some information for the person. I can give you an example, we get a lot of motor bike accidents. A lot of the motor bikes may or may not be what we call registrable. A lot of them are unregistered.

The Hon. JOHN AJAKA: Do you mean scooters?

Ms LULHAM: Yes, motor cross bikes, trail bikes and those sorts of things. A lot of time the question is; is that bike capable of being registered? We ourselves then get that information from them and we sent that off to a forensic engineer who will provide us with advice for that. Another example would be that we had a motorbike accident that actually happened at Oran Park, at one of the events they organise out there, and at first glance we thought that that person probably would not be eligible, but we sent it off to a barrister for some advice about whether that was a motor accident. That is, I guess, why we ask for those to come to us, because then we can direct the inquiries out to people who can provide the advice.

CHAIR: It was very remiss of me, but I did not ask would you like to make an opening statement.

Mr GRELLMAN: We did consider whether it was going to be helpful, but the depth of the questions that have come through and the work that the team has put in to responding as fully as possible we think probably gives the Committee a lot of information. It is perhaps suffice to say from the board's perspective, if I may, that we are feeling very pleased with the way that the scheme is developing. It is still relatively early days. David and Suzanne have built an outstanding team of very committed professionals who have excellent working relationships with key service provider groups, such as the attendant carers, some of whom are in the room today, and there is no complacency; there is no premature relaxation. We are watching carefully, but for a very important and I think outstanding piece of legislation, early signs are very positive. I think that would probably be enough to go on.

The Hon. JOHN AJAKA: Leaving aside the questions that have been sent and I am sure will be answered, are there any areas where you feel more work needs to be done or more assistance is required from Parliament, for example, whether by way of legislation or funding? If you had everything you could possibly have, what do you feel would still be needed to make the system perfect?

Mr GRELLMAN: Well, we know that it will never be perfect.

The Hon. JOHN AJAKA: I would like you to explain to me why it would never be perfect?

Mr GRELLMAN: Because we live in an imperfect world. Let me step back a bit. When a participant comes along, once they understand the way the scheme operates, often Suzanne and her people find that their expectations are unreasonably high as to the level of care that they are going to receive. At the end of the day what we try to do is to find a balance which gives them as much dignity and care and support as possible, but obviously it all comes at a cost and we are running a scheme where we need to be prudent and cautious with the money that is sitting in our care. There is a trade-off between providing outstanding support and care and doing it at a cost that the scheme can bear. I think it would be fair to say that from time to time some participants may feel like their expectation was a little higher than reality, but I suppose that is the sort of tension I am referring to in terms of it is not nirvana, it is not perfection. The participants are in a very unhappy space, they are significantly traumatised; they have lost a lot of body function, which probably they will not get back—

The Hon. JOHN AJAKA: And nothing is every going to cure that.

Mr GRELLMAN: Correct, but coming back to your question, I think I can say that the interest from the Minister and his office, and their willingness to meet with our people, understand the detail and provide the right level of support when we come to the view that perhaps a bit of legislative improvement might be required is very present, so I actually cannot say that there is something that, if I could pick up a magic wand and wave it, we would love to have that we are not getting.

The Hon. JOHN AJAKA: If we go back to what Mr Bowen was talking about earlier with the problems with the old system where large amounts of money were awarded and would run out, one of the major complaints that has come to me, previously as a lawyer and now in Parliament, is that we have taken the option away from someone. We have not really given them the choice, have we? If someone had the choice of being awarded $5 million or $10 million or $1 million where they felt that, at least for their own dignity, they could manage their own affairs, they were not reliant on others to come along each week and provide something—is that still an inherent problem with those who participate in the scheme now?

Mr GRELLMAN: I will have a quick go, but the chief executive is keen to chip in.

The Hon. JOHN AJAKA: We have time for both of you.

Mr GRELLMAN: Thank you. Listen more carefully when David speaks. I have been involved in this area of the community for 15 years now and when the big awards have been paid out in years past and also in workers compensation, there is only one thing you can be sure of: They will either get too much money or not enough. It is just reality. If someone gets a big award and they pass prematurely, their heirs and successors have won the lottery. We have seen examples of that. That development is something that I guess we can all live with, but the difficulty that emerges when someone runs out of money, for all the reasons Mr Bowen mentioned earlier—it is just horrible. They end up in a very bad space and they can fall between the cracks. I have heard the philosophy of the scheme referred to as being somewhat paternalistic—going to your point, we have taken the choice away from them—and they do not get the cash award, they get the care that is reasonably required for them to live to the best extent that their circumstances permit. So the view has been taken that that is probably on balance the better model, but I think it is a debate that will probably continue. Personally, I favour the model that we have, but people do say to me from time to time that it is a bit paternalistic.

Mr BOWEN: It is quite important to us to give to the participants who are both capable and wish to exercise as much control as they can and as much choice as they can in their own lives—certainly the choice of care agency is one that participants or their families have. We have provision under the Act to provide money on a periodic basis to participants, so that we will simply say: Well, here you are, this is what we would have provided instead of you telling us, and we will then engage the care agency, we will give you the money and you can control it yourself—

The Hon. JOHN AJAKA: As an annuity, as a monthly payment?

Mr BOWEN: We have just identified about three participants at this early stage. They are usually obviously going to be adults with spinal cord injury who we think are competent and capable, and may well be interested in doing that, so over the next few months we will be having a discussion with them. It may be an arrangement that they want to test out as well as we want to test out, but in the longer term it could be something where we just come to an annual arrangement with them.

The Hon. JOHN AJAKA: We are not talking about a large one-off lump sum payment?

Mr BOWEN: No, I am talking about periodic payments, probably quarterly or six-monthly initially, perhaps ending up as an annual payment over a period of time. That will allow the person to completely control how the money is spent, what choices they have.

The Hon. JOHN AJAKA: Where does the family fit into this? Is one of the problems that the family feel frustrated that they are no longer able to participate or be involved and assist, they feel that the injured person, whether it be a child or spouse, should be receiving more and more, or do you find that some family members feel they are being put in a situation where they have to put in a huge amount of time and care, but they are not able to be compensated for that?

Mr BOWEN: It is a really interesting issue because getting the balance right is quite critical. Some families want to provide care, and that is just the nature of the family relationship. Where we have maintained a fairly tough position is that we will provide for all of the person's care needs using professional care agencies, but we will not pay family members to become carers.

The Hon. JOHN AJAKA: That was to be my next question.

Mr BOWEN: We have had a couple of requests for that, and this might be something that Dougie would like to address as well. We thought long and hard and we took a lot of advice about this from the broader disability community and from case managers.

The Hon. JOHN AJAKA: That is one of the complaints I am receiving on a regular basis.

Mr BOWEN: The intent behind it is to maintain a family relationship—a spousal relationship or a parent-child relationship, which will involve some elements of support and care in any event, but not to turn that into an injured person-carer relationship—to try to provide for those care needs outside the family so the family can remain functional as a family. There may well be circumstances, and we can certainly contemplate them, where there will be no choice but to use a family member as a carer, but it is certainly not the preference. That was strong advice we got from people who work in the area and the broader disability community.

Mr HERD: It is one of the issues we have discussed as a council—

The Hon. JOHN AJAKA: As barristers or as psychologists?

Mr HERD: The advisory council. I am a professional talking head but the others actually have professional expertise drawn either from the medical profession, the attendant care profession or social work. Our view, I think shared by the board and the staff, is it is absolutely clear that to pay family members for providing professional support to their loved ones would be a catastrophic error, because if we breach that principle we will never be able to return from it.

From all the evidence that any of us can glean from anywhere it is just a mistake. It seems superficially attractive to a family that might find itself in dramatically changed circumstances: a breadwinner loses her role; a loved one finds themselves looking after a member of their family, which makes it more difficult for them to find work. It looks like a good option to pay the family member from what looks like a well-resourced, dare one say rich, public service organisation in the form of an authority, but it does not anticipate the changes that will take place in the relationship.

The creation of that financial nexus between the loved ones has such potential to disrupt and destroy normal family relationships that it is a grave error. However, it is not one that is immediately clear; it becomes clear five, 10 or 15 years down the line when the normal family relationship has been destroyed and the only thing that keeps people together is the fact that somebody is getting $25,000 or $40,000 a year by virtue of being in a relationship with somebody. That is no basis on which to maintain the relationship. That is not to say that the economic circumstances of these families are easy ones, but solving the financial problems of the family by turning a family member into a paid member of the staff of a loved one is not a solution to their problem.

We are identifying the right problem. The families you are hearing from, I am sure, are expressing a genuine need in their lives, but this would be the wrong solution. This scheme is not about income support, if I understand correctly; it is about providing care, rehabilitation and support, and we need to keep the distinction clear or we will make a mistake that you as parliamentarians will have to deal with at some stage in the future because a government department will come back to you saying, "We have run out of money."

CHAIR: Is there potential for it inadvertently to turn into a directive to the family if such a thing were introduced—inadvertently saying to the family okay, you are the carers now, there will be money there? Is there potential for that to happen if that process came about?

Mr HERD: I think there is a risk that that might happen, for a number of reasons. One of the issues we have talked about in the council, and I am sure the staff have had to deal with, is that as we all know we have talked over a number of years about the explosion of the demographic time bomb that we are all sitting and waiting for.

CHAIR: And many of us are entering!

Mr HERD: Absolutely. The baby boomers are coming with their care needs and there is going to be a massive expansion in the demand for support agencies and support staff, so the attendant care industry is going to be put under very severe pressure in the next 10 to 15 years. If we had the expectation that a family member would be paid for providing support to a client of the authority that might lead us to see other departments pressed to find attendant care support workers for their clients who are not authority recipients and to say, "You get funded by the authority so we are not going to give you access to any of our staff because we need them to go and work with people who don't get funded as you do." I think a perverse incentive would be established. If there is a motor traffic accident, there is the risk that your wife will end up being your paid carer.

The Hon. JOHN AJAKA: The main area of concern that I have is that if you have a situation where a young child tragically is seriously injured and needs 24-hour care, and at the time the mother and father were working because the child was going to school, but that ceases to happen, the mother will want to stay home and look after the child but cannot afford to do so financially. That is opposed, as she would see it, to a stranger coming into her home each day to look after the child. You could see some logic in the argument that it would be better for the mother to continue do so, at least for a while, but there is no real provision to permit that at this stage is there?

Ms LULHAM: We have written a policy that says there are certain circumstances in which we can do it, but they are rare and exceptional. I guess the ones that we could perhaps think about are people in rural or remote areas where it would be very hard to attract carers. In some circumstances we may pay for some of the care to be delivered by a family member. I think we would be almost negligent to expect one person to be providing care for someone who needs 24-hour care. That is shift care and you need trained carers. We have said that in the rare circumstances where this happens the family member needs to be employed by the attendant care agency. They need to be trained and they need to have their own workers compensation coverage and have all the occupational health and safety issues dealt with, as with any other carer.

Another aspect relating to the fact that the relationship changes with the dynamics of having paid care is that once you start instituting it and people start relying on that income you cannot stop it. No scheme can afford that into the longer term. In the case of children, if you did do that, our policy says that needs to be reviewed annually to see whether it is still the most appropriate solution. We would be very reluctant to do it for any child once they reached adolescence because no adolescent wants their mother doing that sort of care. One of the reasons we have said that is that it is not justifiable if it is based around income support. There have to be other reasons.

The Hon. DAVID CLARKE: I want to return to this anomaly arising from injury damages being included by courts in matrimonial settlements and possibly in other legal proceedings as well. Mention was made that this has been referred to the Law Society, or that they are on top of this. Would Mr Grellman or Mr Bowen like to comment on where that is at the moment?

Mr BOWEN: A little while ago it was something we identified in gathering evidence relating to those circumstances prior to the creation of this scheme. We were trying to find out why the money ran out. It was an area in which a number of people gave us their own personal examples and we referred it on. I will talk further to the Personal Injury Committee, the Law Society, or the common law Committee of the Bar Association and see whether it has been progressed internally. I suspect that it would require a Commonwealth Government amendment to treat the funds as other than capital funds.

The problem that would arise in all verdicts bar court settlements is that often there is not an apportionment of the damages between different heads of damages people will settle on a lump sum basis, inclusive of their legal costs, and that constitutes their capital. While both sides will have some understanding of how that has been constructed and how much would go for care, it is not particularly written down anywhere that this amount needs to be set aside for care needs, this is the amount for non-economic loss, and this is the amount for loss of future earning capacity.

The Hon. DAVID CLARKE: However, part of the damages could be quarantined, for instance, as a payback to the Department of Social Security for services that it has supplied. This problem would not arise in only matrimonial settlements; it could arise in other situations where people are sued for a whole host of things—breach of contract, defamation or whatever.

Mr BOWEN: That is right. The money, having been received by the injured persons as a settlement, constitutes capital of their estate and it is not quarantined at all from anything in which they may get involved.

The Hon. DAVID CLARKE: It is an important area that needs to be followed up.

Mr BOWEN: I will make that request to the professional associations. It seems to me that that is something in which the legal profession clearly has an interest. The legal profession would be aware of the circumstances of its clients, both as personal injury claimants and as family law claimants.

The Hon. DAVID CLARKE: That could result in a fruitful outcome.

Mr BOWEN: Yes. It might well be a matter that would then warrant a reference to the Attorney General to take to the Standing Committee of Attorneys-General because it is cutting across a number of areas.

CHAIR: I refer, in particular, to young people who are totally dependent. The Physical Disability Council raised an issue relating to young participants potentially being accommodated in aged care facilities. I recognise that this is an issue for the Physical Disability Council and that I am not supposed to make statements. However, I also recognise that it is an enormous issue in country New South Wales. If those young persons are to go to a young persons' centre they will end up being a long way from home because of the numbers of places required. Do you know whether many young persons in the scheme are in this situation at the moment?

Ms LULHAM: We have had four people in a nursing home, three of whom were well over the age of 70. We have one 25-year-old woman in a nursing home in Coffs Harbour. When she went there we gave the family an undertaking that as soon as we had another participant in that area we would look at other alternatives. The nursing home she is in is one of the exempt nursing homes, so she has her own room, an en suite and a lounge room. We are purchasing about another 40 hours of care a week on top of the nursing home stuff, including 28 hours of community access. We have also purchased a fair bit of equipment for her. We perhaps could have provided other options for her, but the family wanted her to go back to Coffs Harbour.

CHAIR: There are geographic considerations verses not putting young people with old people?

Ms LULHAM: Yes. It is an area where we are expecting to have more people. We need one more around that area and we could come up with some other options.

Mr BOWEN: I met the parents of this young woman and I gave them an undertaking that we would do everything we could to avoid a nursing home. Initially, she was scheduled to return to south-east Queensland.

We had some discussions with Youngcare up there, but we were not able to find a facility. It is an area where, in addition to dealing with individual participants, we think we will have to do some needs analysis and we might have to assist in the construction of homes to accommodate young people outside nursing homes.

CHAIR: I have a couple of questions about the coordinator process and there are still some questions and confusion about the role of the coordinator. People perceive some coordinators as operating differently from others, which is interesting. Does this have anything to do with a new position being integrated into the processes or are there other issues relating to them being integrated into the care process?

Mr MACKINNON: It is both those things. It is a very new position and we have set out to have a fair amount of contact with people early on. Again, it is based on the experience reported to us from the Transport Accident Commission [TAC] when there was a significant review of this role in previous years. It is important for us to be engaged early with people to tell them about the scheme because we are the only ones who have a more intricate knowledge about the scheme. Referring to consistency, I think we have been inconsistent. That is very much about the newness and the rate of change that we have gone through in the past two years—from having some basic principles to now having fairly detailed guidelines. That whole process of developing guidelines meant that a variety of approaches were taken until we arrived at one that we thought worked.

CHAIR: Would some of that inconsistency relate also to differences between rehabilitation services?

Mr MACKINNON: Yes. I think we work across them. Some of those differences can be within units and between teams. At least initially I try to have a coordinator per unit to try to bed things down. We have gone past that now; we have 230 people in the scheme and coordinators now have quite a mix of new people. They also visit a number of units. The need for us to be consistent and for us to make things fairly straightforward for the coordinators is increasing. But we cross a whole range of services that have different operating procedures.

CHAIR: Last year it was brought to our attention that there were issues relating to persons originally admitted to the orthopaedic process rather than the brain injury process. Is that sorting out?

Mr MACKINNON: It is a problem. The crux of this is that often the treating teams are not identifying the brain injuries of these people.

CHAIR: With bones being a focus?

Mr MACKINNON: Bones are a focus and there are critical issues around that. It may not be until some time later that someone believes he or she also has a brain injury. At the time it was not life-threatening issue, but it will be a long-term consequence.

Mr BOWEN: We have identified an additional matter and referred to it in our answers. A larger number of older people have been injured than we expected. With brain injury, often there is a misdiagnosis of that as dementia. Hospitals have had a number of instances where they have failed on a number of occasions to properly diagnose a brain injury. That is something where the authority, together with the Motor Accidents Authority, has provided some guidelines that it prepared with the College of Emergency Physicians on mild traumatic brain injury to try to assist in better diagnosis in both the emergency and the acute care phase.

The Hon. JOHN AJAKA: Are you saying that someone came into the hospital after a car accident and instead of being diagnosed as having a brain injury as a result of that accident the hospital assumed that it was dementia to start with?

Mr BOWEN: It is assumed that the vagueness and communication problems someone is having are age-related, even though the family is saying that the person has not had any problem before.

The Hon. JOHN AJAKA: Even though someone has no history of dementia? That is a bit frightening.

Mr BOWEN: Yes.

The Hon. GREG DONNELLY: My question is more general and not one on notice. Do you liaise formally with analogous organisations either in Australia or overseas to track key issues, for example, the digitalisation of information, which can make things operate more efficiently than a paper-based system? In other words, instead of developing, growing and evolving as you do, do you have contact with analogous organisations that offer what you do either domestically or internationally so that you can share with them what is best practice?

Mr BOWEN: There are probably multiple answers.

The Hon. GREG DONNELLY: It is a very general question and I apologise.

Mr BOWEN: At this point we certainly have a number of bilateral relationships with similar organisations within Australia. A number of our service providers, particularly our rehabilitation physicians, have good international contacts and through conferences issues come up in this scheme that are mirrored around the world. Specifically, recently in Australia, about 18 months ago a joint meeting of the heads of CTP and the heads of workers compensation set up a number of subcommittees. One of those particularly is looking at catastrophic injury. I think that subcommittee has now met a couple of times. It is to share experiences in managing lifetime claimants in insurance systems or lifetime care participants in our scheme. It is early days but we are talking about the sort of data we will collect so that we can share the results of interventions in a meaningful way so that if they are using some outcome measure, we know how that would translate to our participants. But that is in the build-up process now. It is a very good initiative.

The Hon. GREG DONNELLY: Should we be looking at or reflecting on issues surrounding injuries from bikes—increasingly those electric bikes or the ones that morph between the traditional pushbike and motorbike—and, of course, motorbikes as we conventionally understand them?

Mr BOWEN: The issues are not particular to this scheme. They come up in CTP generally. It is to do with the coverage of the CTP scheme based on the no fault. Essentially, if the injury is caused by a registered vehicle, it is in this scheme and is the basis for a CTP claim. If it is caused by an unregistered vehicle, there are two other requirements. Firstly, the vehicle has to be registrable, that is, it has to be capable of registration and, secondly, it has to occur on a road and road-related area. Both of those have been subject to significant litigation in CTP going back 50 years or so, but we still get novel cases pop up. The problematic ones that we see are unregistered vehicles on public roads where they are something like a motocross bike, which was never capable of registration, so that is out, as distinct from someone who is on an unregistered bike that has fallen into decay—while it would not currently be capable of registration, it was registrable at the time it was constructed—so that is in. Sometimes these are fairly fine and artificial distinctions, but they have been there a long time. Electric bikes are becoming a very big issue for all these schemes, as they are for the RTA generally, as to what constitutes a registrable vehicle. On one side you have the little motor scooters with an engine in them that have pedal assist and on the other side you have something that looks like a pushbike that has a little motor in it. Currently the boundaries are around engine size and wattage, but the RTA is doing a lot of work looking at whether it needs to broaden the definition of "registrable vehicles", and that will be through into our scheme as well.

The Hon. GREG DONNELLY: Looking into the future, increasingly governments in Australia and overseas are trying to encourage people to use alternate transport to motor vehicles, in other words, conventional pushbikes or these electric-type bikes, and let us assume that they are not registrable. What is the care for individuals who sustain a catastrophic injury from being knocked off one of those machines or bikes? What is your aim for their care? Presumably we will see an increasing incidence of these injuries as a greater number of people use this means of transport?

Mr BOWEN: There have been a number of cases involving injuries to pedestrians from pushbikes. There was a very significant injury to a person on the Iron Cove Bridge, which I know about because it is close to my locality, of a pushbike knocking over a pedestrian. It happens quite a lot in the city with bicycle couriers knocking over pedestrians. I am not aware of any other catastrophic injuries yet. Those people are not eligible to enter this scheme. Neither do they have a CTP claim because there is no CTP insurance. Ostensibly, they can sue the bike rider, but it is unlikely that the bike rider has insurance; certainly, if it is a catastrophic injury, it is unlikely that they have the assets to meet a claim against them. If the number of pushbikes on the road increases and the opportunity for intersection with pedestrians increases, which can cause the injury, I think it will be an issue that the Government will have to look at in providing some sort of coverage for pushbike riders as well along the lines of a green slip scheme. That would be a sensible way to go.

The Hon. JOHN AJAKA: I was reading one of the other submissions from Kate Needham, Executive Director, Greater Metropolitan Clinical Taskforce. She raised three main difficulties: firstly, excessive bureaucracy burdening clinicians with increased paperwork, secondly, that some clinicians find there is an inconsistency in the processes followed by the LTCSA coordinators, resulting in variability between coordinators and, thirdly, meeting timelines and deadlines. I thought we should get an opinion from you on that before we speak to them.

Ms LULHAM: That is fine. Yes, there is an increase in paperwork for people, but there is an increase in work generally. Recently we reviewed all our processes and forms and made changes. I say that acknowledging that people will continue to be required to fill in forms and complete paperwork. We are under scrutiny ourselves in what we spend money on. When people request services we ask that that there is some justification for those requests. We have tried to make it as simple as possible, some of the claims that come to us are fairly small, but most of them range between $30,000 and $60,000 worth of services. So we feel that there needs to be a reasonable amount of justification for those services. One reason why the work has increased is that the number of people who can now access a wider range of services has doubled. Actually, there is double the volume probably of people who can now access private and not-for-profit services that could not before. That is a significant workload issue for them.

