REPORT OF PROCEEDINGS BEFORE

GENERAL PURPOSE STANDING COMMITTEE NO. 2

INQUIRY INTO THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE

Uncorrected proof

At Sydney on Thursday 2 October 2008

The Committee met at 9.00 a.m.

PRESENT

The Hon. R. M. Parker (Chair)

The Hon. A. Catanzariti
Mr I. Cohen
The Hon. G. J. Donnelly
The Hon. M. A. Ficarra
Reverend the Hon. G. K. M. Moyes
The Hon. C. M. Robertson

WENDY HALL, Senior Manager Client Programs, Northcott Disability Services, PO Box 4055, Parramatta, and

REBECCA ANNE PHILLIPS, Manager, Service Development and Government Relations, Northcott Disability Services, PO Box 4055, Parramatta, affirmed and examined:

CHAIR: We have afforded organisations an opportunity to make an opening statement prior to us asking questions about their submissions. That is optional. Do you wish to make an opening statement?

Ms HALL: No, we do not. We think we have probably included everything we need to say in our submission.

CHAIR: Thank you for your comprehensive submission, which focuses on our terms of reference and has some good recommendations. In your submission you list some of the times that clients at one of the Northcott services have been waiting for equipment. Can you give us more information about the sort of equipment they are waiting for and the time periods they are waiting?

Ms HALL: The