I guess it is fair to say that the private sector has probably responded to that more easily because, if there is an increased workload and increased money to purchase the services, they can put people on. That has not been as easy for the public sector brain injury and spinal cord injury unit. Although we pay for these services—for a participant who is in one of those beds, we would be paying $28,000 a month—that money does not go back to the unit but back to the area health service. It means that they are getting an increased workload without getting that funding to meet an increased workload. One of the things we would like to pursue further with them is the idea of having some sort of contract arrangement with them whereby the money that we use to purchase the services goes back to the units to expand the capacity to meet the demand.

CHAIR: Picking up on that specific issue, the Program of Appliances for Disabled People [PADP], as a lot of people know, has a separate line item, which has been done in order to ensure that the dollars go directly to that service. It has been pulled out of the general revenue of that area into a statewide program. Are Enable NSW and you people negotiating about the future of the funding for this program to ensure that the dollars that are going into the program get to the program? For two years, that is what we have heard the issues are.

Ms LULHAM: Enable NSW and us have two different funding streams. We work together.

CHAIR: I know that you are not the same organisation. I was using Enable as an example—and it is not Enable; it was the PADP. That is an example of a program that did come to the area as a line item, was accountable, but now is being pulled into a statewide program. That is not necessarily your solution. What sort of discussions are going on between you people and Health? You are saying that you would like the money to go back to the unit. What discussions are going on between you people and Health about a specific line item for this program?

Ms LULHAM: We are only at the very early stages. We have had a very preliminary discussion with the brain injury directorate at this stage, and not much more than that.

CHAIR: Because it is not their decision.

Ms LULHAM: No. It is made much higher than that, but there are other discussions we would like to have with them around payment for medical services. With Health, we pay the services in two main ways: One is through the bulk billing agreement, and that is for people in acute and mainly in intensive care units, and that is done through the fund.

CHAIR: That is different, yes.

Ms LULHAM: Secondly, we pay for them through a fee schedule, which is a bed day rate for brain injury and we have expanded that to include the spinal cord injury services. That is a bed day rate too for the services that we get included that are in that. What we have been surprised at is the number of accounts we are also receiving particularly from doctors with rights to private practice in hospital for when people are in intensive care and have high-care needs. That offer amounts to an extra couple of hundred dollars a day for participants. We would like to have some discussions with Health about rolling out that fee to encompass all it into one thing because it is a very burdensome thing for us to monitor.

One of the things I guess we would have liked from this Committee is a recommendation that we pursue those negotiations with Health to take that further. I think that is one way of increasing the capacity of both the brain and spinal units to meet the demand. My only other comment is that I think the demand is probably at its maximum point now. We are at the point where people will be moving through the inpatient units. It was building up to this point in time. What we will now have, probably, is a fairly static number of people within the inpatient units, but more and more people out in the community. I guess that is the only good point about it.

CHAIR: But the health services themselves are an integral component of the process, though, whether they are in the community or otherwise, are they not?

Ms LULHAM: Yes.

CHAIR: At the community level, is this divided off?

Ms LULHAM: They are involved in some of the community services out there at the rehab phase, but I would imagine that as people are going on for three, four or five years, it is other community and disability sector organisations we would be dealing with.

The Hon. JOHN AJAKA: I want to go back to the lowest level, if I may. You were saying earlier, and I have understood what you said subsequently, that one of the problems you are having with the area health service system is that you may have a particular public institution that all of a sudden may bring in one or two more patients in this area. It suddenly sends out a bill for additional fees to be paid because it has provided additional services. It receives payment by you, but that payment goes to the area health service, and the area health service suddenly uses that for something that is completely different. It would put a huge burden on this one institution either to not provide the care or take something away from something else, if I can put it in its simplest terms, and that is continuing?

Ms LULHAM: That is true. As I said, it is not just one or two. I think for many units half the people in their units would be lifetime care participants. It has been, I would think, almost a doubling of the workload. As I said, we can pay for the services. It is a matter of trying to—

The Hon. JOHN AJAKA: Keep the money for the service that is being provided? If you had the much older system whereby hospitals have their own internal boards and the money was going straight to the hospital, there is still the possibility that the hospital may have used the money for another cause, but that becomes that hospital's own problem.

Ms LULHAM: Yes.

The Hon. JOHN AJAKA: And you cannot insist, if the money is being paid for a particular service, that that money remains for the specific services?

Ms LULHAM: Not at the moment.

The Hon. JOHN AJAKA: You do not have the legislative authority for that?

Ms LULHAM: No.

The Hon. JOHN AJAKA: I am trying to do this in a nice, simple way, Madam Chair, if I may be allowed to do so.

CHAIR: But I think we actually got the answer.

The Hon. JOHN AJAKA: I realise that, but I just wanted to do to satisfy myself. Thank you.

CHAIR: Just to extend that, we have been told by Health that it is intending to conduct a review of the impact of the scheme on health service resources. Perhaps it is very good timing for you persons to be involved in the process.

Ms LULHAM: Yes. I think that is right.

CHAIR: Not at the cute brain injury level, but with Health itself.

Ms LULHAM: Yes.

CHAIR: Does anybody else have specific issues?

The Hon. GREG DONNELLY: I have a general issue. This is really just to follow on from the comments you made about a reflection for us in terms of the recommendations for our report. You made a very specific point about a particular example. However, addressing my question more generally for the Committee, are there some particular recommendations this time round that you think we should be reflecting on in terms of particular matters for the purpose of putting together a report? Perhaps I should address this question to anyone.

Mr GRELLMAN: I must say I am delighted that you would ask us, but I am not sure that we would.

The Hon. GREG DONNELLY: I am not saying that we will agree with them.

Mr GRELLMAN: No.

The Hon. GREG DONNELLY: I am just suggesting that you might have some that you would like to bowl up to us or give us some particulars of for reflection during our deliberations and in terms of putting together the report.

Mr BOWEN: I would say generally, notwithstanding what are probably some legitimate criticisms in the submissions you have received, we enjoy a good dialogue with all of the service providers and there is good willingness on both sides to try to solve problems. We are aware that we have to meet our own requirements, plus additional demands upon providers of acute care in the community. We also negotiate very hard with our attendant care industry about price. I do not think they would expect anything less. But generally everyone who is working in this area is trying to solve problems, not create them. We are happy to get their feedback. At this phase I think we are really trying to continue to alter, refine and simplify our systems to make it easy for both ourselves as well as our service providers and, at the end of the day, easy for our participants to understand as well.

Mr HERD: Could I make an observation?

The Hon. GREG DONNELLY: Certainly.

Mr HERD: My observation is not so much about this scheme, but what the authority and its work begin to indicate in other areas is a significant question. It is alluded to in the notes, or made explicit in the notes. Somebody needs to have a look at the increasingly obvious fact that where and how one has one's accident or acquires one's disability has a consequence for the quality of the support that you would receive. I do not want to sound flippant but given that we are told when we are young that most accidents happen in the home, if you acquire a brain injury or break your neck or back at home, rather than at work or in a road traffic accident, you may not have as ready access to good-quality services as you would otherwise have.

I think that anomaly will come more and more to the forefront as the scheme develops. It is still very early days for the scheme. I think we all need to remember that. But the more the scheme has participants, the more effective I think it will become in delivery high-quality outcomes for those participants. But let me just throw into stark relief some of the inconsistencies elsewhere in the service system as a whole. I think we have a duty together to look at those questions. Wherever you break your neck, you break your neck and you will have a life-long need for support. I had not realised—there is a very simple example referred to in the notes that were provided to you—that if you are driving along a road in a motor car and somebody throws a brick off a bridge you are not covered, but if the car in front of you throws a brick in your windscreen you will be covered. I do not think it makes much difference to you where the brick came from. I guess we need to try to find a solution to that kind of problem. It is not specifically about the scheme but it certainly will emerge as an issue as a consequence of the scheme's existence.

The Hon. JOHN AJAKA: But the dilemma you have with that is that in your analogy the problem is that the person who is sitting on top of the bridge throwing the brick has never paid any insurance. There is no premium being paid by him. No-one has measured from an actuary point of view that as long as everyone pays this amount we have some money in the kitty. I guess the difference with the workers compensation situation is that you do have insurance. That is not part of this report but the matter you have raised is very interesting in that respect.

Mr HERD: I know we are not supposed to reference individuals but this is an anonymous person. I was surprised, as the chair of the council, to discover that there is at least one over 85-year-old motorcycle victim in our client group. But then if we have an ageing population and we are all living better longer, then we will do the things in our older lives that we might have done in our younger lives. Parliament and the system need to look at that ageing population and its consequences for this kind of scheme. If it is 10 per cent at the moment, I think it is likely just to increase in the future and it poses a whole set of challenges to us as to how we can meet the needs of those people.

CHAIR: I guess the program, in its own way, has developed a model of care that one assumes is being picked up across the board for other reasons. We never know but that is what was indicated the first time you came to speak with us. The other inquiry we have to do with this particular process is the MAA and the MAC that we have now made biannual. There has been some thought and discussions that perhaps this one could become biannual, but I strongly perceive that doing it again next year it will be well and truly bedded in and perhaps that decision could be looked at next year.

Mr BOWEN: I would hope by next year we will have all the guidelines written and then in fact rewritten because at the moment, as you have with anything where there are multiple authors, we have guidelines that are quite stylistically different and some are much more prescriptive than others. Once we have them all in place we will do a rewrite of them and simplify them quite a bit as well. The big issue for the scheme this year, up until now it has been dealing with the acute care and rehabilitation phase and the discharge into the community. Increasingly, as Ms Lulham said, it is about community services and support for people when they are back at home. Those are our challenges in the year ahead.

The Hon. JOHN AJAKA: Obviously the guidelines will be a work in progress but when they are realistically finished, are you able to advise the secretariat that the guidelines are ready, available and if anyone requires a copy to look through them before the next hearing?

Mr BOWEN: Sure. The guidelines are a series of individual guidelines that are all tabled in Parliament at the moment, but once we have finished the ones we have we will try to consolidate them and then retable them. It would be useful for us and participants and the Committee as well.

CHAIR: Is it acceptable to you for this tabled document to be public?

Mr BOWEN: Yes, that is fine.

(The witnesses withdrew)

(Short adjournment)

ADELINE ELIZABETH HODGKINSON, Director, Brain Injury Rehabilitation Unit at Liverpool Hospital, of Locked Bag 7103, Liverpool, and

JOSEPH ANDREW GURKA, Rehabilitation Specialist and Medical Director, Brain Injury Rehabilitation Service, Westmead Hospital, of Darcy Road, Westmead, and

JAMES WALTER MIDDLETON, Director, State Spinal Cord Injury Service, of Post Office Box 6, Ryde, and sworn and examined:

JENNIFER LOUISE JOHNSON, Health Service Manager, Spinal Outreach Service, Royal Rehabilitation Centre, Sydney, of Post Office box 6, Ryde, sworn and examined:

CHAIR: In what capacity to do you appear before the committee?

Dr HODGKINSON: I am appearing in that capacity but also in my role as the Chair of the Greater Metropolitan Clinical Taskforce [GMCT], Brain Injury Rehabilitation Directorate

Dr GURKA: In that capacity.

Dr MIDDLETON: As the director of the Greater Metropolitan Clinical Taskforce, State Spinal Cord Injury Service.

Ms JOHNSON: As the co-chair of the State Spinal Cord Injury Service.

CHAIR: If at any stage you may wish to tender evidence that should be seen or heard only by the committee please indicate that fact and the committee will consider your request. If you take any questions on notice the committee would like the answers by Friday 17 July, if possible. Do you want to make an opening statement?

Dr HODGKINSON: I have looked through all of the questions submitted for this hearing and, apart from a couple of questions, I want to highlight that both the Brain Injury Rehabilitation Directorate and the State Spinal Injury Service have similar issues. Although we may focus on some answers they are also relevant for spinal, and spinal similarly will be speaking for us in some of the issues. We can highlight which ones are particularly relevant across the services as we go.

Dr MIDDLETON: Thanks for the opportunity to provide comment to the standing committee. The State Spinal Cord Injury Service [SSCIS] represents a network of spinal cord injuries specialty services at the Prince of Wales Hospital, the Royal North Shore Hospital, the Royal Rehabilitation Centre, Sydney, the Spinal Outreach and Rural Services and the Hunter Spinal Cord Injury Service. These spinal cord injury specialist services provide a co-ordinated multi-disciplinary model of service delivery in inpatient and non-inpatient settings across acute, subacute rehabilitation, outpatient and outreach environments to individuals who have acquired a persistent spinal cord injury as the result of trauma or a non-progressive disease condition.

SSCIS works in partnership with key stakeholders involved in the provision of support services of people with spinal cord injury, including in government, the Lifetime Care and Support Authority, EnableNSW, the Department of Ageing, Disability and Homecare and the Department of Housing particularly and non-government organisations such as ParaQuad New South Wales, Spinal Cord Injuries Australia and Northcott Paediatric Spinal Outreach Service. The introduction of the Lifetime Care and Support Scheme by the Government, funded by levies on the compulsory third party insurance premiums, has been a very significant, important and most welcome development in the provision of no-fault funding for supporting the treatment, rehabilitation and lifetime costs for people with severe and permanent disabilities.

The benefits of insurance funding being available immediately through Lifetime Care and Support Authority rather than victims having to wait often for a lengthy court case and a decision around compensation, are far-reaching and should facilitate discharge from hospital with greater levels of support and community participation. We would like to acknowledge that the Lifetime Care and Support Authority has achieved a remarkable amount in the short period of time to establish this scheme and all the necessary supporting policies, procedures, guidelines and systems that are required to implement and administer the scheme effectively. It is without doubt well-designed and going to set benchmarks for other jurisdictions.

Within this context though, and still being in its formative stages, from the perspective of the spinal cord injury service and the expert clinicians we represent, there have been substantial impacts on clinical services due to the introduction of more paperwork and bureaucracy that has detracted time available away from clinical treatment and redirected resources. In general, there are well-developed guidelines; however, difficulties arise due to the inconsistency between different coordinators in terms of interpreting and applying the guidelines and then communicating them to clinicians. Coordinators do not have the same level of understanding about highly specialised and complex health-related issues, medical language and clinical reasoning. In addition, other factors affecting timeliness of outcomes include inflexible systems that do not respond to the changing clinical environment and health status of a person with spinal cord injury.

We see our role in a positive relationship with the Lifetime Care and Support Authority achieving improved outcomes for clients by providing clinical leadership, expert care and advocacy for client-centred outcomes within a clinical and environmental context. As the scheme is evolving we see opportunities to work more closely in partnership with the Lifetime Care and Support Authority and Area Health Services to develop a mutual understanding of each other's organisational cultures and perspectives, more clearly delineate roles and expectations, refine processes and efficiency of systems and communication mechanisms to meet the requirements of the scheme, and deliver the best outcomes to the participants who have been injured.

CHAIR: I remember that last year, when some of you came to speak with us, the issue of coordinators not necessarily being an integral part of the process came forward and I would like to expand on that. First of all, are the coordinators not an integral component of the teams? I would just like an explanation.

Dr HODGKINSON: The coordinators are employees of the Lifetime Care and Support Authority and they are appointed to coordinate from lifetime care's perspective the rehabilitation and continuing care of the participant. They interact with the team, but they are not part of the treating team, and I think when a rehabilitation team becomes involved with a patient we look at the patient as a whole, all aspects of their care and support structures, and we may be privy to information that is not necessarily relevant to the Lifetime Care and Support Authority, external issues that the family are dealing with unrelated to the injury, which may have some bearing and, if it is relevant, we inform them, but in some ways we really need to keep the treating team as a treating team focused only on that and then to communicate as best we can with the coordinator.

Dr GURKA: I do not have too much to add to that other than to say that the lifetime care coordinators are not clinicians and certainly we would not consider them to be part of our clinical team and therefore part of our clinical team processes through our case conferencing and family conferencing, et cetera. The way we involve the coordinators in our processes is outside of that formal clinical context and we would meet with them outside of that and discuss coordination of care with them, but generally do not see them as part of the clinical team and the clinical decision making.

Dr MIDDLETON: I also probably do not have much to add, but possibly as the scheme grows there are more coordinators and I think it does create more problems because there is not necessarily a direct involvement in clinical decision making and understanding. I think in the early days of the scheme there were specific coordinators appointed more as liaison-type people with the units. It might be that there is some value in looking at communication mechanisms and ways of developing, and I think possibly training and education of the coordinators around health issues, the organisational structures, and I think there is some room for Health to improve as well, but I think we do need to look at better mechanisms to enhance communication and facilitate the understanding because certainly at the moment there can be misunderstandings created just by the lack of direct involvement or an adequate way of liaising.

CHAIR: Does the Greater Metropolitan Clinical Taskforce become involved in the processes of the Lifetime Care and Support Authority? Are you part of the consultation process?

Dr HODGKINSON: In decision making from lifetime care's perspective?

CHAIR: Yes, are any of you on the board?

Dr HODGKINSON: Yes—well, I am not on the board, I am on the advisory council.

Dr MIDDLETON: So am I.

Dr HODGKINSON: Yes, Jim is as well.

CHAIR: Does this issue come forward?

Dr HODGKINSON: It is raised. I think the difficulty with the lifetime care coordinator's role is that it is a new role. It is not a direct parallel of what we, as clinical teams, are familiar with in terms of the case manager or the rehabilitation adviser for an insurance company who took a different role. This is a role where there is much closer involvement at a level and an expectation that they will meet regularly with the participant and that is done separate from the clinical team, and I think some of the issues arise in that the participants themselves and their families do not necessarily understand the roles of the lifetime care coordinator as separate from a clinical team, so they will raise clinical issues with the lifetime care coordinator who then feels obliged to do something, and then that puts pressure on him, what he then has to respond to, and there is not always the smooth communication and direction back to the clinical team to address those issues.

CHAIR: Any ideas on a solution for this issue?

Ms JOHNSON: I think some of it is about training and supervision. There is, particularly as the scheme is growing and there are more coordinators coming in, a lack of coordinated approach to training and management of individual issues, and I think there also needs to be an interface between the clinicians and the coordinators at the clinical level because at the moment people sit in two camps and there is not a real forum for understanding each other and each other's perspectives.

CHAIR: So perhaps occasionally at the clinical meeting if that person was an integral component—

Dr HODGKINSON: Each service has managed the communication issue differently, but what we established early on was a regular monthly meeting with the lifetime care coordinator to specifically address those issues, but that is starting to break down now partly because we have many more coordinators to deal with and so it becomes a harder thing to organise a meeting with four or five coordinators and then the number of cases we are involved with, so we will have to revisit that structure and talk to the lifetime care coordinators to try to resolve issues.

CHAIR: The policy documents are being rewritten. Have you been integrated into that process, because apparently they are still not neat, they are disparate and have different styles?

Ms JOHNSON: They are rewritten as things evolve and that is valid. The process of communicating the changes is a little bit cumbersome. People fill out forms in good faith and think they are doing the right thing but find that the form has changed twice since the last time they filled it out. That presents difficulty and delays and makes more work because you do things three times over.

The Hon. GREG DONNELLY: I think you have received some questions on notice to be provided to the Committee.

CHAIR: The questions we have today are a bit different to the ones they have had on notice.

The Hon. GREG DONNELLY: In your submission you note a number of positive outcomes for LTCS participants. Could you expand on the issues canvassed in your submission?

Dr GURKA: From a client perspective, the introduction of the scheme has certainly enabled some patients to achieve outcomes they would not have achieved were it not for the scheme. There are a far greater number of people now who have access to therapy services, equipment and care who would not have had that access under previous accident schemes. Probably the best way I can explain that is to give an example of a patient that came through our service who was severely brain damaged to the extent that after a period of hospitalisation he required a high level of care 24 hours a day. He was unable to return to his pre-injury environment because the social situation there was not in a position to accommodate his care because of lack of support and appropriate accommodation. Through the Lifetime Care Scheme we were able to set up this person in supported accommodation, which was essentially a group home, where he had access to care and was able to live in the community. He was provided with whatever equipment he needed to manage in that environment, whereas prior to the establishment of the scheme this person would have been at higher risk of ending up in a nursing home, which would have been a very inappropriate outcome for him.

That was a good outcome and it is an example of how outcomes have been able to be achieved. The process that we had to go through is another issue. It took a long time and there were aspects of the scheme that probably prolonged the endpoint beyond what it should have been. That is another issue and if we are talking purely about the outcome, it was a good one. There were process issues that we had to deal with along the way, which will probably come out in other things.

The Hon. GREG DONNELLY: I want to deal with people's understanding of the scheme itself. Obviously these are people who have experienced catastrophic injury. Is there a general understanding about the scheme within the brain and spinal units where they are being treated and are there appropriate ways and means of communicating what the scheme offers to the individuals who may benefit from it and their families? I am trying to get a picture of the understanding of this scheme across the State. For example, the scheme is not something we read about in the paper on an ongoing basis. Is the niche marketing of the scheme and what it offers to people who need it, when they most need it, sufficiently promoted?

Dr HODGKINSON: At the direct service level with the rehabilitation teams dealing with the participants I think there is a relatively good understanding. There certainly is at a team level; if one person does not have all the information some others will have more information. There is the knowledge that is able to support participants and raise clearer expectations of what the scheme is there for and what it will deliver in the long term. I think the awareness gap is outside the direct rehabilitation teams. Within Liverpool Hospital the acute services remain uninformed. The social workers have attended detailed training provided by Lifetime Care and Support. I do not think it has in any way changed their understanding of what is available and it has certainly not changed their practices. They are not identifying people early and referring early to the scheme.

The Hon. GREG DONNELLY: Do you have a view about why that is the case and why there appears not to be a change and education of people about this scheme as they are exposed to it?

Dr HODGKINSON: I think the whole CTP [compulsory third party] scheme in Australia is not something that people carry around in their heads.

The Hon. GREG DONNELLY: It is seen as very complex.

Dr HODGKINSON: They do not understand that. Even educated people such as our CEO or deputy CEO referred to the Lifetime Care Scheme as the RTA [Roads and Traffic Authority]. There is a very big difference between the two. It shows that it is not in people's general awareness. I generally introduce it by saying, "You paid extra on your green slip last year", and then they work out what the scheme might be doing, but they still do not have a lot of understanding.

Ms JOHNSON: I think the clients themselves are overwhelmed by the scheme when they come into the units. They have never heard of it and they do not understand what it means to them. The social workers actually take the brunt of the workload in interpreting the benefits of the scheme to the individual. Whereas in the past the social workers might have concentrated on psychosocial adjustment issues, they are now spending a lot of time assisting the client to understand the scheme and the benefits of the scheme. That is quite overwhelming for many people.

The Hon. JOHN AJAKA: And we are dealing with clients, or one of their family, who have just suffered major trauma, so we are not dealing with someone who is in a nice relaxed mode to start with when they first come in.

The Hon. GREG DONNELLY: On this issue of educating people and informing them, do you think there is more the scheme itself should or could be doing to address the gap you have identified?

Dr HODGKINSON: I think perhaps they could be doing more of what they are doing. They have already done some education but I think they might need to keep doing similar education.

The Hon. GREG DONNELLY: To continue or increase the amount of education that they are providing to target groups?

Dr HODGKINSON: Yes, because one education session will never be enough.

The Hon. GREG DONNELLY: We had witnesses from the scheme this morning and they indicated to us in their evidence that they are readily available to provide information. If there is misunderstanding, uncertainty or a question mark over certain aspects of the scheme at a local level there is a ready ability to contact the scheme directly and obtain that information to assist the person seeking it. Can you comment on that? Do you find the scheme is efficient in the way it is open to receiving requests for information and then providing it?

Dr HODGKINSON: Speaking from my experience, yes. There is good communication over a particular issue. The scheme members are available at all levels to answer questions about particular issues—what would and would not be included, and what services would be provided. If someone is required to come out and give some specific education they can do that.

The Hon. GREG DONNELLY: So you find they are diligent and effective and efficient in the way they provide information?

Dr HODGKINSON: Yes.

The Hon. GREG DONNELLY: You raised in your submission a memorandum of understanding between the LTCSA and NSW Health to deal with issues, and you nominated a few issues. Would you like to comment on the memorandum of understanding and whether you think that might be worth developing?

Dr HODGKINSON: I think that is important. We come from a background where the Brain Injury Rehabilitation Service and the State Spinal Cord Injury Service have been established as a statewide network. They are relatively well resourced through an agreement between the Motor Accidents Authority and the Department of Health, which was established partly as a self-funding arrangement to draw funds specifically from the compensation scheme into Health that relates to outcomes and rehabilitation. That system has developed a core group of expertise. The number of spinally injured and brain injured at this level is fairly small, so you need to concentrate the services and the expertise into specialist units. That has been a good scheme.

Problems are now arising because that scheme is old and some of the effects and the benefits of the funding drawn into the scheme have become historical. With recent pressures on the health dollar there is a contraction of rehabilitation services. It is easy for rehabilitation to miss out because it is dealing with the after effects of severe injury, and the health dollar will be soaked up by acute care services. It is important to establish someone's optimum recovery and transition into the community to avoid losing long-term care. Lifetime care is something that has the potential to draw money into health services to meet that current gap. The difficulty is that lifetime care funding goes into the general revenue of Health and it then becomes dispersed as the chief executive officers of each area health service choose.

Nothing directly targets that funding to rehabilitation. We are in a situation where allied health in particular is targeted with health cuts. Our capacity to provide the services that we provided previously is diminishing, even when there is an opportunity for increased funding. There is the real risk that it will diminish services, expertise would be lost and dispersed and probably could not be met by the private sector to the same degree. There is a concentration around certain hospitals and regional structures that means that Health in Australia tends to have the super specialities within the public sector. A memorandum of understanding would allow lifetime care to be assured, and that the services for which they are paying and the expectation of a quality service would be delivered. Hopefully it would be combined with an assurance from Health that the funding provided would go towards rehabilitation services rather than being absorbed into the black hole of deficits.

The Hon. GREG DONNELLY: With the detailed explanation you provided covering that range of issues I gather you are saying that you see the establishment of this memorandum of understanding as a priority? In our deliberations is that something we should be contemplating when we are making recommendations about this issue?

Dr HODGKINSON: Definitely.

Dr GURKA: Just to add to that, it is important for the memorandum of understanding to recognise the minimum standard of resources that our programs require in order to deliver the services that are being paid for. Therefore, how the revenue from lifetime care is handled will have to be looked at closely. Every area health service deals with revenue in a different way. Some revenue comes back to units and some revenue does not go back to units directly. What is going back to units is not necessarily coming back as real money that they can expend; it is just coming to meet a revenue target that might be unrealistically set. By default, what happens is that a lot of the lifetime care revenue is paying for public hospital services non-participants in the scheme. It is a huge issue that needs to be reviewed.

CHAIR: Is it defined as a line item in your health system? Do you know?

Dr HODGKINSON: At the health level it is my understanding that revenue from compensable patients is one line item.

CHAIR: Is it jumbled together?

Dr HODGKINSON: Yes. There is no separate coding for lifetime care. At a hospital level there might been some separation, but once it is all combined at the health level it is compensable.

Dr MIDDLETON: From the spinal perspective we have been trying to work on a memorandum, not with lifetime care but with the Area Health Services, the Statewide Directorate and the Statewide Services Development Branch. At an Area level, because of the way in which the budget is allocated through the resource distribution formula—from the Department of Health to the Areas—there is no transparency around the allocation to specialised services. At an Area level there is no direction from Health as to how those dollars should be spent. Area health services have the extremely difficult job of delivering services for local residents and statewide speciality services as best they can.

Wound up into that is the issue of revenue cost recovery. It does not flow back into the delivery of services. I think at the moment it is difficult with current pressures on health and service reductions. Traditionally, over time we have seen all our services take cuts in proportion to local areas reducing services as well. Currently, we are not able to deliver the level of expectation required by the Lifetime Care and Support Scheme. It is reasonable to expect it, given that it provides a reasonable level of funding. I wanted to highlight the fact that I think it is a complex but important issue.

The Hon. JOHN AJAKA: I have heard about the positives of the scheme, which are great, but in the short time we have left I want to focus on the negatives of the scheme, as that is the only area we can improve. Going back to the forms, it always concerns me when I hear stories about people filling out forms and finding out that, because of precedents, they have to redo those forms, especially when we are dealing in an area where people are suffering major tragedy or trauma. How often is that occurring? Have the changes resulted in better forms, or should the old form have been accepted?

Dr MIDDLETON: I acknowledge that there have been improvements. Some of the positive things include the standardisation of forms, in particular, between the Lifetime Care and Support Authority and EnableNSW, for instance, which has been helpful. There has been an effort to streamline forms and to reduce the amount of repetition. Because of the sheer weight load of forms, every item of service equipment has to be put on a separate request. It is the extent of the clinical justification, the quotes, the listing of all the pieces of equipment that were trialled, the reasons why, their cost, and why that is—

CHAIR: From a Program of Appliances for Disabled People [PADP] type process?

Dr MIDDLETON: Yes, but it is far more extensive than PADP. In the opinion of clinicians it is disproportionate to the need. A lot of our clients have fairly predictable levels of care and equipment needs based on their level of impairment and their disability. The clinicians were overwhelmed by having to create a form for each request. For example, a request went in from a physiotherapist for what we would deem six seemingly related items and was told that they all had to come on different forms and they were all sorts of different forms—some had to be on the community care plan, some had to be on equipment requests, some had to be on service requests. Delivering health care is not itemised. I think Adeline mentioned that in the beginning. We see it as complex and integrated. The scheme sees it as each thing is an item that has to be requested, and that makes it difficult. From the impact of this the clinical teams have responded by creating templates, cutting and pasting a lot of the justification. It still needs to be customised in some senses, but even with that process in place, it still takes 20 to 30 minutes to complete a simple form. Very complex forms, for instance care requirements, can take an hour or an hour and a half. So if you do that 15 or 20 times—

The Hon. JOHN AJAKA: A day?

Dr MIDDLETON: Not necessarily a day, but it is taking away days of time. We have estimated that it is 10 to 20 per cent of critical time for each clinician, not just a coordinator, out of the system. Whilst the forms have definitely been streamlined, there is still a lot of repetition and there is just an enormous number of forms.

The Hon. JOHN AJAKA: If one physiotherapist wants to commence treatment, rehabilitation or whatever, with a patient and needs six different pieces of equipment for that one patient, does that physiotherapist have to fill out six different forms?

Ms JOHNSON: Theoretically, yes, depending on the items of equipment. There are some low-cost items that have been accepted as not having to go through an approval process, but they tend to be low cost and very mainstream. For example, if somebody is ordering some pulleys and a set of parallel bars, a set of splints for the legs and a set of weights, they may all have to go on different forms. In addition, if they then want to package that all up and get them going to an outpatient service to have specific gait training—

The Hon. JOHN AJAKA: For example, to a person's home?

Ms JOHNSON: That is right. That would need another separate form. We actually have an example that we would like to table that has that process. A therapist has tried to integrate the information in a way that makes clinical sense, but from the authority's point of view it was rejected because it was not on the right form and it had to be resubmitted. We understand that you need to fill out the right forms, but their system did not match the clinical situation where a client had complex needs and a lot of justification. This form took an hour and a half to complete without looking at the quotes. The clinician then was asked to do that multiple times. I did a bit of research prior to this. I asked if clinicians could count up the number of forms for a T10 paraplegic, that is a relatively low level of need. There were eight forms for an occupational therapist that they completed for that client around equipment. The social worker had completed another set of eight forms and the physiotherapist had completed another set of forms. There were many forms to achieve the one thing, which is setting the person up in the community for discharge. The bottom line is that that comes out of the clinical time that people need to be spending with the client. That is the most important thing.

Document tabled.

The Hon. JOHN AJAKA: As opposed to spending an extra hour and a half treating that client, you are spending an hour and a half filling out forms. Not only does the clinician have that frustration, but also has to explain to his or her patients, and to the family members, that this is occurring: "Sorry, I haven't got the pulleys that you need because I filled out the forms, it took an hour and a half, they got rejected, I've got to fill them out again." I assume there is a waiting period between submitting the form and actually receiving the item. Apart from that, are items being rejected simply on a cost basis as opposed to a need basis?

Dr MIDDLETON: I do not think they are being rejected on a cost basis, but there is quite a deal of potential for dispute over the reasonable and necessary nature of some items. Some are quite clear cut.

CHAIR: Has there been a dispute?

Dr MIDDLETON: Not formally, but I guess in terms of—

The Hon. JOHN AJAKA: Rejections?

Dr MIDDLETON: Yes. There is actually inconsistency between different coordinators in what they do or do not approve. Even simple things like taxi vouchers will be approved by one coordinator, but not by another coordinator. Overnight accommodation for family members might be approved or not approved. They are simple examples. Some more complex examples relate to recreation and exercise and other things. There is a feeling by the clinicians that sometimes coordinators intervene in the clinical decision-making process and take some decisions themselves.

The Hon. JOHN AJAKA: Are coordinators qualified to the same level as the clinicians in relation to actual needs?

Dr MIDDLETON: No. Obviously, it is impossible for the coordinators to be experts in every discipline, but many come from non-clinical backgrounds or more administrative sort of backgrounds anyway.

There are clinicians who have come through the system as well, but they are not necessarily the majority. No, coordinators do not have the same level of reasoning, expertise and knowledge as the clinicians.

The Hon. JOHN AJAKA: I do not mean this in a derogatory way, but it is the only way I can express it. Is it bean counting by the coordinators when they feel the budget has gone a little over the mark for a particular patient or they need to keep the costs down within a parameter? Is it a choice of well, you can have four out of the five, choose the four because you are not getting all five?

Dr HODGKINSON: My opinion is that it is not so much about the dollars but about the justification. A lot of care is being spent in ensuring that every service or equipment provided is fully justified and fully thought through. Hearing the other side as well, I know that at least the first two high-cost wheelchairs purchased for two participants in fact had to be re-done at a later stage due to some errors.

CHAIR: The forms or the wheelchairs?

Dr HODGKINSON: The wheelchairs themselves.

The Hon. JOHN AJAKA: In hindsight the wrong equipment was ordered?

Dr HODGKINSON: Yes, in hindsight. You can understand that they do not really want to be buying two wheelchairs, so they have raised the bar in the required justification and the thinking through. Sometimes that is needed if you are dealing with a clinician with not a lot of experience. But when they are highly experienced people coming from a position of much greater knowledge, perhaps that degree of scrutiny is not needed.

The Hon. JOHN AJAKA: But again you are dealing with a patient where changes are going to occur and the clinician will be able to be specific with equipment. Surely it is almost an impossible exact science, if I can use that word?

Dr GURKA: We actually raised this with the authority recently saying that quite often people are discharged from hospital with definitive equipment because that is when they need their equipment, to leave hospital, but it may not necessarily be the time in their recovery where they have actually stabilised and their equipment needs might change. We are talking to the authority about whether or not we can look at a process whereby the equipment we give them when they go home could be hired or temporary.

The Hon. JOHN AJAKA: Online equipment as opposed to permanent and updated?

Dr GURKA: They have been receptive to that idea and plan on coming out and talking to us about how that might be achieved. I think they are receptive to these things when you raise them. I do not think I have encountered a situation where I have had the feeling that a coordinator has been doing bean counting, as you suggest. The one situation where I think they tend to put a ceiling on how much they are prepared to spend is home modifications. We have had situations in which we have been trying to get somebody back home and, to get them home, they need work done to the house. It has been assessed. An occupational therapist [OT] home assessor has gone out there and made recommendations. The builder's quotes have come back and the authority has come back and said, "No, this is too much. We're not prepared to spend more than $50,000. Look for a solution that is less than $50,000." We have not come across that with equipment, though.

The Hon. DAVID CLARKE: Regarding the spinal injury service, in your submission you indicate that in the implementation of the Lifetime Care and Support Scheme, a three-tier system has arisen. Can you explain what you are getting at there?

Dr MIDDLETON: The three tiers we are talking about are now the Lifetime Care and Support Scheme, the public system and I guess other compensable schemes, whether that is workers compensation or DVA. There are three different systems occurring in parallel. What we are finding is that it is the same person, whether that is the person with T10 paraplegia, or a person with a high level C6 tetraplegia, through each of the systems. In terms of equipment, for instance, it would be Enable, which would now be through PADP; through the public system, it would be the Lifetime Care and Support Scheme, or other compensable schemes, and the person will end up with different levels of equipment and availability of care.

Given that essentially all of the clients are all mixing in the same environment and are trying to be rehabilitated to the same high level, they all talk to each other. They all see and compare. It is becoming an increasingly difficult environment. Clients are becoming increasingly aware of what they may or may not have access to because of the way they were injured and the scheme that they have ended up in. I guess that is the challenge for administering these things fairly and equitably.

Ms JOHNSON: I add to that that the process for getting approval for Enable and Lifetime Care is exactly the same. The forms have been mutually agreed. From a clinician's perspective, they go through and justify a powered wheelchair for a paraplegic, and the same one for a lifetime care paraplegic, but the publicly funded one will get a completely different chair even though the clinicians have provided the same rationalisation on the same form. So that puts the clinician in an awkward spot of trying to explain to the client why they have exactly the same injury but they have a different outcome, even though the process and the rationalisation are the same. It is just an awkward position in that it is a bit inequitable.

Dr MIDDLETON: I also add that although the forms between Enable and Lifetime Care are the same, the turnaround times and the approval processing are different. There seems to be a 10-day maximum turnaround time with Lifetime Care and seven days with Enable. Some of the current experience is that in fact we are getting approvals more quickly, although maybe for lesser equipment through Enable, through the public system, than through the Lifetime Care and Support Scheme. Clearly, some of the bureaucracy and the processing is different, even though exactly the same request might go in at the same time. There are different tiers. The downside of the consistency is that although it has been very helpful to have consistent forms and processes around Enable, now that is a greater burden in terms of justification and all those things than ever it was in the past.

The Hon. JOHN AJAKA: How do you access the forms? Are they online?

Dr MIDDLETON: Yes.

The Hon. JOHN AJAKA: All clinicians can access them online?

Dr MIDDLETON: Yes.

CHAIR: In your case, is Enable now centralised, or is it still local?

Dr MIDDLETON: It is centralised, but there is still all the local stuff. Once people are discharged, it is dealing with all the local stuff.

CHAIR: It is outside our terms of reference, but I was just interested.

The Hon. JOHN AJAKA: Because you see so many of these patients, when we talk about the no fault new scheme, yes, it is wonderful. Whereas someone who would have suffered a brain injury because it is their fault in an accident would not have obtained compensation, now they are suddenly covered and they have all of these schemes and so on that are available that people never have had before. It is difficult to criticise the system. But when you have a situation in which it was clearly not a person's fault but someone else's fault, under the old scheme and they would have received a lump sum payment and would have been able to take care of their own needs and make their own decisions. However, now they are suddenly finding themselves in a lifetime and care situation where you have to fill out your form, you have to wait, you have to obtain approval, and it might be rejected. Where does that leave them on a mental level? Where does that leave them with their family and frustrations, et cetera?

Dr HODGKINSON: There are situations where that occurs. In the one case I would like to describe, it was actually to the person's benefit. Early on there was quite a lot of discussion between the lifetime care coordinator and the rehabilitation adviser for the insurance company. It was a woman with young children who had been injured and who had been a key member of the family business. There were a lot of needs outside her immediate care needs. The compulsory third party [CTP] scheme was able to meet those in terms of advancing sums that would assist in the case, which proceeded to a third party settlement. The children who were in the car at the time of the accident had their own claims and were then eligible for some support and counselling.

I did not see that there was any disadvantage to her through having the two schemes, and in the long run it can be to her advantage. The third party scheme also has its idiosyncrasies and its own lot forms. I think we are more familiar with that and the process is a bit simpler, but in terms of knowing that the Lifetime Care and Support Scheme will make decisions about the care requirements of the woman, based on care needs rather than on a financial and claim management basis, that gives us some assurance that she will get the care she requires. In some ways it is worth the extra paperwork to offset tension that you might get with things perhaps being supplied a bit more readily under the third party scheme.

Dr GURKA: I think it would be fair to say that under the old third party scheme, which is still current, there seemed to be a lot more flexibility in some of the solutions that you could work through with clients, such as the insurer and even the patient's legal representative, whereas the Lifetime Care and Support Scheme seems to have fairly rigid policies around some of the things that they will and will not approve, particularly when it comes to things like accommodation, leisure, recreation and those sorts of issues. I think we always felt that we were able to be more flexible in finding solutions to clients when dealing with third party insurers. We were hoping that we could have a time to talk about accommodation and leisure.

CHAIR: We resumed 10 minutes later than scheduled. Please do.

Dr HODGKINSON: The burning issue is leisure and recreation and, again contrasting the two schemes, a CTP scheme can compensate for loss whereas the Lifetime Care and Support Scheme as I understand it really can provide necessary and reasonable care and support, but not necessarily compensation. The recently released draft guidelines in terms of leisure and recreation have taken a fairly restricted view of what we see as necessary in terms of facilitating recovery in our patients. One of the issues comes down to how we view leisure and recreation. I think I am talking from a brain injury perspective, not necessarily spinal.

Ms JOHNSON: But not entirely.

Dr HODGKINSON: Not entirely because some of them also have brain injuries. Although initially following a severe brain injury there may be a lot of physical and cognitive impairments, one of the lasting impairments or disabilities is psychosocial disability. This may be a person's personality has changed their ability to interact with people, their ability for form relationships; to plan how they would get through their day to a return to work is affected by their injury itself. So the use of leisure and recreation from our perspective, when we are proposing leisure and recreation we are looking at it broader than just filling up the person's day. An unemployed person who is bored at home may seek alternative activities that you would expect he or she has the ability to engage in and plan and organise himself, whereas a brain-injured person who is sitting at home with nothing to do has maybe additional physical and cognitive impairments but also has that inability to plan and organise his recreation and leisure activities.

We are using the structured activities that we then propose as part of a person's leisure and recreational program to achieve a psychosocial rehabilitation, to reduce the psychosocial impairment so that it becomes in itself a therapy. I think this is the idea that when we propose leisure and recreation, are we proposing it as something just as a luxury, as an enjoyment for that person, or are we proposing it as a therapy? For example, we have been given the decision that someone who applied to go to a gym program, it was approved for a certain period of time while there were physical goals of fitness but once we needed to keep that in place as a structured activity that would facilitate that person's interaction with the community and engagement in the community, and therefore lessen psychosocial disability, it was refused because it was no longer a physical goal and in fact became a leisure and recreation goal and therefore it was not approved. I think it was a loss for that patient.

CHAIR: Are you working on redefining? Are you working with the lifetime care and support people on a definition for this?

Dr GURKA: They released draft guidelines, a discussion paper actually, around this a couple of months ago and actually sought input and these things were raised by us. As a result of that feedback they have produced guidelines and our concerns have not actually been addressed in those guidelines.

CHAIR: You are still not comfortable with the outcome.

Dr GURKA: They still see leisure and recreation as that and therefore they will not fund that activity. They will fund any care support or equipment that is required to support recreation but they are quite strong that they will not fund the actual activity itself. I guess that is where we have a concern because, as Dr Hodgkinson said, probably the biggest, long-lasting disability from brain injury is psychosocial and social isolation, depression and all of those things that result. So the activity is seen as a therapeutic intervention to prevent those things and therefore we strongly feel that there should be funding.

CHAIR: We have a very short time for you to do accommodation.

Dr HODGKINSON: That issue was discussed and took up a lot of discussion time at the last council meeting. Certainly, all the clinicians there were very strong and firm in their view. I think there is a thought that these are draft guidelines rather than finalised. I would like to invite somebody additional maybe to talk at the next council meeting to try to target that or even possibly to the board to try to put our case more clearly.

The Hon. JOHN AJAKA: Plus you can send any further written information to us as a question on notice.

Dr HODGKINSON: Accommodation is an ongoing issue. There are solutions being proposed but, as Dr Gurka said, some of the solutions are very slow to move to resolution. One of the critical things is not the funding available to support the person in a home but the home itself. That is either a modified home or a home that can later develop into a group home. At Liverpool we are fairly disadvantaged in that probably the majority of our patients come from areas of social deprivation and want to return to their accommodation and their immediate family but they may be areas that are not really good investment options for a supported accommodation service that might be looking to have some capital invested in homes which will grow. The land value in some of the poorer suburbs in south-west Sydney is low. There is not an attractive option to some accommodation services. So that is what we would see as the way to go for lifetime care and support to look more closely at provision of houses.

CHAIR: Knowing that it is very early days and we are not seeing a lot of what is happening, do you know whether a lot of the investment by Housing at the moment is into modified homes? I happen to know there is a little bit going in. Do you think that will be helpful?

Dr MIDDLETON: Yes, there is work going on that will definitely be helpful. I think Lifetime Care and support could play a major role in facilitating inter-agency work on this, particularly as transitional accommodation for people with spinal cord injury is a major issue. Any of the currently available options are generally unavailable. Our services—we have exit blocks and are even having difficulties getting some of our very acutely injured patients in now because of the blocks due to this. So it is a major challenge to be addressed.

CHAIR: There are quite a lot of questions that we still have to ask you which we will put on paper. I thank you for coming. Is there anything you would like to tell us before you go that is urgent, apart from those major issues which we have taken on board?

Dr HODGKINSON: No.

CHAIR: Are you happy for the document you tabled to be a public document? We can keep it private. Can the secretariat contact you later and check on that issue?

Dr MIDDLETON: Sure. The concern would be around confidentiality.

CHAIR: You have done a lot of de-identification.

Dr MIDDLETON: We have but I guess it was more to help the Committee to illustrate the problem. I think I would prefer it was not part of the public document.

CHAIR: I think the Committee will agree that confidentiality is appropriate.

(The witnesses withdrew)

ROSS VICTOR LETHERBARROW, Chair, Common Law Committee, New South Wales Bar Association, State Chambers, Level 36, 52 Martin Place, Sydney, sworn and examined, and

ANDREW JOHN STONE, Member, Common Law Committee, New South Wales Bar Association, Sir James Martin Chambers, 31/52 Martin Place, Sydney, affirmed and examined:

CHAIR: In what capacity do you appear before the committee?

Mr STONE: I am a member of the Common Law Committee of the New South Wales Bar Association.

Mr LETHERBARROW: I am the chair of the Common Law Committee of the New South Wales Bar Association.

CHAIR: If you take questions on notice would you reply to them by Friday 17 July?

Mr LETHERBARROW: Certainly.

CHAIR: Do you want to make an opening statement? The Law Society said that you are representing them today, so we will watch.

The Hon. GREG DONNELLY: We will send it a copy of the transcript.

Mr STONE: If only it would tell us, but we are more than happy to.

CHAIR: Not quite, it said it agreed with you.

Mr LETHERBARROW: By way of opening, the Bar Association, in conjunction with legal practitioners throughout the State, agree it is a good scheme and a good policy. Our concerns are basically about the way the scheme is implemented and to make sure that the services provided are not inflexibly provided through too much bureaucracy, and also that the scheme remains affordable in the long term and that it does not, because of affordability problems as it progresses, thereby reduce the standard of services. But overall we think it is a good scheme. I do not know if I need to say this or not, but a lot of the time there is a lot of suspicion that the Bar Association and the Law Society are here to try to maintain their fees. We make no fees in this scheme and we will not even in relation to our suggestions. We are trying to appear to take the high ground but we believe we are not doing so. In other words, we are not here for any reason of trying to line our own pockets which, I know, often seems to be the perception of the legal profession by others.

CHAIR: On behalf of this committee I do not think through the entire inquiry process for the past six years we would infer such a thing. We recognise the value of your work within the process.

Mr LETHERBARROW: Thank you. It was not directed at you.

CHAIR: I know that.

Mr STONE: There are others who like to throw rocks.

CHAIR: Do you want to say anything?

Mr STONE: I was going to add that we are very much conscious that the people entering this scheme now will be in this scheme long after all of us have gone. There are children in this scheme who will be there for 40, 50, 60 years into the future. The guidelines that are put in place now, the practices that are put in place now, have to be able to be sustainable in the long term. Our view is also very much for the long term. For the people have forsaken what would otherwise be compensable rights in exchange for the benefits that this scheme confers we are very much concerned to see that in 40, 50 or 60 years' time those benefits are still being provided. It is frightening when you think just how far ahead that looks. I cannot think of any scheme that this State has ever put in place that has remained unchanged or solidly, financially viable for 50 or 60 years. It is a very long term.

CHAIR: Does the legal profession have a role in this scheme? Do you know if it has been participating in the buy-in process?

Mr STONE: The buy-in process has not yet started. It is only a recent addition to the scheme. I know you have a question for us on that matter. The role of the Bar continues to be several. We still have clients who have compensable rights that need to be determined, where we are dealing with their compensable rights, in conjunction with them also receiving scheme benefits. We are sorting out their general damages and their economic loss at the same time as they are getting their rights under this Act. I have been in the role of going down to the authority with a client who had compensable rights to sort out their scheme rights, not on the basis I was charging for it but simply because I thought I could help make sure they got the right treatment in a circumstance where they were coming home, had to move into a new house and to make sure that all of the costs associated with that move were being properly covered. I should say it was all done very well, very professionally and very thoroughly. We have that role as well. Finally the authority continues to consult us about its guidelines and regulations and we continue to offer it our opinions.

The Hon. DAVID CLARKE: Earlier we heard about an anomaly of injury damages received by catastrophically injured persons for lifetime care and support being classified by the courts as capital for the purpose of being included in matrimonial distribution.

CHAIR: A lot of people are being sued.

The Hon. DAVID CLARKE: That is right. Money is being dispensed, for instance, in divorce proceedings. Are you familiar with that problem?

Mr STONE: Divorce is not my field by a long margin.

The Hon. DAVID CLARKE: It could arise in other situations.

Mr STONE: I am happily married, which is where a lot of barristers come into contact with divorce.

The Hon. DAVID CLARKE: A large number of marriages end in divorce, and presumably there is a similar proportion of those who have been catastrophically injured who have received damages, or face that problem, or are being sued for other purposes where this capital which has been given to them for the purpose of lifetime care and support, is eaten into for the payment of damages in other proceedings.

Mr STONE: I would have thought that where you receive lump sum compensation under what I will call the old scheme, where it incorporates a lump sum that covers your general damages or non-economic loss, your economic loss and your future care and treatment needs, that the economic loss would fairly, if it could be severed out and dealt with, be part of matrimonial proceedings because that is the income that was supporting the family, and that properly ought to be accountable as part of divorce proceedings. On the other hand, the general damages for pain and suffering, and care and treatment, I would not have thought ought to be touched in divorce proceedings. But there I am talking from legal theory rather than from practical experience of what actually occurs.

The Hon. DAVID CLARKE: The committee has been told that it is being made available for it.

CHAIR: The problem is for the persons wanting to do the buy-in.

Mr LETHERBARROW: Can I just say that there is an answer to this, and we are probably not the two people to give it to you. But if you want to give us a question on notice we can refer it to our members who specialise in this area. I have had a few cases over the years, and I have had to ask others, but it is something to which we can give you a definitive answer.

The Hon. DAVID CLARKE: Thank you. Will you run through your arguments relating to the proposition that the guidelines of the scheme are ultra vires the Act? What can be done to address that issue?

Mr STONE: The Act says that if you are in the scheme you get your reasonable and necessary treatment expenses paid. The guidelines say: here is what we shall consider to be reasonable and necessary, and that might be a new wheelchair every five years. If you come along and say "I have a perfectly good and reasonable need for a wheelchair after four years" you would hope the authority would have the flexibility to say

"Right, then you shall have one". If they do not, in reliance upon the guidelines, then in effect their action, based on the guidelines, is not supported by the Act. If it is reasonable and necessary to have a wheelchair after four years then it has to be paid and you cannot have guidelines, in effect, subordinate legislation, undermining the substantive legislation. That is the concept of ultra vires that I would hope is not strange to the people around this table.

Even more relevantly, where the guidelines say, "We won't pay at all for this category of thing because we view it as not being reasonable and necessary" again, if it is objectively reasonable and necessary and they are just making an arbitrary decision in the guidelines not to pay for it, the guidelines are ultra vires the Act. Let me give you a simple example of that. The guidelines say that a carer can accompany you on holidays for a maximum four weeks per year, in order for people to still be able to have holidays, but only within Australia. If you live in Australia but your parents live in New Zealand and before your accident you regularly travelled to New Zealand once a year to visit them, and you would still like to visit them once a year and you cannot do it without the carer, that at the moment under the guidelines is bad luck. My view would be that if in effect a judge viewed that it was reasonable and necessary for you to travel to New Zealand then the carer ought to accompany you. So again the prohibition or restriction in the guidelines is ultra vires the legislation. Before I move on to fixing it, does that at least answer that part of the question adequately?

The Hon. JOHN AJAKA: You say "ultra vires the legislation", but is it not more a situation of the guidelines defining what is considered to be reasonable in the circumstances as opposed to ultra vires the legislation?

Mr STONE: But if you define it in a way that is not consistent with the primary legislation, that is where you bring the ultra vires in. And here is your answer as to how to fix it, which is one of two things. The solution we advocate is to make the guidelines consistent with the Act. In other words, to pay for whatever is reasonable and necessary and not put these arbitrary restrictions in place. The other thing you can do, and I am obliged out of honesty to tell you this while I don't particularly want to, is if you insert a clause into the Act that says, "Reasonable and necessary is whatever we say it is", that fixes the problem. Of course, I do not favour that because I do not like having tucked away into guidelines, which are further from the review of Parliament, the potential for clauses that take away people's substantial rights and needs. We are in no way advocating that solution, but you asked and I am telling you.

Mr LETHERBARROW: The point is a fairly discrete one. The guidelines cannot narrow the Act. If the Act says it is reasonable, the guidelines cannot say that "reasonable" means unreasonable, and in relation to some of the guidelines that is what they try to do. Lawyers can say, "Look, the guidelines are ultra vires, they are contrary to the Act."

The Hon. DAVID CLARKE: So you are saying the reverse is actually being done?

Mr LETHERBARROW: Yes.

The Hon. DAVID CLARKE: The Act is being cut down by the regulations?

Mr STONE: Yes.

Mr LETHERBARROW: That is what is happening and that is our concern. "Ultra vires" is probably the right legal term, but really it just means that they are contradicting the Act. The Act says the overriding purpose is reasonableness, but some of the guidelines are not reasonable, and what we would suggest is that the guidelines have inserted into them a principle that accords with the Act that, even though there are certain suggestions made throughout the guidelines, the overriding principle is still reasonableness, so that there is some flexibility built into the guidelines.

Mr STONE: I can give you an illustration that the previous speakers from the medical profession were talking about when they mentioned recreational needs. The authority in its guidelines says, "We will fund a carer to accompany you, if necessary, for recreational activities." In other words, if you became agitated when you do not have somebody with you and need a companion in order to take you to access a movie at the cinema, then the carer will come with you, but they say, "We will not pay for either your cinema ticket or for the carer's cinema ticket." In compensable proceedings you probably cannot recover your cinema ticket because that is something that people incur day to day, but the extra expense of the carer's cinema ticket is something that would be a compensable right. It is something that I would back myself in front of a judge on an administrative appeal to say that the authority's guidelines prohibiting the recovery of the extra cinema ticket for the carer is ultra vires what is reasonable and necessary as a care and treatment expense.

That is a very simple example, and of course it becomes more prohibitive if, for example, you are a paraplegic and to take your children on a holiday to Dreamworld you need the carer to be able to accompany you. They will pay for the carer to come, they will pay for the carer's transport, but at the gates of Dreamworld you leave the carer behind because you have to pay the carer's entry fee into Dreamworld. It is hard enough for a single person on two legs to take three kids through Dreamworld—try doing it in a wheelchair.

The Hon. DAVID CLARKE: So who will interpret these toned-down guidelines?

Mr STONE: The first right of review is you can bring an internal appeal within the authority, and one of our complaints is that that is a complex process for which resources are not available to people who are injured to access, but then if push comes to shove you take an administrative appeal in the Supreme Court where you probably could recover legal expenses. We do not want that to become a new source of work for us, we would like to think it does not get there.

The Hon. DAVID CLARKE: Have you got a shortcut process? To have to go to the Supreme Court on what may be fairly minor things, for instance, the Dreamworld example—

Mr STONE: Which is why the authority gets away with it, because nobody ever justifies running a Supreme Court action over Dreamworld tickets.

The Hon. DAVID CLARKE: Can we receive some guidance or assistance as to how there is a practical and inexpensive way of being able to challenge these guidelines?

Mr STONE: There is a review mechanism set up within the legislation where you can challenge what is reasonable and necessary.

The Hon. JOHN AJAKA: And that is where you come in to the issue of advocacy?

Mr STONE: And that is where we say advocacy at least ought to be—not necessarily paid lawyers at 40 paces, but at least ought to be a social worker making the argument who has some access to legal resources to put up a better quality submission than a social worker legally untrained would make on their own, which is where we have not been getting anywhere with our advocacy service's argument.

The Hon. JOHN AJAKA: Focusing on advocacy, which is the area I have some concerns with, you could have a situation where a person could hire any lawyer and the cost to the scheme would be astronomical. You clearly do not want a situation where somebody is paying $3,000 for counsel to appear in relation to a movie ticket that is worth $22.

Mr STONE: We do not want that.

The Hon. JOHN AJAKA: Are you speaking of a system of having a panel of advocates, available at a fairly modest fee or even pro bono, who are there to assist these litigants to hopefully set up some precedents to prevent further claims being made?

Mr LETHERBARROW: I think that summarises it and, whilst I do not speak for the other associations, I am sure there would be any one of a number of lawyers who would literally volunteer pro bono to do this if they could. I could probably name half a dozen now and there would be no funds involved, and hopefully it would set some precedents whereby the decisions that were unreasonable would stop being made.

The Hon. DAVID CLARKE: You should not be expected to do that to fix something that is deficient in those guidelines.

Mr LETHERBARROW: No.

The Hon. DAVID CLARKE: You should not have to provide a pro bono service to fix something that is deficient and should be fixed and dealt with in another way.

Mr LETHERBARROW: If that is all we can hope for, obviously I think we would be prepared to ask people, but if there could be some funding of some sort that would be better.

The Hon. JOHN AJAKA: The prevention of an advocate appearing needs to be stopped; we need to permit advocates to appear. We need to permit the creation of a pro bono system, through the Law Society or I could think of half a dozen small firms that would be more than happy to put up their hands—

Mr LETHERBARROW: And some of the big firms.

The Hon. JOHN AJAKA: I can think of half a dozen counsel chambers that would do exactly the same thing, so that at least a written submission could be made on their behalf as an advocate or, as you said, you could go in and argue for two minutes and say, "This is complete nonsense and I can give you 10 reasons why." That is really what you are stressing, so that it puts absolutely no burden on the system other than bringing out the rights of claimants to say, "I had the right to buy the extra ticket and it should have been paid for."

Mr LETHERBARROW: And it may stop more expensive litigation because if there is no way of making yourself heard within the system and the decisions are unreasonable then people will challenge them and there will be Supreme Court cases, so it may well save costs.

Mr STONE: The problem is that the internal dispute resolution mechanisms are still going to have to apply the guidelines. You are not going to get the internal dispute resolution mechanisms rolling the guidelines on the basis of the Act. If you want to run an ultra vires argument the only place you are going to win it is in the Supreme Court and what I fear is that, after the first one has won, 48 hours later you will see a legislative amendment that fixes the problem in the way that I do not want. But I can very confidently predict that I will be back here in two years time and by then there will be a legislative amendment saying: "Reasonable" is what we think it is.

CHAIR: No, we are doing it next year.

Mr STONE: Well, it might take two years, but I just have the feeling that that is ultimately going to be the solution; that there is going to be a legislative fix to define "reasonable" as being what the authority thinks it is.

The Hon. JOHN AJAKA: Going to the guidelines, are they one clear and concise set of guidelines? We are starting to hear evidence that there is a little bit of here, there and everywhere—that is the impression I have been getting.

Mr STONE: In some ways I prefer to have flexibility within the guidelines. That is in part why this problem has not come up. Let me make this point: The current generation are the people who set up this scheme, the people running it. You have people like David Bowen, Suzanne Lulham and Neil Mackinnon. They were all here with you this morning and I have had plenty of meetings with them and an awful lot of discussions across an array of issues. They are good people of good will. They are running this scheme I think fairly well, apart from some of the issues that you have heard about. What concerns me more is not them, not their replacements, but their replacements' replacements as it gets bigger, as it gets harder to manage, as it becomes more unwieldy, who want clearer and more precise guidelines, who lose the flexibility to deal with things on a case by case basis. My concern is that in 10 or 15 years time there will be a hard and fast set of guidelines that are restrictive and that are being applied inflexibly. I am not necessarily critical of guidelines that have a degree of flexibility and discretion within them. It does lead to issues of inconsistency when you have different people exercising a different degree of discretion. I think that is a lesser evil, because of course if there has to be consistency they bring consistency to the lowest common denominator and the least benefit rather than the most generous. I prefer the alternative.

CHAIR: Can I extend that a little? We had discussions with the last witnesses in relation to the form processes, which relate to the approval processes, which in turn relate to the protocol. My concern is that if you standardise the forms and exactly what you could have them for to such a finite level you would perhaps remove the possibilities of variation, which is just what you are saying. What do you think?

Mr STONE: We thankfully stay well away from that side of the form filling.

CHAIR: I know that you are not involved with the forms but the forms are part of the implementation of the protocols.

Mr LETHERBARROW: I think standardised forms would be a very good idea. It was apparent from the last group of witnesses they are having problems with the bureaucratic aspect of this scheme.

The Hon. JOHN AJAKA: The red tape.

Mr LETHERBARROW: I fear the red tape is going to get worse. A lot of insurers say privately that they are very worried about how much this scheme will ultimately cost and a lot of sceptics from our side of the fence think that in a few years time it will start to become more expensive, the guidelines will start to be imposed more strictly and the level of the services will decline. If that is to happen it will be even more important that people have some form of right to argue that the guidelines are being interpreted against them. There has to be some mechanism—you cannot expect a brain-injured person or a severely spine-injured person to be able to argue their own rights. It can be done cheaply without, as Andrew said, putting lawyers at 40 paces into the system, which we do not want. That is what we have to try to achieve.

Mr STONE: Lawyers as a background resource rather than front-line actors would be the way to put it.

The Hon. JOHN AJAKA: How do you overcome this problem? If someone puts in a claim and it is rejected how do you convey to someone who has a brain injury that he might have a right to seek advice from an advocate, firstly, and then for the advocate to take it on? Even that is going to be a very limited circumstance as well.

Mr LETHERBARROW: A lot of people give up when they are knocked back. They just go, "Oh well, I am not entitled to it apparently", when they are. If a decision is made against them, probably some document should be provided to them—

The Hon. JOHN AJAKA: That notifies them of the choices—a, b, c—"and here is an advocate's number".

Mr LETHERBARROW: Exactly. I think that is important otherwise, if some pro bono scheme is put in, people simply will not know how to contact it or even be aware of its existence.

Mr STONE: One of the things we have pointed out to the authority in our submission on advocacy is that the advocate will form a useful buffer. There will unfortunately be a small subset of people who will have little left to do with their lives other than spend most of it fighting with the Lifetime Care and Support Authority over their entitlements.

CHAIR: It does not seem that is the norm yet.

Mr STONE: No, but there will be. This is a group of substantially brain-injured people who have associated psychiatric conditions. If you can at least hear an independent advocate say, "No, you are being unreasonable, you ought to accept the authority's decision", that is an important buffer in providing outside counsel to people to help them in their dealings with the authority.

The Hon. JOHN AJAKA: That is a good point.

CHAIR: You were going to talk to us about the buy-in scheme.

Mr STONE: I am going to have to talk about discount rates. I know this makes everybody's head hurt but I will do my best to make it as simple as I can. When you are awarded a lump sum to cover future expenses it is not as simple as saying, "My costs are $100 a week, or $1,000 a week, multiply that by the number of weeks I have the need." Because you are getting the lump sum upfront they have to take into account first of all the investment return that you can make on the lump sum, less the effect of inflation and less the tax you are paying on the investment return.

The Hon. JOHN AJAKA: But there are schedule tables.

Mr STONE: There are. The State of New South Wales has legislated that when you are compensated there is a 5 per cent discount rate. In other words, it assumes that your investment return less the rate of inflation leaves a gap of 5 per cent. That is not the true discount rate. The true discount rate is in the order of 1 to 2 per cent. The suggestion is there are 300-odd people who have not yet resolved their cases as well as all those people who have already resolved their cases and got their lump sums to whom the Lifetime Care and Support Authority can quote a price saying, "Here is what it costs to buy in, would you like to do it?" I have to say, given the rampant medical inflation, if I had clients and the price was right I would recommend that they do it. The problem is: can the price be right? Can the lump sum you are getting for your compensation match what the authority charges to buy in?

We met with the authority after you had seen our submission and before the bill was passed and asked what they were going to use as the discount rate. We have established that they are in fact using a 2 per cent discount rate. They are assuming a 6 per cent return on investment and 4 per cent inflation, leaving a net 2 per cent. What that means, to give you a couple of examples, is that somebody whose costs run at $5,000 a week—24-hour care in fact costs more than that; it is up to about $7,000 or $8,000 a week—for 30 years, will receive $4.1 million in lump sum compensation for that expense over that period of time. That is on a 5 per cent discount rate. Apply a 2 per cent discount rate to what the authority is going to charge and it is $5.9 million. In other words, they are asking for $1.8 million more than you got. If we take it out to 50 years for a child, still at $5,000 a week, the compensation is $4.9 million and the authority's charge, applying their 2 per cent rate, is $8.3 million, a gap of $3.4 million. Nobody has the spare change to cover the gap.

Mr LETHERBARROW: So no-one will buy in.

The Hon. JOHN AJAKA: For the cases that have not finished, would you as counsel not ascertain what a buy-in cost would be for a particular person as part of your evidence before the judge and say, "Judge, he wants to buy in, it's going to cost him $8.5 million, that is what he is seeking"?

Mr LETHERBARROW: You cannot do it because the legislation under which the actions are brought nominates 5 per cent. So the judge says, "That's right, you're going to be ripped off here but I can't do any more because under the Motor Accidents Act, the workers compensation legislation and the Civil Liability Act it is 5 per cent." There is nothing you can do about it.

The Hon. JOHN AJAKA: Can you not treat the buying-in as a disbursement that is no different from other medical disbursements, and say, "We've got a set figure, your Honour. This is what it's going to cost him to buy in and that's exactly what he wants to do; he is seeking that amount as a disbursement", if I can use that term?

Mr STONE: In effect what you are doing is saying to the CTP insurer, who at the moment for the 30-year $5,000 a week scenario has a liability of $4.1 million, "Instead we would like you to pay $5.9 million. We want you to pay $1.8 million more." The reason you cannot do that is the insurers very cleverly insisted on, or obtained, a clause in the deed to the original 1988 Act, which is still binding on the 1999 Act, that says if the Parliament ever retrospectively legislates to increase their liability it is the State of New South Wales that pays the gap. You cannot do it.

The Hon. JOHN AJAKA: What is the recommendation you are asking of us—that the Lifetime Care and Support Authority should not be using a 2 per cent rate and must use the same discount rate as the current—

Mr LETHERBARROW: That causes a problem because they will go broke.

Mr STONE: It is not fully funded.

The Hon. JOHN AJAKA: I have concerns because I cannot see how anyone who was compensated in the past having the funds to buy in, unless they have invested their money in an incredible way. You are saying the buy-in is just not going to occur.

Mr STONE: There is no easy answer because you cannot retrospectively legislate to fix things for those who are getting their damages now. The problems stems from a 5 per cent discount rate. It is in effect a cross-subsidy by accident victims of the motor accidents scheme. The 5 per cent discount rate is just unfair. It is why the High Court picked a 3 per cent discount rate at common law and why the United Kingdom Government currently has a 2 per cent discount rate and is looking at lowering it. The long-term answer is to amend the Civil

Liability Act and the motor accident legislation to have a fair 2 or 3 per cent discount rate. Stop asking accident victims to subsidise insurance premiums. That will not retrospectively fix this problem. I do not think this problem can be retrospectively fixed without either the LTCS Authority subsidising the buy-in, which is fine as long as you do not say it is fully funded, because it is not, or accepting that people getting lump sum compensation cannot afford it. I have reduced to writing what I have just told you, so I would be happy to table that.

The Hon. DAVID CLARKE: Until this is fixed a great injustice is being perpetrated.

Mr STONE: It has been for the better part of 20 years—since you introduced a 5 per cent mandatory discount rate to let insurers off the hook.

Mr LETHERBARROW: The Lifetime Care and Support Scheme will result in people simply not buying in because they would be economically crazy to do so.

Mr STONE: It is not that they would be economically crazy to do so; it is just that they do not have the money.

Mr LETHERBARROW: The scheme cannot give them a cheaper rate because it will not be able to withstand the years in front of it.

CHAIR: Thank you for bringing that to our attention. The other issue that has been raised relates to spinal injuries and to the two-year interim period. As you have seen in your questions, the authority advised us that spinal classifications are sometimes not definitive early on and the two-year interim participation period is appropriate.

Mr STONE: That is true.

CHAIR: Does that answer your concerns?

Mr LETHERBARROW: Yes.

Mr STONE: Yes. If the authority were prepared to be flexible about allowing spinal cord injuries to be given permanent membership earlier that would meet our concern.

Mr LETHERBARROW: The short answer to question No. 3 is yes.

CHAIR: If people are in an interim participation program do they not get the same benefits as permanent participants, or is it just a feeling of knowing where they are going?

Mr STONE: It is partly that. With somebody who has a severe spinal cord injury, if the spinal cord is broken and it is not getting better, that is a given. In some cases you could work out that person's compensable rights—that is, the things outside the scheme such as general damages and economic loss—fairly rapidly. You would know that he or she was getting the maximum allowable under the legislation for general damages. If quadriplegics will not be returning to work you calculate out their wages. Theoretically, you should be able to settle a quadriplegic case, or the compensable component of it, weeks after the accident, provided there was no liability issue.

However, if you had to wait two years for the guarantee, if a person was in the Lifetime Care and Support Scheme, any lawyer who did not want their insurance premiums to be substantially raised would not sign off on those rights with the insurer before he or she knew that that person was a permanent member of lifetime care. The authority could fix that. If a lawyer comes to us and says, "We are ready to settle everything else; will you make them permanent?" and that person says yes, the problem is solved.

The Hon. JOHN AJAKA: If you were at fault in an accident and you were covered by the Lifetime Care and Support Scheme you could be at an advantage over someone who clearly was not at fault and who had full rights to sue the person who was at fault. You would have to wait for a period of two years to see what other compensation you would receive.

Mr STONE: If you were at fault, as long as somebody keeps writing the cheques, to be frank, you would not care whether you were interim or permanent. It is not a major problem provided the authority is flexible. It has indicated that it is willing to be flexible, so that really solves that problem.

CHAIR: Could you give us your legal perspective? A couple of times we have heard about the uninsured—bicycle riders, off road vehicle drivers, and those sorts of people. Do you have a legal perspective on that issue? In places like Sydney many people ride around on pushbikes. We had the terrible example of a pedestrian who was badly injured by a pushbike rider and no insurance was available, which made it incredibly difficult. Do you have any ideas about or any resolutions for this issue? Do you think pushbike riders should take out insurance?

Mr STONE: It involves difficult practical enforcement issues. It could involve fishing licences and other things that you might want to get enforced. I am afraid the ultimate answer is to have a social welfare safety net that looks after them just as well as it looks after people who fall out of trees or who sustain spinal or brain injuries in all sorts of other ways. The dollars in this scheme can stretch only so far. Each time you take it a stretch further the money has to come from somewhere.

CHAIR: Yes. It could not be lumped into another area.

Mr STONE: You asked in general terms what we should do about cyclists running over people. You should have better enforcement, predominantly with courier companies, around the Sydney central business district. This is purely a personal perspective. I think you would struggle to try to licence everybody who wants to ride a bicycle.

Mr LETHERBARROW: A case that went to the High Court involved someone who was injured as a result of being struck by a bicycle. That person hung onto the verdict but the courier company simply went into liquidation and damages were never obtained. At the moment, anyone hit by a bicycle has no real prospect of getting anything back. I think the insurers would probably scream blue murder if they were told that they had to cover such injuries. I suppose it is more a social question than a legal one.

The Hon. JOHN AJAKA: We were given the good example of a brick being thrown from an overhead bridge onto someone. That is a similar example.

Mr LETHERBARROW: It would be great if everybody was covered for everything, but financially that would not work.

Mr STONE: With the bike courier companies you have the additional problem that most of them try to employ as contractors those who are otherwise known as itinerant travellers rather than making them employees. But again there are bigger legal policy issues involved that are worthy of debate on another occasion.

CHAIR: These days there are fewer couriers and more adventurers.

Mr LETHERBARROW: You have to be very careful walking around the city.

CHAIR: Some issues have arisen as a result of our inquiry today, which we will put on notice. Thank you for appearing before the Committee today.

Mr LETHERBARROW: Thank you for the invitation.

Mr STONE: It has been a pleasure.

(**The witnesses withdrew.**)

(**Luncheon adjournment.**)

CHAIR: Welcome to the second review of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council that the law and justice committee does annually. That was put into the law when the law was first put together for this program. We have some guidelines in relation to broadcasting, but the people who do our media here understand them so I do not need to go through those. If you have any messages or bits of paper that you want to tender to the Committee or anybody who is here, the secretariat people will assist you to do that. Committee hearings are not intended to provide a forum for people to make adverse reflections about others. The protection afforded to Committee witnesses under parliamentary privilege should not be abused during these hearings. I therefore request witnesses avoid the mention of other individuals unless it is absolutely essential to address the terms of reference.

JOHN GREGORY MALOUF, Private Citizen, and

DANIEL ADRIAN MALOUF, Private Citizen, and

ZIVANA SPITTLES, Private Citizen, and

LEANNE MICHELLE BELL, Private Citizen, and

RICKI-LEE BELL, Private Citizen, and

RODNEY PHILLIP McDONALD, Private Citizen, affirmed and examined:

CHAIR: In what capacity are you appearing before the Committee today?

Mr J. MALOUF: I am a carer for my son, Daniel.

Mr D. MALOUF: As a participant in the Lifetime Care and Support Scheme.

Ms SPITTLES: As a carer.

Ms L. BELL: As Ricki-Lee's carer.

Ms R. BELL: As a participant in the Lifetime Care and Support Scheme.

Mr McDONALD: I am a family carer for Ricki-Lee.

CHAIR: If anything that you want to say you perceive should be seen or heard only by the Committee, please indicate that and the Committee will consider your request. I remind everyone that under the legislation that refers this inquiry to the Committee we have no power to investigate a particular participant or application for participation. Under the legislation, we have no rights to interfere with the processes. We look at how the process is working and then we look at what recommendations as a Committee we can make to the Government about any possible changes for the process and the legislation. I would like each of the groups in turn to tell us how you became involved with the Lifetime Care and Support Authority program. We will start with the Malouf family.

Mr J. MALOUF: We were involved because my son was struck down in the city by a car. He took the full blow of the accident to his head and was in a coma for 10 days in St Vincent's Hospital. That is how we came to be involved with lifetime care.

CHAIR: Can you give us a bit of information about how you actually became part of the process of the program?

Mr J. MALOUF: It was a situation where there were certain criteria that Daniel had to meet before he could be involved in the program. Because of the trauma of the accident, I believe he exceeded those limits quite substantially and that is why he was accepted into the lifetime care.

CHAIR: How long did that happen after the original accident?

Mr J. MALOUF: We were informed within 24 hours by the social worker at St Vincents that he would possibly be accepted into the scheme. The official acceptance happened when he was at Liverpool brain injury unit so that would have been three to four months after.

CHAIR: What was the timeframe for that? Can you tell us when that happened?

Mr J. MALOUF: It was 3 December 2006 was the accident, so about three months after that, March of the following year.

CHAIR: That was very soon after the program was initiated?

Mr J. MALOUF: Daniel is actually the first participant.

CHAIR: On all sides in Parliament and every individual are so proud and pleased about this piece of legislation. What you have said is really nice for us to hear.

Mr J. MALOUF: Good, because we are very appreciative of it, I can assure you.

Ms SPITTLES: My son Joel had a car accident on 1 February 2008 when his vehicle hit a tree. He was the only one involved so he was classed as an at-fault driver. We were under the assumption that we would have to just battle with this on our own. Joel sustained quite a severe traumatic brain injury, as well as some spinal injuries. It was not until possibly three weeks into his recovery that we found out he may qualify for lifetime care and support. I did not even know it existed, so it was a big relief for our family.

CHAIR: For how long was he in hospital?

Ms SPITTLES: He was in intensive care for 16 days and then he was in Royal North Shore Hospital, in the neurosurgical level for three weeks, and then he went to Royal Rehabilitation at Ryde and he was there for about eight weeks, I think. He is recovering very well.

CHAIR: Did the social workers at the rehabilitation service make you aware of it?

Ms SPITTLES: To be honest, the coordinator from Lifetime Care and Support approached me.

The Hon. JOHN AJAKA: Came to visit you?

Ms SPITTLES: Yes.

CHAIR: Where?

Ms SPITTLES: At Royal North Shore Hospital.

The Hon. JOHN AJAKA: How did the coordinator find out about your son?

Ms SPITTLES: I do not know. I was just fairly happy to hear from them. It was a very caring approach and very supportive approach because at that time in your life you just do not know where you are going to go with this injury. It was just a relief for our family, not just to hear about it but the support we received from Lifetime Care.

CHAIR: And the Bell and McDonald family?

Mr McDONALD: I think I have been nominated as a spokesman.

Ms L. BELL: He knows more than me.

Mr McDONALD: It was only 4 November 2008 Ricky was thrown from a vehicle. The driver took off before the door was shut and did an erratic U-turn over a median strip. She went straight into intensive care. She was in an induced coma for, I believe, 12 days. While she was in intensive care the social worker from that department spoke to us and said that Ricky would more than likely be a good candidate for Lifetime Care and Support, so that was our first introduction to it. After Ricky came out of intensive care she went down to GT—

this is at the John Hunter Hospital—where Karen DeJuliis from Lifetime Care and Support came and visited us and again said that Ricky would be a candidate for it, and she was pretty sure by Ricky's condition because she has suffered a very traumatic brain injury which at the moment is still ongoing.

The social worker introduced it, Karen came and sort of represented Lifetime Care and Support and did all the appropriate work and that. We have not really had to do a thing, which is a relief for us because we are busy with Ricky. I cannot be sure but maybe about two months after the initial accident they let us know that Ricky was accepted, which I presume is just the normal procedure. She was a live-in patient at Hunter Brain Injury in Derby Street, Newcastle, for probably about two months and now she is just an outpatient going back and forth approximately three times a week. We have not really had to do anything, only fill out and just sign a couple of forms. It has been good.

The Hon. JOHN AJAKA: Thank you very much for coming in; it helps the committee enormously to try to get the other side of the picture, as opposed to just reading about it. I ask now that you are in the scheme do any areas of it frustrate you that may not be occurring? We have heard all the wonderful positives but do you see a way to improve the scheme?

Mr J. MALOUF: It is a very difficult question to answer. I have been going over this since we have been in the scheme and, honestly, no. It has helped us immensely. It has been very easy for us to be assimilated into it. The assistance that Daniel has got to get to his doctors' appointments, the level and comprehensive care he has received—thank God it is there, is all I can really say. To me, as a carer, there have not been any negatives. As a participant, there maybe other things there but as a carer it has been really great. To find negatives—throw buckets of money at me, maybe, but that is not the object of the scheme.

The Hon. JOHN AJAKA: That is the next question in another way.

Ms SPITTLES: Honestly, I cannot say a negative thing about it myself. It has been a relief for our family. Joel has received a lot of support, the same thing. He has had a lot of facilities offered to him. He has had carers with him for quite a number of months just because of some of his behavioural and social issues. He has had speech therapists, occupational therapists, physiotherapists, gym memberships paid for to help strengthen his back muscles. We have even had the help of a cleaner, which has been great. Just the support that we get from the rehabilitation centre, because that is covered by Lifetime Care and Support, is amazing. It is the emotional support as well that we get. We get counselling for our family to help us with situations that arise, because there are a lot of difficulties involved with brain injuries and some relationships can become very toxic. It has been so helpful for us because we now keep positive and patient with our son. I cannot say a negative thing about it; it has given our life back.

The Hon. JOHN AJAKA: Mr McDonald?

Mr McDONALD: I have to agree with the rest of them. At first when Ricki was seeing specialists and that and getting approvals through to see them, it was—not frustrating—but as it would get closer to the appointment we still had not heard back from Lifetime Care and Support whether it had been approved or not. It never ever became an issue; it eventually came through. I think now that the ball is rolling and they realise that Ricki is seeing different kinds of specialists, it has definitely improved now that they are aware of that.

The Hon. DAVID CLARKE: Is there anything that you have sought through the scheme that you have been knocked back on or has been reduced?

Mr McDONALD: Yes, that was the first thing actually, and that is quite amusing because the physiotherapist or, I think, Ricki's case manager suggested something about hip-hop dancing might be—

Ms L. BELL: Because of her arm—it would help her arm movements.

Mr McDONALD: Just to get her arm going.

Ms L. BELL: In that brain injury place.

Mr McDONALD: I think it is something that Ricki would probably have enjoyed doing but it was not really her idea, they sort of sparked it up.

The Hon. DAVID CLARKE: But it was something that you thought could be of help?

Mr McDONALD: I do not think it would have hurt, no.

Ms L. BELL: The physio suggested it.

The Hon. DAVID CLARKE: The physio suggested that it would be of use and that has been rejected?

Ms L. BELL: That is the first thing that has ever been rejected, and it was only $50.

The Hon. JOHN AJAKA: What about the others? Have you ever had a situation where something has been requested? We heard from some clinicians that one of their most frustrating aspects has been the paperwork in the situation of the forms—the wrong forms, redoing the forms, putting in 10 forms for 10 different item—and I got their views on that. But I wanted to know from your perspective, are you sensing the same problems or you are not really experiencing it, it is more their side of it?

Ms SPITTLES: Basically, while going through the rehab our case manager does all that paperwork. We often look at it and sign off on it and it is like, there is no way I would be able to do that. So they cushion that for the family, which is great, because it is very difficult filling out those forms and saying things over and over. I think we would be going crazy.

The Hon. JOHN AJAKA: Are you experiencing that they are spending so much time filling out forms and better quality time could be spent with you, or are you not seeing a difference?

Ms SPITTLES: We are not seeing a difference. We are being protected from that, which is great—it should continue.

The Hon. GREG DONNELLY: Could I ask a question just on a terminology issue? You said "case manager". Is a case manager different from a coordinator?

Ms SPITTLES: The case manager is from the brain injury unit. You are given a case manager and she basically manages all aspects of their recovery.

CHAIR: A clinical case manager.

The Hon. JOHN AJAKA: The coordinator comes from the Lifetime Care and Support. The final question from my perspective: As family carers as well, are you being paid to care, or is it an issue that you are not being paid? Does that come into the equation in any way? We heard earlier that they would prefer that all carers be outside help, if I can use that terminology, as opposed to paying family to be carers.

Mr J. MALOUF: I never seek payment for being a carer. Caring for six children anyway I have a lot of family support, so that is really not an issue for our family. No would be the answer to that.

Ms SPITTLES: I never receive payment for being a carer. We did have carers allocated to us to spend time with Joel, but that was a positive thing because you do need a break. It is very intense and it is very emotionally draining.

The Hon. JOHN AJAKA: If you had the choice that they were to pay you to stay there as opposed to giving it to an outsider to come in—their argument was that it was healthier for you as well as the person being cared for to have it done from the outside. I just wanted to know if you would see it the same way.

Ms SPITTLES: Originally in the beginning it would have been good to be paid because I took many, many months off work, and we did struggle financially with that. It would have been great to have received some payment. I had to go back to work, and that is when the carers really stepped up. But then it was a relief to have that break as well. It is a kind of a Catch-22. It is hard to let go of that person once they have been injured like that.

The Hon. JOHN AJAKA: That was one of their exact concerns as well.

Ms SPITTLES: You just want to protect them all the time, and no-one is going to be able to understand what they have been through and how they think and feel. But there are a lot of very caring people out there. I am really glad that I did go back to work though; it has been great for me.

The Hon. DAVID CLARKE: Are you saying you are not entitled to any assistance if there is financial assistance as a carer?

Ms SPITTLES: I do not think so.

CHAIR: Only from the Commonwealth carer's allowance, which is a different process.

The Hon. DAVID CLARKE: But not under this scheme?

Ms SPITTLES: No, not under this scheme.

The Hon. DAVID CLARKE: Would you not think that with somebody who is part of the family for whom you had to give up your work for a time, do you not think that a family member would be the most obvious person to be a carer?

Ms SPITTLES: Yes.

The Hon. DAVID CLARKE: And there should be some system where there is financial backup for family members to be carers, particularly when they are giving up working? That would seem an obvious thing. Would you not see that as something that could improve the scheme?

Ms SPITTLES: That would be amazing. That scheme would be perfect.

The Hon. DAVID CLARKE: But why should it have to be amazing? Why should that not be the case as of right? Why should that have to be something special? Why would it not be just taken for granted that that should be the case, that a family member is given financial assistance?

Ms SPITTLES: In honesty, you are with that person 24 hours a day and no one is going to be able to do that in the beginning.

The Hon. DAVID CLARKE: That is what I am saying.

The Hon. JOHN AJAKA: If I can understand just what your evidence is. Had it at least been available to you in the very beginning—it is not as if you are saying you would like to continue for ever and a day, but at least in the beginning, because you are the person there in the beginning. You are not likely to return to work the very next day under any circumstances, but it is rather than having a carer come in. But there must be a time that yes you do want to return to work. You have the break and the carers then come and take over. That, to you, would be the perfect situation?

Ms SPITTLES: Yes, that would be very practical.

The Hon. DAVID CLARKE: So that would be something where the scheme could be improved?

Ms SPITTLES: Yes.

The Hon. DAVID CLARKE: Could I ask you, Mr McDonald, when you mentioned about the dancing, do you think there should be more flexibility to allow, on smaller things like this, some leeway where you can go and get these things? It is a bit tough that you go out there for something that you all agree is going to be of help and is going to be uplifting, something that you really think is going to be helpful here, and you get knocked back on something so small. Do you think there should be more flexibility in the scheme?

Mr McDONALD: Yes, true. At least while Ricki is doing the rehab it is something that she might look forward to going to because it is not the same thing. So if she is dancing or doing something she is enjoying and it is helping her as well, and especially with minimum cost.

The Hon. DAVID CLARKE: It is going to help emotionally?

Mr McDONALD: Exactly, yes.

The Hon. DAVID CLARKE: And physically and all of these other ways, and it was suggested by your physiotherapist and you were knocked back.

Mr McDONALD: Yes.

The Hon. JOHN AJAKA: There was talk earlier from the Bar Association—the lawyers—that maybe a situation of having advocacy available to you—lawyers on a pro bono basis, not costing either the scheme or yourself something, to be able to ask them questions such as did they have the right to be dancing—would be of great assistance to you, because obviously you are not going to go on an appeal and go to court and hire a lawyer if you are knocked back on dancing, but maybe if a phone call was made and someone said it is your right, you have a right to demand it, you have an entitlement to it. How do you feel about the advocacy issue? Has that ever come up so far?

Mr McDONALD: We have only been in it for eight months, and at the moment our focus is on Ricki. She has obviously still got a lot of major issues that we have to concentrate on. I guess Leanne and myself put ourselves second and Ricki first. As far as the advocacy, I am not even sure what you mean by that.

The Hon. GREG DONNELLY: Someone to speak on your behalf in terms of raising an issue and arguing a matter, if you have an issue—a spokesperson.

Mr McDONALD: Okay. Well, we only got that yesterday. If we went back in and spoke to Ricki's case manager I am pretty sure something as simple as that would get sorted out anyway. At the moment it is just a small thing.

The Hon. JOHN AJAKA: Mr Malouf, have you had any experience in this area?

Mr J. MALOUF: No, we have pretty much received everything that Daniel should. On the care side of things—and obviously the focus is on Daniel here—as carers, in a scheme that is so new, you tend not to ask for things because you are so grateful to be receiving what you are getting. To start to demand things from the system might seem a little bit odd, I would say, but the care that he has with the psychiatrists, the psychologists—I mean he is a teenage boy, so he has issues to start with. They have worked through these things with Daniel.

The Hon. JOHN AJAKA: I heard that you are a father of six.

Mr J. MALOUF: Yes, and they have worked through things with Daniel, because it is difficult after a brain injury, let alone being a teenager, and that level of care was spontaneous as far as I was concerned. I did not know what the scheme was going to do. You are more worried as a parent about (a) will he survive and (b) what will he be like if he does survive. Those things consume you, not how much money do I get or can I get this or that or other things. But as time progressed Daniel wanted to learn how to drive, he got medical clearance and lifetime care has been giving him lessons so we can get him on his feet to get to respective jobs. I have not tested the waters in asking for anything at this point in time, just very grateful for what it has done.

The Hon. DAVID CLARKE: Would it have been of assistance had there been some financial back-up to you as a carer?

Mr J. MALOUF: Well, of course, I would be a fool to say "No", but as I said before the focus is on Daniel's survival and, from my perspective, in our situation, he has older sisters and his mum, and we had enough internal family support not to have to seek external support from anyone. But everyone's case is different, and this is probably where you are directing yourselves. Benefits and whatever need to be looked at on a case by case situation. If there is a disadvantaged family then they are going to need help.

The Hon. DAVID CLARKE: So if there was an area that you were looking at, you would say that this could be an area that would be of advantage, whereby there is some financial assistance to carers who are family members?

Mr J. MALOUF: If it affects their income and therefore affects the rest of the family members, that is logical.

The Hon. DAVID CLARKE: And probably in the majority of cases it may well affect their income?

Mr J. MALOUF: It very well may, yes, exactly.

CHAIR: I would like to pick up the issue about physiotherapy and dancing. This is where we need to think about recommendations and there is discussion currently going on about the definition of recreation and leisure. There is discussion between practitioners and the lifetime care and support organisers. When you talk about the physiotherapy suggestion being knocked back, it sounds as though that could be assisted by extending the protocols for recreation and leisure. An example we were given this morning was somebody doing a gym activity as part of their clinical service which had become part of their social interaction process and then they were told that they did not need to go to the gym any more for physical reasons, but the persons asking about it were talking about it in relation to recreation and leisure. That is a perfect example of the sort of issue that could come up. Could you give us some ideas on what you think about that? I think Daniel is dealing with it, getting his car licence.

Mr McDONALD: Ricki had a car licence before, but now it has been taken off her or revoked, so I would not look at that as something—like that is part of rehab to get her back to where she was, so I would not class that as leisure.

CHAIR: If she turns into a fantastic dancer and absolutely loves it and it becomes a part of her future as far as leisure and recreation, would you perceive that perhaps that is part of the process because that is where she is getting her social interaction? Would you expect from such a process that social interaction would increase with people outside the family circle? What would you reckon, Ricki?

Ms R. BELL: Yes, I think so.

CHAIR: Do you have much social interaction now?

Ms R. BELL: No.

CHAIR: This would be more a group activity.

Ms R. BELL: Yes.

Mr McDONALD: There is a thing called Headstart that is outside the brain injury service. I do not think Ricki is quite ready for anything like that, but that is something that we are looking into. When that does come around—like I said, it has only been eight months, so I am not sure whether lifetime care and support would support that because that is more of a social activity thing. They might go bowling, they might go to the movies once a week or they might go to the wetlands, but it is more of a socialising thing where they are getting out and meeting other people that have more than likely been through the same sort of experience, so if that is what you are getting towards, things like that, and I am not sure about the cost with those things, whether you have to pay your own way, but that would not be an issue for us anyway really. We would not be looking for them to do something that we were hoping Ricki could do if she never had an injury, if you can understand what I am saying. We are not there to get something that Ricki would not have had before this.

The Hon. JOHN AJAKA: How do you know what you are entitled to? How does this information come through to you? Is it the caseworker coming in, sitting down with you and telling you the aspects and you go each and every day, or are you given information which you read, or if you suddenly think of something you go and ask? One of the concerns I have is that there may be benefits for people out there, but they just do not know about it and are not being told about it?

Mr McDONALD: Yes, you are right. They do send brochures out. When we first got them, everything was there. To be honest with you I never read the whole lot because, like I said, at the moment we are focusing on Ricki and she does have major issues that at the moment are very time consuming, like two or three times a week it is in and out of town—we have eye doctors, ear, nose and throat, there is the brain injury, the maxillofacial guy, so at the moment we are focusing on that and anything that is outside of that square or outside of that line we are not looking at anyway because we do not have the time to do that, but down the track absolutely.

Ms SPITTLES: My son Joel was into photography, taking little shots every now and then before his accident. Because he had that interest, lifetime care and support paid extra travel time with his carers and they would always make that extra effort to take him somewhere special, go for a bushwalk or go to the city to take photos. In the whole process of doing that he was learning skills, he was learning how to plan a trip to the city, he was learning how to manage his money, he was interacting with the carer and other people he met along the way, so some of those little interests that they have certainly build up their confidence and give them back some skills that they have lost.

Joel is very much into rapping and he really, really wants to do a singing course, but I have not approached that as yet. We feel that would probably really benefit him. He has lost a lot of his friends. His social situation has certainly changed. With his lack of insight he can make some bad choices. To have a focus and something that he really likes would work very positively for him. I must say I have not pushed that. It has been mentioned at times with his case manager. That is a bit like the hip-hop dancing. It would really benefit Joel. He will spend the time and write down a few words and think about things. He does not like to read now and he does not like to concentrate and focus. That would really benefit him.

CHAIR: Do you think it would be worthwhile the Committee making a recommendation about recognising recreation and leisure activities?

Ms SPITTLES: One of the goals on his paperwork from the rehab was to try to rap some songs and tape them. He is really resisting the speech therapy, which he really needs, especially with communicating. They were going to work on that with him to help him write songs. A friend recently taped him singing, but we have not heard it as yet. He is supposedly going to be very famous.

CHAIR: We all have kids.

Ms SPITTLES: The rehab team is aware of that and they are trying to utilise that interest to benefit Joel's communication skills.

The Hon. DAVID CLARKE: Have you raised that with the case manager to see whether that is the sort of activity that will be covered?

Ms SPITTLES: I have, and I have actually looked it up on the Internet. I have spoken to someone about it. It is just not in our local area.

The Hon. DAVID CLARKE: What did the case manager say when you raised it? Did the case manager say it was something that would be encompassed in the scheme?

Ms SPITTLES: Yes. She was very interested. They do really listen to our requests. They listen very much to Joel and they know what his interests are and they really try to—

CHAIR: Facilitate.

Ms SPITTLES: Each case is individual and they certainly cater to his likes and dislikes. He does not like going to rehab any more so they have meetings at a cafe. He is still getting the help that he needs, but he finds it upsetting. They do things to assist Joel, and obviously that is all paid for at some point. But the singing is a bit like the dancing. I think that would really excite Joel and give him something to look forward to and it would benefit him. Maybe I will push that a little more now that we have talked about it.

CHAIR: What do you think Daniel? Do you think it would be a good thing for the program to endorse as a reasonable process in relation to recreation and leisure?

Mr D. MALOUF: I think I am asking for too much when my case managers ask about organising stuff like driving lessons. I just think I am asking for too much because they have already given me so much. I do not know.

CHAIR: Are you pretty comfortable with what you have now?

Mr D. MALOUF: I do not really have an opinion on it.

CHAIR: That is very good.

The Hon. JOHN AJAKA: That is a good opinion.

CHAIR: Yes, that is an opinion.

Mr D. MALOUF: Okay.

The Hon. GREG DONNELLY: My question relates to the role of the coordinator. Can you give the Committee a reflection of your experience in dealing with the lifetime care and support coordinator—that is, how that relationship has developed, how it has worked and if there have been any problems, issues or difficulties. Please take us through your experiences with the coordinator.

Mr J. MALOUF: We generally deal with the caseworker. We put our requests and find out our information through our caseworker. Marie is in the background, which is probably a good thing because it helps her to structure the needs of so many.

The Hon. GREG DONNELLY: That is "so many" that she is looking after in terms of coordinating.

Mr J. MALOUF: Yes, I assume we are not the only ones she is looking after. Most of our requests are directed to the caseworker and then the caseworker puts them to the coordinator. I believe that is how the structure works. Once again, Daniel is getting everything he needs, so it is working positively for us.

The Hon. GREG DONNELLY: So your experience is that the communication channels appear to be open and working pretty well between the two?

Mr J. MALOUF: Marie was very involved with us in the early stages as Daniel was just qualifying and just after qualifying. We had a number of meetings with doctors and social workers trying to come up with a plan from the family's point of view of what Daniel would need. Marie was very involved at that point. Once that was pretty much established, then everything folded back to the caseworker and that information was delivered that way. I am not sure how many other cases Marie has, but it would be difficult for her to deal one-on-one with every individual person to get the services and the right things in motion.

The Hon. GREG DONNELLY: It has been put to us that there could be issues or difficulties for affected individuals who are in isolated or remote regional and rural locations. Can you give us a rough idea of where you are located?

Mr J. MALOUF: We are in Sydney.

The Hon. GREG DONNELLY: You are Sydney based?

Mr J. MALOUF: Yes. The services are all here.

The Hon. GREG DONNELLY: So access is straightforward.

Mr J. MALOUF: Yes, it is excellent. Lifetime care takes care of getting Daniel to all the appropriate places at the appropriate time with taxi vouchers because I have to work. His case manager will also pick him up and get him to appointments.

CHAIR: His clinical case manager, not the coordinator?

Mr J. MALOUF: The case manager. She will pick him up and get him to his appointments. It all goes back to the brain injury unit, where they taught him how to walk again, how to get on a train, how to handle money and how to make those sorts of decisions. It is not one individual involved in this process.

The Hon. GREG DONNELLY: It is a team of people.

Mr J. MALOUF: It is a full team, and that team needs a coordinator and most coordinators tend to delegate.

The Hon. GREG DONNELLY: Of course.

Mr J. MALOUF: I think that is how the structure works. But being in the city, everything is pretty straightforward for us.

The Hon. GREG DONNELLY: Thank you for that. Ms Spittles, I would like to hear about your experience in terms of dealing with the coordinator.

Ms SPITTLES: Our coordinator is Rosie Kettlewell. As I said, I met her at Royal North Shore Hospital. She came across as, and is, a very caring individual. She has a lot of understanding about brain injuries. When you are dealing with government officers you tend to hit a brick wall. To speak to someone so understanding and responsive to questions and our needs was amazing. Rosie also took the time to visit the hospital on a number of occasions. She also visited the brain injury unit and sat through our meetings, so she always knew what was happening with Joel and how he was progressing. She also took the time to ring us at home to see how we were going. On at least two or three occasions she happened to ring when I was very upset and emotional about what we were going through. She took the pain away, said the right things and put me back on track by explaining why some of the behaviour we were experiencing was happening. I found that very beneficial. My husband went back to work full time within a week of the accident. As I said, we were struggling and a lot fell on my shoulders, and she was aware of that.

The Hon. GREG DONNELLY: Very supportive.

Ms SPITTLES: You do not expect that. It was amazing to have that and I really appreciated it.

The Hon. GREG DONNELLY: Are you Sydney based?

Ms SPITTLES: Yes.

CHAIR: Can I impose on you to tell us how old your son is?

Ms SPITTLES: At the time of the accident he was 17. He will be 19 next month.

Mr McDONALD: Our experience is pretty much the same. If any of the physios or speech therapists have any issues, they will go to Ricki's case manager. If we have anything while we are in there, we will speak to them or to Kathy, the case manager. If we are at home and there are any problems—that is, if the specialist has prescribed a different medication—they have an account set up at the chemist. There have been a couple of issues but I do not think they were with Lifetime Care and Support; I think it was the chemist saying they will not do a particular thing. For example, it has to be nominated what treatment it is—what pills, or cream for her eyes.

The Hon. GREG DONNELLY: What is the coordinator's role in Ricki's circumstances? Is that the same one where the coordinator was quite involved at the commencement?

Mr McDONALD: And a lot of different people. As Mr Malouf said, with brain injury there is a case manager who looks after so many patients at that unit, whereas I believe the coordinator looks after—we are from Newcastle, by the way, and I am not sure what others are around there—the Hunter and up the valley. I think Cathy actually deals with all those different ones in different areas whereas the case manager specifically looks after people in Derby Street.

The Hon. GREG DONNELLY: I am not familiar with the nitty gritty of the process. Are there instances where you have to make a payment and get a reimbursement? If the answer is yes, what are the lead times like for being reimbursed? In other words, what is the turnaround time for expenses?

Mr McDONALD: I do not know about everyone else but I just make a block because we take Ricki into Derby Street three days a week and there are doctor's appointments. Our main claim is for travelling. I just let that build up and every six weeks I write that down. Any nitty gritty things from the chemist or anything that Ricki needs—what else have we claimed?

Ms L. BELL: Mouthwash.

Mr McDONALD: There are not a lot of things. It would be lucky to be $100 in six weeks. We claim that and it probably takes them three to four weeks to get that back to us. Is that what you are asking?

The Hon. GREG DONNELLY: Yes, the process of making the expense and putting in the claim. I am just trying to get a sense of the time frame.

Mr McDONALD: I would say three to four weeks.

The Hon. GREG DONNELLY: Is the turnaround time similar for others?

Mr D. MALOUF: I had double vision when I first came out of hospital and I went to eye appointments with a private doctor down the road. My case manager used to pay with the company credit card and sort all that out. She would sort out anything major so I did not have to deal with it. If I have to catch the train into the city because my case manager is tied up or something they will reimburse me for the ticket and all that.

The Hon. GREG DONNELLY: So you make the payment for the ticket and you then submit a claim?

Mr D. MALOUF: Yes, keep the ticket or the receipt and then give it to my case manager and she will get the money.

CHAIR: That sounds like how we live!

The Hon. GREG DONNELLY: Daniel, does it turn around pretty quickly once you put your claim in? Is it a week or two?

Mr D. MALOUF: My case manager is really helpful. If she has got the money on her she usually gives it to me.

The Hon. GREG DONNELLY: Can I get your case manager's number!

The Hon. JOHN AJAKA: We would all like that!

Mr D. MALOUF: She is really helpful like that.

The Hon. GREG DONNELLY: But obviously to be accountable you produce the receipt and it is all properly maintained and recorded?

Mr D. MALOUF: Yes, she will go through that because she will get the money anyway. She gave me money before and she will give me money to get home and then grab the ticket off me later and it will be dealt with.

The Hon. GREG DONNELLY: At the moment when you are producing information about expenses do you do any of that electronically over the Internet or is it all paper-based? The reason I am asking is that the Lifetime Care and Support Authority witnesses today were talking about upgrading and doing more electronic transaction of business and communication between people who are part of the scheme and the administration. Is anything done electronically at the moment or is it done manually?

Mr McDONALD: Ours is all just done manually and paper based. That is probably a good thing for me.

CHAIR: I was going to ask whether it would help.

The Hon. GREG DONNELLY: Yes, help or hinder.

Mr McDONALD: I use the Internet but I am more confident—

The Hon. GREG DONNELLY: I am sure they will not introduce a system where everyone has to do it one way, but in terms of moving forward—

Mr McDONALD: If that happens I would be prepared to learn to do it if it makes it easier for everyone else. I am sure it is easier than the paperwork. I would just have to learn.

The Hon. GREG DONNELLY: We have had evidence today from some witnesses about levels of frustration at what often appeared to be multiple pieces of paperwork that had to be completed. That contrasts with your evidence that it seems to have gone very smoothly and there have been people to assist in completing the paperwork.

Mr McDONALD: The only paperwork we really have is the claim forms. There is nothing else to do. I do not know what sort of work the case manager and the coordinator have but I am sure it is a fair bit.

The Hon. GREG DONNELLY: You do not have a big impost?

Mr McDONALD: No, not at all.

The Hon. JOHN AJAKA: In relation to catching a train and paying for it out of your own pocket and then claiming for it, given that so much transport is used on a regular basis has consideration has been given to giving Daniel a monthly or yearly pass just to free him up to travel more? Have you requested that or has it been looked at?

Mr J. MALOUF: No. His major fallback would be a taxi voucher. No, that has never been asked; never approached that at all.

Ms SPITTLES: Joel has never claimed back money for his transport costs. It is something he has always pulled out of his youth allowance or wages that he was earning.

The Hon. JOHN AJAKA: Even going to doctors' appointments?

Ms SPITTLES: Usually the carers would take him but if he needed to travel anywhere it was an expense he paid for himself.

The Hon. DAVID CLARKE: Travel anywhere in regard to treatment or rehabilitation?

Ms SPITTLES: Sometimes going to the city and doing his photography and doing this and that. It is all part of his therapy. He would pay for that himself.

The Hon. DAVID CLARKE: Has the caseworker pointed out to you that he is entitled to claim for that?

Ms SPITTLES: No. Obviously it was all covered in his carers' costs but it was an expense that Joel paid for himself.

The Hon. JOHN AJAKA: He may not be entitled to it.

The Hon. DAVID CLARKE: Do you understand that he is entitled to this or that he may not be, or do you not know?

Ms SPITTLES: I think if he was going to a specific appointment he would always have a carer take him there anyway, so that main cost was covered. He has only recently started driving but before that it was a major expense going everywhere by public transport.

The Hon. JOHN AJAKA: It may be something we can look into and ask more about.

The Hon. DAVID CLARKE: It may be something you should look into as well to see what he is entitled to get in that regard.

Ms SPITTLES: He is driving now, so he has not kept tickets.

CHAIR: Are there any other issues that any of you would like to tell us about before we wind up or anything you would like to say about the scheme? Have we not asked you something you came here to tell us? Your information has been incredibly useful. It is all very well for us to do reviews on specific programs but without having feedback from the persons receiving the program it does not necessarily weld in for us. Thank you very much for coming this afternoon.

(Short adjournment)

(The witnesses withdrew)

MARTINE SHOSHANA SIMONS, Senior Social Worker, Department of Rehabilitation, Children's Hospital Westmead, and

JUANITA ISABEL NORONHA, Case Manager, Department of Rehabilitation, Children's Hospital, Westmead, sworn and examined:

CHAIR: In what capacity are you appearing before the Committee?

Ms SIMONS: As a senior social worker and clinical specialist in brain injury from the Brain Injury Service in the Department of Rehabilitation at the Children's Hospital at Westmead.

Ms NORONHA: I am a case manager, with a social work background, at the Brain Injury Service, Children's Hospital at Westmead.

CHAIR: Are you conversant with the terms of reference of the inquiry?

Ms SIMONS: Yes, I am.

Ms NORONHA: Yes.

CHAIR: If you should consider at any stage certain documents or evidence you may wish to tender should be seen or heard only by the Committee, please indicate that and the Committee will consider your request. If we ask any questions you prefer to take on notice or extra questions we do not get to finish this afternoon, we would appreciate those answers by Friday 17 July. Would either or both of you like to start by making a short statement?

Ms SIMONS: No. We would prefer to answer your questions. As I think you are aware, we have attended the whole day of the hearing. There are a couple of pieces of information that, should the Committee wish, I could give some clarification about, some matters that were raised earlier.

CHAIR: Could you start by doing that, in case we run out of time?

Ms SIMONS: I will not be able to do that for all of the questions, because that is contained in pages of notes, but one of the things we can quickly talk about is the issue of a carer attending with a participant at a recreational activity. There is something called a Companion Card that has recently become available in New South Wales. It started in one of the other States—perhaps it was South Australia, I am not sure of that—but it has recently become available. It is for all citizens, all the community of New South Wales whether you are part of the lifetime care or whether you need it for other disability issues. Information is readily available on the Internet now.

The Hon. JOHN AJAKA: Are the participants made aware of this?

Ms SIMONS: Certainly the clients of our Brain Injury Service and our Spinal Cord Injury Service are made aware of it where it is relevant.

CHAIR: Can you let the Committee know about the work of the Department of Rehabilitation, that you work for, and how it interacts with the Lifetime Care and Support Authority? If you were there when the lifetime care and support process came into being, can you add to that what sort of difference it has made to your work, your workload and the processes you are using for your work? Is it in any way influencing your work in general?

Ms SIMONS: I will commence, and, Juanita, please will free to add. I have prepared an answer to this question. The Department of Rehabilitation comprises five clinical teams of which the Brain Injury Service and the Spinal Cord Injury and Disease Service are two. We provide services to children who have been involved in motor vehicle accidents sustaining a traumatic brain injury or a spinal cord injury, and we provide inpatient and outpatient services in rehabilitation. Our brain injury service has worked with the Motor Accidents Scheme since it was established in 1988. So, we have many years experience in dealing with clinical and medicolegal aspects of working with children and families where they have had claims under the CTP Scheme.

Since the inception of the Lifetime Care Scheme for children we have provided services for four children with spinal cord injury and 16 children with severe brain injury. Because there is a disparity between the number of spinal cord injuries and the number of brain injuries, most of our experience is with the clients with brain injury. So, our answers will reflect that.

We are a multidisciplinary team that offers long-term follow-up for children and adolescents until their transition to adult services or until it is deemed that they do not need our rehabilitation services further. So, we provide case management, nursing, medical, occupational therapy, physiotherapy, clinical neuropsychology, clinical psychology services, speech pathology and social work services, using a team approach to provide a coordinated approach to rehabilitation.

I would like the Committee to be aware that in our service we see children and adolescents with acquired brain injury from other causes, which may range from falls, submersion accidents, adverse outcomes of medical procedures, sports injuries, non-accidental injuries such as shaking or assault, and accidents in the home. The children who are traumatically injured in motor vehicle accidents are part of quite a large client base. Our primary purpose is to provide medical and nursing care, psychosocial support, education, and information about traumatic brain injury to enable children to return to their family and the community, and then to follow them up. We work with the Lifetime Care and Support Scheme.

Once we identify that a child's injuries are sufficiently severe so as to qualify him or her to apply to be an interim participant of the scheme, simultaneously we also facilitate an application to the Motor Accidents Authority Scheme, which runs parallel to these children for lifetime care. We work with the family and with the Lifetime Care and Support Authority to facilitate an understanding of the scheme, to assist with the application for participation, and to facilitate a meeting with the lifetime care coordinator. The role of the case manager and clinicians with lifetime care may include submitting ongoing community living plans, assessment requests, care needs assessments, and service and information requests—all those forms to which earlier witnesses referred during the day. The case manager in our team coordinates those requests and is the key liaison person with the Lifetime Care and Support Authority to advocate for the child's rehabilitation needs.

CHAIR: Thank you.

The Hon. JOHN AJAKA: I have read with interest your earlier submission and you have been present throughout the hearing, which makes it much easier. Clearly, there are some fabulous positives about this scheme.

Ms SIMONS: Absolutely.

The Hon. JOHN AJAKA: I am playing devil's advocate at the moment. After listening to the negatives I got the feeling when it came to the paperwork, bureaucracy, et cetera, that it was almost a case of the Lifetime Care and Support Authority verses the clinicians. It was a case of the caseworker verses the coordinator. I would like your views on the coordinator and caseworker scenario. What is frustrating and what is occurring that you believe should not be occurring?

Ms NORONHA: In some ways that ties in with one of the questions that you forwarded to us with regard to the early introduction of the coordinator to the unit and the outcome of that. The Lifetime Care and Support Authority believes that requests for early access are important. We as clinicians—and at some levels practitioners—agree that if we introduce the family to the scheme early the benefits will be there and the planning process will be smoother. Early introduction is a philosophy of which we are also aware. However, as providers we feel that when a child is injured it is a catastrophic event and families are often in a state of grief and shock. Often they do not have the headspace to deal with what they perceive as being insurance issues.

The Hon. JOHN AJAKA: By that do you mean an outsider coming into their home?

Ms NORONHA: That is right—an outsider coming in and providing them with a lot of paperwork, or trying to explain the scheme, or anything like that. Furthermore, at this time of crisis families often look for hope. They are hopeful that their child will get better and their child will be well and able to leave the hospital. At that point in time starting to talk about a Lifetime Care Scheme, in the view of the Rehabilitation Department or the coordinator, may be pessimistic or negative rather than seen as something that is reassuring and helpful. An example of this would be one of our clients' parents who related a story to us. This child had been in the paediatric intensive care unit for two weeks. Soon after the child went into the ward, which meant that the child was still not necessarily stable, but stable enough to come out of the intensive care unit—

The Hon. JOHN AJAKA: But still in the hospital?

Ms NORONHA: The child was still in the hospital but his or her condition was quite acute. A Lifetime Care Coordinator approached the parent and obviously had the best intention of explaining scheme. This parent was articulate and able to say that she was not ready to do that. Eventually, she lost the forms. It was only at some later point in time that she was able to fill out those forms. The clinical nurse consultant—our link person between the inpatient and the outpatient—related a situation to me. At times she has been asked by the Lifetime Care and Support Authority to facilitate talking about the scheme sooner than she and the team felt the family might be ready to approach the Scheme. Usually she has had looks of shock and people saying, "Why are you asking me about this?" Often there is a reluctance to address the issue. I suppose that is our comment about early introduction.

The Hon. JOHN AJAKA: Instead of too little too late you are saying it is too much too early?

Ms NORONHA: Perhaps.

The Hon. DAVID CLARK: But will there be reverse situations where relatives and parents will be relieved to know that there is this support structure?

Ms NORONHA: Absolutely. However, when the Lifetime Care Coordinator has been introduced in a timely way, it has been a positive experience.

The Hon. JOHN AJAKA: Who determines the timely way?

Ms NORONHA: The key issue, which is also in our submission, is that we feel the clinical judgement should be on the rehabilitation team to decide when that should occur.

The Hon. JOHN AJAKA: If the lifetime coordinator were to approach you, speak to you first and between you both you structured a position as to when, where and how, would that be far better than simply approaching mum or dad on day one?

Ms NORONHA: Absolutely.

The Hon. JOHN AJAKA: Because you have been approached you will know that it is there. You are seeing mum and dad and the participant is in hospital anyway. From your point of view should it be done in that structured way rather than letting them know straightaway from day one?

Ms NORONHA: Yes.

Ms SIMONS: Yes.

The Hon. DAVID CLARKE: Have you raised it with the Scheme?

Ms SIMONS: Yes.

The Hon. DAVID CLARKE: How did it react?

Ms SIMONS: It reacted positively. I wanted to add that as time has gone on we have had regular communication and contact with Lifetime Care and Support Scheme personnel. For the most part it is positive, as you would be aware.

CHAIR: You want the right to say when they can be pulled in? Is that what you are asking for?

Ms NORONHA: Yes.

Ms SIMONS: Indeed. When that happens it really works well. In some ways it is painful for the parents with whom we work to hear that their child will have long-term consequences from his or her injury. It is a very painful process. It is not that we are trying, inappropriately, to shield them from clinical information. We have skills and experience in the issues of loss and grief, responses to trauma and catastrophic injury. If a family member were to ask us or to say early on, "We are worried about how we will manage. We wonder what we will do," or they have heard of another instance or ask us how they compare, clearly we will provide the information immediately. However, we will not do that by the intensive care unit bedside.

The Hon. DAVID CLARKE: When you say you have raised it and you have received a very positive response from the scheme authorities, do you mean by that that they are still considering it or they have accepted your submission and that the matter has now resolved itself?

Ms NORONHA: It is inconsistent. That is one of the things I think sometimes is a little bit inconsistent.

The Hon. JOHN AJAKA: There is no memorandum of understanding.

Ms NORONHA: There is no memorandum of understanding.

The Hon. DAVID CLARKE: When you say it is inconsistent, are you getting conflicting advice? What do you mean when you say it is inconsistent?

Ms NORONHA: When I say it is inconsistent, I suppose our interaction is primarily with the Coordinator, so it is in terms of when the Coordinator is making contact and asking for early access.

The Hon. JOHN AJAKA: And there are different coordinators?

Ms NORONHA: Yes. However, I have to say that that situation has improved, so it is a developing thing and it is something that Lifetime Care is open to. At one level it is a working relationship that is actually progressing positively, however, there is also perhaps a memorandum of understanding that this may be something that should be—again, as I said, a clinical judgement, we feel, with the treating team.

The Hon. DAVID CLARKE: Are you saying that it is the de facto situation now that the decision is with the treating team?

Ms NORONHA: I suppose sometimes there is more pressure on the treating team to do this sooner rather than later.

CHAIR: Do you know why?

Ms NORONHA: I am only just guessing, but I suppose it is because Lifetime Care feels that the sooner the participants get into the scheme, the quicker we can provide services. Our experience is that we try to move at the pace of the family and we see that rehabilitation as a long, long term service for these children.

The Hon. DAVID CLARKE: It is not a one-size-fits-all. You take each situation individually?

Ms NORONHA: That is right, and even when they are in hospital, they are in an acute phase and there is a long time after that that they continue to be in a rehabilitation service, so we see this as not necessarily an acute thing; we see this as something that can happen over a period of time.

Ms SIMONS: When a child is admitted to hospital and comes to our intensive care, we learn about that child's admission very quickly and as soon as we do, and we learn about the accident's circumstances and extent of the brain injury, we are already, as a team, are thinking possibly lifetime care, possibly not. I think what we are asking is for the Lifetime Care Scheme to rest assured that it is uppermost in the minds of the treating team. The fact that we actually want to introduce the idea to family or carers in a more timely manner is something that we would like them to respect, because we will never forget about the Lifetime Care Scheme because it is an integral part of how we work, just as the CTP Scheme has been for many years.

The Hon. JOHN AJAKA: If I can just go on to a different area. Have you experienced situations—and I am talking about equipment or treatment—where you have felt that certain equipment would be desirable, in particular, at home for a participant to assist with rehabilitation where you have found, firstly, the paperwork is driving you crazy and, secondly, that you are being refused and you do not understand why it is being refused? Have you had any experiences in that area?

Ms NORONHA: I have to say that Lifetime Care at this point in time has been mostly really good at providing the services that we have requested. We have documented that in terms of all the benefits. Transport especially has been a really positive thing for many of our clients, which, if they did not have the transport, the frequency and ease at which they can come back for outpatient appointments would be difficult. The provision of equipment in order for children to be discharged in a timely manner has always been appropriate and open to those submissions and requests.

The area I suppose we have difficulty—and we have heard this throughout the day—is the bureaucratic paperwork and the administrative processes that take away from clinical time. A good example that I can provide is that it took a case manager almost a day to write a care needs assessment request for attendant care for a child who really only needed five hours a week attendant care services and the care was not even complex; it was really supervision and monitoring. It was not behaviour management or physical care needs.

The Hon. JOHN AJAKA: What would it take so long—a day?

Ms NORONHA: It took her that long to gather the information, collate the request and actually do the form.

Ms SIMONS: And provide the very, very detailed information that Lifetime Care requires for every single request. We have had a number of conversations about this and I know that in the early days of the scheme we talked about the fact that where there was potentially repetitive information, we could cut and paste from previous forms. The forms electronically have quite a complex nature and format.

The Hon. JOHN AJAKA: I looked up one of them.

Ms SIMONS: Also, clinically, we do not always want to be cutting and pasting because we want to ensure that our requests are individualised for that particular child and family, and that is a timely thing.

The Hon. JOHN AJAKA: So there is no electronic record situation where, for example, participant A comes into your hospital or another hospital, information is put in and Lifetime Care can access that, so that as each entry is put in and updated, every clinician does not have to reinvent the wheel on each and every document?

Ms NORONHA: That is not available at this time.

The Hon. JOHN AJAKA: That does not exist.

CHAIR: The law will not allow for the exchange of information like that.

Ms NORONHA: Privacy and confidentiality.

The Hon. DAVID CLARKE: Is it not the situation sometimes with these forms although they are complex, when you go through them line by line there may be a very valid reason why that particular piece of information is required. Have you actually gone through a form and said, "Hey, that information is not really needed."

Ms NORONHA: Let me give you an example where perhaps two forms are very similar but they need to be done for two different situations. There is an assessment request form and there is a service request form. Say, for example, you need an assessment for speech therapy, you need to put in this form and if you need to then ask for the provision of a service, you need to fill out another form. These forms are almost identical in their format, but then you still need to fill them twice. We would recommend, when thinking about these things, why cannot there be one form because normally if you are asking for an assessment, you are likely to have to need the service. If, as a result of the assessment, there is no need for a service, that information can be provided. There is no need to follow on. You could potentially use a form that requests an assessment and a service. That is an example.

The Hon. DAVID CLARKE: Have you raised that specific example and said, "Hey, this can be simplified"?

Ms NORONHA: I think that we have had discussions with Lifetime Care about the laborious nature of the forms and the bureaucracy. I think we have raised this.

The Hon. DAVID CLARKE: What is the reaction you get when you raise this?

Ms NORONHA: We personally have not raised this. I think this has been raised at the steering committee level. We are at the coalface doing the work. We provide this to our head of department or head of the service and they take it to the steering committee.

The Hon. JOHN AJAKA: Can I ask you this last question on the forms? Do you feel, having regard to your expertise and in particular those clinicians who are part of the hospital, that it should be sufficient if you as the clinician or the doctor were to write the request saying, "It is needed in my opinion, full stop", without having to go through reams of explanation. In other words, your opinion should be sufficient?

Ms NORONHA: As a case manager my job is to formally liaise and pull together lots of information. I see no problem in providing some justification for services. I do not think that is an unreasonable thing because that is what we are always thinking about anyway for our clients' needs. Sometimes when we have the request actually come back saying "needing more clarification" there are times when I think the information should be adequate and our clinical judgement should be accepted. Sometimes we think, okay, this is not an unreasonable need for clarification, and that is fine. Sometimes the accident perhaps has compounded, especially when complex psychosocial issues are related to pre-accident issues that impact on how a family is coping or how a child is coping or whatever, but perhaps that is not necessary information that needs to be in a lot of detail.

Ms SIMONS: Actually placed in written form.

The Hon. DAVID CLARKE: With the impact of a pre-existing condition, does that not show that it is a complex situation and maybe that additional information is needed to clarify what is pre-existing, what is not and what overlaps?

Ms NORONHA: Sure.

The Hon. DAVID CLARKE: That may be a good example to explain why sometimes these forms are complex?

Ms NORONHA: I do not know that that explains why the forms are complex, but I think that is a clarification.

The Hon. DAVID CLARKE: They require a lot of information?

Ms NORONHA: Yes. I think clarification is fair. Sometimes part of the difficulty with the bureaucracy is that going back and forth needing a lot more detail. Again, that is where I think because we are an experienced service that has been there for a long time that sometimes our clinical judgement has to be accepted. Sometimes perhaps it is better to actually do some of that clarification verbally. We are happy to do that. Some of the difficulty I think that we have encountered is that approvals are given by different—

CHAIR: Levels?

The Hon. JOHN AJAKA: Coordinators?

Ms NORONHA: Not coordinators, at a different level but by a variety of different people. Sometimes that creates more repetition of information because whoever is approving at one point in time may have some of that information and then somebody else approves another request, the same request months before.

CHAIR: Which is why they want all the information on the form.

Ms SIMONS: We understand that you have the same coordinator for the child, but the coordinator actually is not the person approving the service. So, each form that we have completed for a particular request could be going to another person.

CHAIR: Will be.

Ms NORONHA: Yes.

Ms SIMONS: That is part of the reason they are requiring such detail.

The Hon. DAVID CLARKE: It could be compared to seeing a doctor. You see a doctor and he records what information he is given because that patient may go to another doctor. Whoever may be given this verbal information may resign from the department and move overseas.

Ms NORONHA: Sure.

Ms SIMONS: Yes.

The Hon. DAVID CLARKE: Is it not also a situation about which we have to be very careful?

Ms NORONHA: Sure.

Ms SIMONS: Could I talk a little about the therapeutic support to families and my concern as a social worker and clinical psychologist?

The Hon. JOHN AJAKA: Please do.

Ms SIMONS: There is no easy answer to this, but families already are struggling with some issues before an accident occurs to their child. This is not an exhaustive list but some of the things we could be working with may include pre-existing child protection issues; misuse of alcohol; illicit drug use; family conflict that includes domestic violence; marital discord; stresses induced by substandard or inappropriate housing; the challenges or disadvantages, if there are any, from coming from a culturally and linguistically diverse background; chronic illness of parents or siblings; and pre-accident learning and behavioural problems for the child with a traumatic brain injury or for their siblings. It is a very complex situation in that we working with families in a holistic way and we cannot separate all of those issues and say, "Stop talking about that or telling me about that because we are talking about the brain injury." Similarly, in making care or service requests as lifetime care, we cannot hide that information because that is part of who the child is. The child is part of that family that is struggling with those issues.

We understand that Lifetime Care, similar to the CTP scheme, wants to be able to separate those issues and provide reasonable and necessary rehabilitation and therapeutic services that are related to the brain injury. From our perspective as clinicians we will deal with all the issues because they impinge on the recovery from the brain injury and how families are able to respond to it. So, the way we support them is that we will have to try to deal with all of those issues in the best way we possibly can. We will provide that information to Lifetime Care. We are aware that families have consented for us to provide information, but as clinicians we also have some professional responsibilities in regard to confidentiality. So, sometimes issues come up that we need to deal with in a counselling and therapeutic situation—how do I say this—that run alongside the brain injury rehab issues and we will not separate them, but we really will not have permission from the parents to discuss these issues.

CHAIR: The scheme is not actually trying to take over the medical treatment. What you say is quite reasonable.

Ms NORONHA: Yes.

The Hon. GREG DONNELLY: My question is general in nature. Let us take the hypothetical example of a young person who is catastrophically injured in a motor accident. Obviously, he or she has access to all that flows from this scheme?

Ms NORONHA: Yes.

The Hon. GREG DONNELLY: I think you were present when the previous witnesses were giving evidence?

Ms NORONHA: Yes.

The Hon. GREG DONNELLY: They were the carers and, indeed, the people benefiting directly. They had great praise for the scheme and had great satisfaction generally with what has been provided to them. However, the reality of providing such a scheme to a group of people injured in a particular circumstance creates a different scenario for other young people. Let us take the example you mentioned earlier of the young person who falls out of a tree or has an accident at home and sustains a serious brain or spinal cord injury. Obviously, the future is quite different for them in their treatment?

Ms NORONHA: Yes.

The Hon. GREG DONNELLY: To be quite frank, and referring to the previous witnesses, it is almost as if anything they want essentially is provided to them?

Ms NORONHA: Yes.

Ms SIMONS: Yes

The Hon. GREG DONNELLY: Obviously, that is not the case for other people. From your experience does it create issues or tensions that some people are the beneficiaries of services, for which they are very grateful—a small group have pretty much open access to virtually anything and everything they need within the whole scope of our health system—and others are not? I know it was a long-winded question, but it was providing background.

Ms NORONHA: We are a little bit different from some of the adult brain injury units that are freestanding and have inpatients who are in the Brain Injury Unit side by side. Our children are in a surgical ward mixed with a lot of other children. So I think sometimes parents are not all that aware about what one person is getting as compared with another. Once they become outpatients, often they do not have that much contact, to be able to make a comparison. However, we are aware of the inequity of the system. We were happy when the no-fault system was introduced together with Lifetime Care, especially for catastrophic accident victims where fault is no longer an issue. Those clients will, in fact, be entitled to a service that previously they were not entitled to, and we believe that is a positive thing.

The Hon. GREG DONNELLY: I am not arguing against what is there. But does it create tensions or issues that we need to be aware of?

Ms SIMONS: I wrote down the words "parent group". We have a parent's advisory committee within our whole department where parents may link up. Apart from doing their really positive contribution to the development of our service, they are meeting and having coffee and talking about what is happening with their children and about the level of service. So I think it is highly likely that there are parents, say, whose child was involved in a submersion accident, whose access to services is grossly different from those available to parents whose child has been injured in a motor vehicle accident.

As a brain injury team as part of the outpatient team, I think it would be fair to say that the clinical treatment, therapy and medical nursing treatment we are able to give those children at an inpatient level and as outpatients is an equal level of treatment. We are situated in a public hospital, so we have the capacity to do that, bearing in mind the capacity and the workload of the team as a whole. I am aware that Madam Chairman has asked me a question about workload that I have not yet addressed, and I will get to that in time.

For the parents whose children have illnesses or injuries caused by things other than a motor vehicle accident, they access services within the New South Wales health system, they access services from the Department of Ageing, Disability and Home Care, they access services from the Department of Housing, and a range of other services. But they need to compete for those services with many other people. They may be on waiting lists for quite some time. Certainly with the advent of EnableNSW, I think the equipment provision aspect of that has vastly improved and we will continue to see improvements in that as that department progresses.

The Hon. GREG DONNELLY: You think of your own circumstances if your child happened to be injured as a result of one set of circumstances compared with another. You would have to say, you would feel so envious of people in those circumstances.

Ms SIMONS: Yes. To step back historically, we are not a freestanding unit. When the Motor Accidents Authority funding was first given within the health system, one of the reasons that the paediatric service was allowed to provide services to all children with acquired brain injury was that the specialist paediatricians, who were still providing that service, said, "I can't go to the child in bed A and provide a multidisciplinary team and an optimal service and then walk past bed B because of the method of injury." So we have been able, within the health system, to continue to provide that service.

The Hon. JOHN AJAKA: That is as long as it is within the hospital system.

Ms SIMONS: That is right.

The Hon. JOHN AJAKA: The real problem occurs when the participant goes back home. What is available to the two participants is completely different?

Ms SIMONS: That is right. In terms of our therapy and outreach, those services are still there. But in terms of access to other services, it really does become a two-tiered system.

The Hon. GREG DONNELLY: That is what I was alluding to. In your statement at about page 4 you refer to therapeutic support for family members. Do you want to make specific comments about that issue?

Ms SIMONS: I think I have already addressed some of those issues. I have already said that we try to provide our services in a holistic manner. Many of the families we see at our hospital are quite vulnerable families, so we are providing our services long term. Because we work in a long-term manner with families, some of the families who come with the most life challenges often are not ready to address those sorts of things; they are very focused on their child's injury and getting them home. It may be some time down the track in the rehabilitation process that they are able to consider having psychological intervention or family therapy that may assist with their ability to cope with the accident. One of the benefits of being a team that can provide long-term care is that when the family is ready to do that, we are ready to provide that service. Although we are still in the early stages of the Lifetime Care and Support Scheme, when a family is ready to participate in that way I am sure they would support us being able to do that.

I want to add, though, that sometimes it may be appropriate to see family members who are not just the most immediate family members—they are not just mother and father. We deal with many blended families, we see the siblings of the child, and we may see grandparents, aunts and uncles. Each family constellation is different. Earlier in this hearing we heard that sometimes behaviour can be socially somewhat inappropriate or difficult. So, further down the track it may be useful to meet these extended family members to talk about the fact that the child is not being naughty on purpose, or that the parents are not bad parents, that these behaviours are very challenging. It is what we call psycho education—helping them to look at strategies to deal with that, and developing their understanding of the nature of the child's brain injury. They are the sorts of things we would do.

CHAIR: My question relates to the request for eight years for the assessment. My question is based on the Committee's hearing last year, in which we were requested to increase the assessment time to five years of age. The Committee put in a recommendation to the Minister for that to occur, and since then the Minister has amended the Act to reflect the five years. One year later we are being requested—not just by you—to increase the age to eight years. I do not believe it will be possible for the Committee to put a recommendation for eight years when our recommendation last year, after receiving advice, was five years. I would like to hear what you have to say about this.

Ms SIMONS: I discussed this quite thoroughly with Dr Mary-Clare Waugh, who is the Acting Head of the Rehabilitation Department at the moment. She was the head of the brain injury service and had a high level of involvement, as did other team members, in the paediatric steering committee when the Lifetime Care and Support Scheme was being established. From a paediatric rehabilitation point of view, we always recommended that it be eight years. I understand that you have had evidence to the contrary about that. But certainly the information I have received is that for a number of reasons we did request the extension to eight years. Having said that, we are very pleased that the amendment has been passed and that at least there is an increase from five years. I understand what you are saying—that it is very difficult for this Committee to return to Parliament with an additional request—and if you would like more information or clarification about that, I am happy to take questions.

CHAIR: If we are going to be able to consider it at all, we will have to have some more information because we had lots of evidence last time about the five years, which is why we took it on as a responsible suggestion.

Ms NORONHA: One of the things that we thought about eight years was that the WeeFIM, which is the tool that is used for the criteria, is really norm-ed at eight years for development and independence. So it was done from that point of view. In terms of the WeeFIM—I do not know if we have enough time for this?

CHAIR: No.

Ms NORONHA: But I would just like to very quickly say that from our perspective the WeeFIM itself, as a tool of the criteria for admission, is not sufficient.

CHAIR: Yes. You put that in your submission. I am quite sure we will have more questions for you, and we will send them to you. We would like answers to be returned by 17 July. Thank you very much attending, for your enthusiasm, and for being part of the program.

Ms NORONHA: Thank you.

Ms SIMONS: Thank you for the opportunity.

The Hon. JOHN AJAKA: Thank you. Your evidence was most informative.

(The witnesses withdrew)

DENISE GILLIAN YOUNG, Social Worker, Australian Association of Social Workers (NSW) and Brain Injury Professional Interest Group, c/- Dr Grahame Simpson, Brain Injury Rehabilitation Unit, Liverpool Hospital, Locked Bag 7103, Liverpool BC, 1871, affirmed and examined (by teleconference):

GRAHAME KENNETH SIMPSON, Research Team Leader—Senior Social Worker, Australian Association of Social Workers (NSW) and Social Workers in Brain Injury Professional Interest Group, c/- Brain Injury Rehabilitation Unit, Liverpool Hospital, Locked Bag 7103, Liverpool BC, 1871, and

DIANE MAREE TURNER, Social Work Professional Leader—Clinical Social Worker in Brain Injury Unit, Australian Association of Social Workers (NSW) and Social Workers in Brain Injury Professional Interest Group, c/- Royal Rehabilitation Centre—Sydney, P. O. Box 6, Ryde, 1680, sworn and examined:

CHAIR: I welcome witnesses to the second review of the Lifetime Care and Support Scheme. We did our first review of the scheme last year. We did not do it the first year because time was too short. Ms Young, in what capacity are you appearing before the Committee? Are you appearing as an individual or as a representative of an organisation?

Ms YOUNG: I am appearing as a member of the Social Workers Association and the Brain Injury Professional Interest Group.

CHAIR: Dr Simpson, in what capacity are you appearing before the Committee?

Dr SIMPSON: As a member of the Australian Social Workers Association of Brain Injury Professional Interest Group.

CHAIR: Mrs Turner, in what capacity are you appearing before the Committee?

Mrs TURNER: As a member of the Social Workers Association and Brain Injury Professional Interest Group.

CHAIR: Sometimes we ask questions that are a bit wider than what you have in front of you, and if you prefer to send the answers back, it is quite acceptable to say that you will take it on notice; but we would very much like the replies by 17 July so that they will form part of your evidence. Would any of the three of you like to start by making a short statement?

Dr SIMPSON: I will make a short statement. We would like to thank the Committee for the opportunity to speak to you today. Thank you particularly for making Denise available by phone: It is a huge help. We are supporters of the Lifetime Care and Support Scheme and the authority. We think it is a good thing. I started working in the area in 1987 with TransCover, and it was a very brief period of TransCover. Over all that time we always looked towards some sort of a no-fault scheme. We are supporters of the scheme and our submission is in the spirit of trying to refine and improve the scheme.

We will outline a significant number of roles that social workers play in respect of the scheme, including introducing families to the scheme, shepherding people through various stages, and also as direct service providers in the scheme. In terms of the holistic approach, one of the fundamental questions is: If we are saving people from catastrophic injuries, what are we saving them for? We feel that the holistic intent of the scheme provides a very positive answer to that particular challenge.

We will raise two issues we have in relation to treatment of families as part of this. We think there are some issues around the interpretation of who comprises a family, and significant others, relating to a person with a traumatic injury and, in terms of family support and maintaining friendship networks, the requirement for a broader range of interventions than just counselling and behavioural management.

We agree that the Lifetime Care and Support Authority often does support families in a broad way, and our concern is more one of consistency in how that is applied. We will be suggesting that, in part, some of the concerns we will raise will be met by providing some brief training to authority staff. Then there will probably be just a few miscellaneous issues relating to eligibility that we will raise at the end under the final question.

CHAIR: Thank you very much.

The Hon. GREG DONNELLY: This question is general in its nature and is just an overview. It is a question about the role and work of social workers in relation to interaction with the authority. How does that function and operate? Is it smooth? Are there issues? Are there ways that can be suggested for our recommendations to improve how that will operate? The question is quite general, so feel free to range across the issues.

Dr SIMPSON: We have allocated ourselves certain questions for each to answer.

The Hon. GREG DONNELLY: Sure.

Dr SIMPSON: My colleague Denise will answer this one.

Ms YOUNG: Fine. I will begin by talking about the types of roles that social workers play in relation to the Lifetime Care and Support Scheme.

The Hon. GREG DONNELLY: Thank you.

Ms YOUNG: There is quite a large number of them, so I will just go through and list them, if that is all right.

The Hon. GREG DONNELLY: Yes.

Ms YOUNG: First of all, we social workers play a part in informing people, or certainly the family members of injured people, about the existence of the scheme and help test their eligibility by making sure that applications are lodged with all the associated relevant material. That can be difficult for some social workers in some acute settings, particularly if a person is unconscious in the intensive care unit, or close to the intensive care unit, it is hard to know if they are going to meet the criteria. For some people it is pretty obvious after a few days but for others it is less obvious. So there is an issue that some social workers do not do it in the acute setting, but that is the first part of it.

One of our other roles is that we want to ensure that rehabilitation coordinators within the appropriate rehabilitation service where the person goes are allocated and that there is liaison opened with the right lifetime care and support case coordinator. It is often possible that the rehabilitation-coordination person within the service is a social worker. For instance, I do a lot of that work in my service. We have a large role in coordinating the discharge plan. That means we have quite a significant role in developing community discharge plans, care needs assessment and community living plans, and also liaising with other care agencies if they have to be involved, and making sure it all comes together for the plan.

Social workers also work with the person with the injury—in our case with the brain injury—to make sure that their goals for recovery and their life are reflected in the plan that workers prepare. Social workers also work with the person with the brain injury to make sure that they understand what goals other staff members are working on, to make sure that they understand what processes are going to be used, not only within the rehabilitation sector but also within the whole lifetime care and support liaison and coordination sector.

Another really important area of our work is with family members. So we have to make sure that their needs and issues are addressed. Social workers often will take the opportunity to explore the personal responses of members of the family to the changes that have happened in their family life as a result of the traumatic injury. Sometimes we will work with the family as a whole, and other times we will work with different members of the family individually. Because obviously each member of the family is going to have to deal with changed family roles, and they need to try and identify what sort of part they wish to continue to play in the life of the person with the injury. That is not normally early in the peace but, depending on the sort of injury that people have, some family members find that quite difficult to deal with and live with and they may choose to not be involved in the person's life in the same way.

We also have to work with family members who might have been estranged from the person at the time of injury but who are still obviously concerned about the person, and try to work out what sort of role or contact they will have with that person later on. Often that happens if the person who is injured is a parent who might have been separated or divorced from the other parent, they have to be involved in some way for the care and wellbeing of the children of the injured person.

The next area in which social workers are involved is working with friends and other members of the social network. It is really important that these people understand what has happened to the person with the injury, how they can play a really meaningful part in the person's recovery over time, and also help them work out that it may be that they can be really meaningfully involved and very important to the person but they do not have to sustain the same type and intensity of relationship that they had before, if they do not feel they can. So it is quite delicate work.

Finally, we work to help the person themselves, family members and other workers to ensure that the person with the injury becomes as full as possible a participant in the life of their family and in their community. We want people with brain injuries to continue to be participants and not to be observers of life. Certainly that whole idea of participation is not only important to social work but we can identify that it is very important to the lifetime care and support scheme. I suppose what I am saying is that social workers have not only a practical role but we have a significant role in the whole issue of relationships and the way in which the person recovers, and that the family, in which they are a strong part, and the social network continue to be able to function appropriately.

The Hon. GREG DONNELLY: My next question is for Dr Simpson. Dr Simpson, you alluded to the definition issue around "family" and you indicated that you wanted to comment on some attendant issues to that. Can I invite you to make those comments now?

Dr SIMPSON: We have two concerns in this area, and this is based on the experiences of members of the Social Workers in Brain Injury group. I guess the first issue we have is that the families and significant others perhaps are being interpreted too narrowly at times by the Lifetime Care and Support Authority [LTCSA]. There is often a shorthanded way that health and rehabilitation staff will work with families, where they will latch on to a primary carer or one family member who is often at the hospital, and then really channel everything through that person. If we go back to the psychosocial assessment, which is the LTCS 104, it talks about a broader range of family members. When we actually look at whom they will supply or provide support for, when we make requests, sometimes there are questions around providing support for people beyond those narrow, immediate family members.

We provided two case examples of siblings where there was a lot of difficulty in getting support. In one of those cases, after quite a bit of advocacy, support of a limited nature was provided. This was in relation to a young man who was very close to the brother who had the traumatic injury. The way he responded to the injury was by acting out. He started to display some behavioural disturbance and he got into trouble with the police, but it was directly related to the anxiety and the distress he experienced with the injury of his brother. The social worker had substantial difficulty in getting the case coordinator to approve support in relation to treatment for that particular brother. The other example we give relates to a young woman with paraplegia. Once again the authority was happy to support the accommodation and transport costs of the parents but not of the sister who lived in another State and who was very close to her sister and played an important role in her wellbeing and longer-term outcome.

We do think that there are a couple of complicating factors for the lifetime staff. One of these has already been alluded to: the issue that sometimes some family members may have premorbid psychosocial difficulties—we think that is one area of ambiguity. So the staff are sometimes concerned if we are moving into treating other issues. Once again it is very hard to know where one draws the line. The other area that might be a complicating factor in some of these decisions is that sometimes the relationships may be ambiguous or contested within the family system. We have already talked a little bit about that and we will give some more examples of that as we go along.

In trying to respond to these issues we wondered whether or not the authority could draw upon the definition of "family" that the National Health and Medical Research Council has used. I am not sure if we actually supplied that in the submission, but their definition of "family" includes the immediate biological family, the family of acquisition and the family of choice and friends. We would think that is actually there within the scheme but it does not seem to flow through to practice—I guess that is our issue. We wonder whether or not the psychosocial assessment process could provide the opportunity for the initial identification of key family members beyond just the partner of parents, which are traditionally the ones that are targeted. Then we have also suggested about the possibility of providing some brief training to the case coordinators and we will talk more about that later on when we respond to the question about training.

The first thing is that sometimes we are just concerned that although there is room for expansive definition of families and significant others, sometimes the staff may be interpreting it more narrowly. The second thing is the concern that the sort of interventions for targeting families and significant others just fits under this frame of counselling and behavioural intervention. All the time there is a growing range of different interventions that have been developed, both within Australia and internationally, in terms of treating and supporting families and maintaining and supporting friendship networks.

We just feel that it would be useful if there could be some sort of expansion beyond just the terms "counselling" and "behaviour management". For example, in terms of maintaining social networks, there is now a lot of work being done around the social networking technology through Facebook, email and things like that. These can be critical issues in terms of the way that the people remain connected, because we know that social isolation is one of the biggest challenges that particularly people with brain injury face, but it does not fall easily under a counselling framework. There are a couple of other options. There is the community access code, but that has a function more on activity than on maintaining the network. We do not think it would take a lot to broaden that definition slightly and would encompass a whole range of other ways that we provide support and intervention to both families and friendship networks. So that is the key point that we would like to make.

CHAIR: Does this fit in with the recreation and leisure that is bubbling around today?

Dr SIMPSON: I am sorry, I have not been party to the previous—

CHAIR: I guess it relates to socialisation type issues. An example was given to us of somebody who had a gym membership and because the need for the physical intervention at the gym had gone, however, the social interaction at the gym was still very important.

Dr SIMPSON: It is a little bit different to that because that is about making new friends.

CHAIR: So it is an extension.

Dr SIMPSON: Yes.

Mrs TURNER: The international classification of functioning talks about community access and participation. Dr Simpson has just mentioned a case where it is new friends, but we are looking at also maintaining existing relationships which promote those things, and recreation and leisure certainly do play a role in that, particularly if someone is not able to work because that is also an area where people make social networks in many cases.

The Hon. JOHN AJAKA: There were just two areas that were raised by a previous witness, interestingly, and only one witness—

CHAIR: Excuse me. Ms Young, can you hear this?

Ms YOUNG: Yes, as long as the member does not speak any softer.

The Hon. JOHN AJAKA: The issue of the name "lifetime care" was raised that gave some concern, and that maybe we should be looking at changing the name. Especially for the initial participants, the last thing they want to be told is, "This is for life and there is no chance of recovery". By just having that name, there is that stigma. Do you have a view on that?

Dr SIMPSON: I certainly had more of an issue around the "care" phrase probably than the "lifetime" because once again the majority of people with traumatic brain injury do not actually need care. What they need is support. That is why it is important that it is care and support. I think that is a very important issue. I guess lifetime—certainly, I have worked in the field for 22 years on the community team so I have seen some clients over 10, 15, 20 years, and some of the research we have done has been among people who have lived that. I would say that there are many people who in fact do not necessarily want to be identified for the whole of their life as a person with a traumatic injury. There certainly would be a proportion of people who move into a place where they have some equilibrium in their life, where they have a quality of life. I would never assume that everyone who had had a catastrophic injury would need lifetime care. There will certainly be a proportion who do but it certainly would not accurately describe everybody's situation.

Mrs TURNER: In some cases people require ongoing services, and Ms Simons, who gave evidence, alluded to that. Having the opportunity to have the services that one needs to enable them to participate in the community is very important. As Dr Simpson said, sometimes that may not be long term but sometimes you have people catastrophically injured who require care. Brain injured people do sometimes require care. People may have a combination of brain and spinal cord injury, for example. So it depends on the individual. I guess I would be hoping that whatever the name was it continued to provide the services that the people needed.

The Hon. JOHN AJAKA: Another issue started to develop a little today. For example, we heard there is no real place for payment of family carers and that the preferred option is for outside carers to be paid. I heard the argument for why long term that is a preferred option and that made quite a good deal of sense. There also seems to be some real argument that some consideration should be given to payment to family carers in the very early part of the process and then, if I can use the word, wean them off it with the outside carers. It seems very strange to me that if a mother is working full time, her child is seriously injured, to suddenly say to that mother, "We'll bring in an outside carer straight away into your home to look after your child. You go back to work." That just will not happen. The mother will have enough problems without having to feel that she is abandoning the child. Do you have an opinion on that?

Ms YOUNG: I can see the issue both ways. I can kind of understand why people say it is good to have outside people come in. But I can see that there might be a benefit in the early days. I think sometimes the people who are not working are the ones who seem to wear a lot of burden of the care in the early days. They do not have to make the decision about going back to work, but the others may need to go back to work and they certainly do. It is very individual. I think they have a lot of choice. I would like to think that there would be circumstances where family members could be paid for a period of time but I think ultimately it raises the issue about—the time at which the issue will be really important is when it looks like the person is not going to make a lot more change from whatever point they might get to. Sometimes the relationships with family members are vital to keep the person moving and progressing. Other times you need that independent but outside person who is not emotionally attached to the person to be able to do the encouraging and the family member can then be a family member or a supporter in that network, rather than the person who has to wave the big therapy stick in the same way.

Sometimes people with brain injuries need to be able to maintain their involvement, and to maintain their involvement in a range of things they need a significant amount of encouragement to do it. People who do not have the emotional attachment, I think, do better at that. It depends very much on the person in the family and very much on the individual situation. So maybe some scope without a preference but it is very easy for people to get trapped in their families.

The Hon. JOHN AJAKA: Do you see a difference in the circumstances where, for example, the mother was working at the time of the accident and clearly had a career in that respect and the funds were needed for the family's welfare, as opposed to a mother who was home duties and was not working at the time of the accident?

Ms YOUNG: Possibly except that it is possible that the main carer, who is possibly the mother, may have gone on to do something in the workforce if the injury had not happened, if you know what I am saying.

The Hon. JOHN AJAKA: Yes, I do.

Ms YOUNG: I have mixed feelings. I understand why people are saying that family members would like to have the choice, but I can also see that sometimes it becomes a bit of a bind. People want to keep on doing something that may in fact not be helpful for them, either the person with the injury or the family member. A lot of people have real trouble with people coming into their home.

Mrs TURNER: I think the issue is choice. We have provision in Australia for people to get carers payments, if they are a carer. Carers allowances, of course, are not means tested. But I found that some families do want to choose to do that, whether it is for a shorter or a longer period of time. It would be great if there was provision in the scheme for people who made that choice to have the option to do that. If someone is caring for a relative with a brain injury, particularly someone who also has a significant physical injury, then they forfeit the opportunity to get paid employment. So they can be significantly financially disadvantaged. Some families prefer to do that and other families prefer to have paid carers. The issue of privacy, of course, is important. But there is not that capability within the scheme at the moment.

Dr SIMPSON: Two other points: We also need to be concerned about what the person with the traumatic injury wants. A 30-year-old male does not necessarily want mum tagging along with him everywhere.

The Hon. JOHN AJAKA: I can understand that.

Dr SIMPSON: Yes. The other point would be that the Office of the Protective Commissioner has some experience of this because they fund families to provide care. So they would know all the advantages and disadvantages.

The Hon. DAVID CLARKE: Your submission suggests training for lifetime care and support coordinators with regard to how brain injuries impacts on a family system and how to address these impacts. Can you elaborate on what you propose there?

Dr SIMPSON: This could be something that would be part of an initial orientation or continuing education program. My colleagues and I have developed a Web-based training program with nine self-study modules in the area of TBI [traumatic brain injury]. Some of the MAA accredited carer agencies already use this program. We are currently negotiating with the Department of Ageing, Disability and Home Care for DADHC staff to be using this program as they start to look at providing a service to brain injury. We have also received funding from the Lifetime Care and Support Authority for one of the projects under this most recent round, a building family resilience project. One of the deliverables from that project is an additional module to this program, which will be about working with families. We feel it will be quite easy to adapt that so it could provide some broader education as well as, maybe, tailor it to some of the specific challenges that the care coordinators would face on a number of the issues that we have been raising relating to families. People can normally complete the study modules in about two hours. They have a self-assessment task at the end that people can complete. This is the whole changing face of training. We feel that that might be a way to address some of the concerns and issues that we have been raising.

CHAIR: You said earlier you would like to expand on the education processes. Was that what you wanted to say?

Dr SIMPSON: Yes.

CHAIR: Are you comfortable with the work they are doing to make more consistent the decisions from co-ordinators and more consistent services? Do you know about that?

Dr SIMPSON: No. Certainly we take the point that the authority raised in response to our suggestions. We would certainly acknowledge that, in fact, there are many times when a range of family members do get support. Our real issue there is one of consistency. It seems to happen in some circumstances but in others it does not. That is why we wondered whether some of the problems were related to these issues when people have other pre-morbid conditions or there might be slightly ambiguous sorts of relationships. We could not really see a pattern to it.

CHAIR: Has your organisation been participating in any way with the Lifetime Care and Support Authority? Are social workers represented on the council, do you know?

Dr SIMPSON: Not to my knowledge.

CHAIR: It is more medical and clinical persons, not social workers?

Mrs TURNER: Yes, regrettably.

CHAIR: They operate off a system of protocol design. Do you think fairly clear guidelines would be able to be developed for the processes that you are advocating?

Dr SIMPSON: Partly what we are saying is we think that the guidelines seem to be there and it is really just the application of that in particular instances. I mean, the scope is pretty good and this continual reference to family and significant others. That is why we were suggesting training to a certain extent because in other fields of research if you have a problem with what is called reliability, training is one of the best ways of improving reliability so that you then have people consistently making decisions. One of the other points that we wanted to make under section 8, the other things, is to talk a little bit more about some of the difficulties in identifying key family members because it is not always a straight forward process in these situations. This is something that social workers are extremely experienced and well versed at taking. No, generally our issue is around consistency and how that might be improved.

CHAIR: Will you expand on that now? I want to hear about the cyclist issue before we close.

Dr SIMPSON: I will read out what a colleague supplied me with. This is a colleague who works in an acute major teaching hospital in Sydney. She wrote:

> The anomaly is that cyclists, while utilising the road network, remain without access to the LTCS scheme unless struck by a motor vehicle that has third party coverage. That creates the anomaly that while they are meant to be equal users with equal rights under all other rules of the road they are excluded from access to the scheme. Cyclists are frequently registered within Cycle Australia at a State and national level and thus could easily be included by an extension of existing registration schemes. Sadly, I have encountered a cyclist who has sustained a high-level quadriplegia and because it occurred without fault being attributable to another party, he is without compensation or access to the true means of lifelong support. He has duel insurance within New South Wales and Australia cycling organisations but this is for a total of less than $120,000. In this day and age of wishing to reduce the carbon footprint, it is an anomaly that we are not treating cyclists with the same duty of care when it comes to catastrophic injuries sustained when using the road system.

CHAIR: The committee has received quite a bit of discussion about that today and it was in several of the submissions in relation to the equity issues. It is difficult to collect from every cyclist. The person mentioned by your colleague belongs to an organisation but the majority of them in Sydney do not belong to such organisations. Do you think the Government could introduce a licence for cyclists and get away with it.

The Hon. GREG DONNELLY: And enforce it.

Mrs TURNER: That is a matter for the Government.

CHAIR: Cyclists do not even give-way. They go through red lights.

Mrs TURNER: That is a matter for the Government to consider but certainly they are road users and there are some instances, such as have been listed by my colleague, that they could have injuries on the road and not be covered. Certainly in New Zealand there is the Accident Compensation Corporation that covers people who are injured in any way, shape or form in New Zealand. Our scheme, of course, is a lot more narrow than that but we were just wanting to encourage thought about the needs of other road users.

CHAIR: It is also about the collection of insurance.

Dr SIMPSON: Yes, to cover the costs.

CHAIR: Which is how this was set up.

Mrs TURNER: And that is more an actuarial question, maybe there could be further investigation.

CHAIR: It is a political question.

Mrs TURNER: Yes, sorry, most definitely. I stand corrected.

CHAIR: Are social workers often case managers?

Dr SIMPSON: Yes.

CHAIR: Coordinators and case workers are not clinical-based persons. Last year there were a lot of issues put forward. Do you see perceive as a group that this is working through the process of the case workers working with the coordinators?

Dr SIMPSON: This issue is for both case managers as well as social workers, and social workers often play a case management role. I attended the recent consultation meeting that the Lifetime Care and Support Authority [LCSA] conducted around the issue of case management. We do feel that this is a work in progress. I think one of the differences between New South Wales and Victoria is that in New South Wales there was already a very well operating system of community based management and rehabilitation for people with brain injury and so now we are trying to superimpose another scheme on top of that, whereas in Victoria there was not any similar network. The TAC in some senses was a simpler thing. Obviously the service network does not completely match the clientele that the LCSA has but there is a considerable overlap. I think there needs to be some extremely careful work around defining those roles.

The LCSA experience, of course, is that different case managers have different expectations as well, of the coordinators so it is a two-way street I think. We certainly feel there are some ways forward in how that sort of issue might be addressed. Case management is not a unitary thing, there are different types of case management. There are roles such as case monitoring which, in fact, have a different set of activities to case management. It might be that amongst some of those definitions there might be some ways of clarifying how the two service systems might actually operate in harmony together.

CHAIR: I think that is the wisest thing I have ever heard on this particular issue. Some of our questions you may not have answered but due to time limits the secretariat will send them to you, together with any other questions, and it would be appreciated if you would furnish replies by 17 July. Do you want to say anything else?

Dr SIMPSON: Firstly, the issue of cases still not being identified. Denise would speak to this.

Ms YOUNG: I certainly had a number of people who I have had to enrol in the scheme. I work in the community in Bathurst and by the time people get to our community based rehabilitation setting have been through at least one acute hospital and sometimes two. I have enrolled three clients, two of whom have been to one acute hospital and they were seen by social workers and other people but, for whatever reason, their needs were not identified as meeting the criteria. No-one spoke to them at all and no-one even lodged a severe injury advice form to Lifetime Care. One person had a severe injury and a Lifetime advice form lodged which was great because it meant when they came to me it was obvious that they met the criteria and we could proceed from there. At least something was known.

But I also had another client who had been through an acute hospital in the city and another acute hospital and then rehabilitation unit in the country, not ours, and by the time we found out about the person they had actually been hospital for 5½ months and their brain injury issues had not been identified at all. I just think there is an issue of somewhere or other a lack of knowledge about Lifetime Care in some parts of the acute hospital network. I will say that two of those people, whilst they had had some involvement with the neurosurgical team, none of them had been through any brain injury rehabilitation service. So it is more an acute hospital without a brain injury service. They did not have spinal cord injury.

I just wanted to say that there does seem to be a bit of a gap there. Luckily we were able to get those people involved at the point that they were heading home, so that was wonderful. I was surprised that so far down the track for at least two of those people it was me, out in the country in a little hospital, who was doing the enrolment.

CHAIR: It is not a little hospital, it is a regional referral hospital of great import.

Dr SIMPSON: My colleague has one other point that we would like to put.

Mrs TURNER: Yes, one of the things that we would encourage Lifetime Care and Support to continue to be sensitive to is that in regard to psycho social matters, things to do with adjustment, it is important to be sensitive to the time frame for the achievement of the goals. It is not nearly as clear-cut as to when those goals will be achieved. It is not always possible for people to achieve adjustment to catastrophic injury in a short period of time so they may at one point in time work through some issues. They may not be ready to work through other issues and so they may need time later to review and monitor their progress. The orientation of lifetime care and support seems to be striving to combine the focus of impairment and function which we acknowledge are critically important with the broader psycho-social concern for wellbeing and that includes a focus on participation in the life of the family and the community, as we have mentioned earlier, but also things to do with quality of life which provides people with the opportunity to move beyond rehabilitation to live within the community. It is affirming the dignity and worth of people with disabilities and the contribution they can make to our society. It resonates with the philosophy of the Disability Services Act and it fits well with a whole-of-government approach to disability. We are hopeful that it will continue to be reflected in the outcomes that are seen amongst Lifetime Care and Support clients.

CHAIR: Thank you for your valuable input today.

Mrs TURNER: Thank you very much for the opportunity.

CHAIR: Thank you Denise.

Ms YOUNG: That is alright, not a problem, goodbye.

(The witnesses withdrew)

(The Committee adjourned at 4.45 p.m.)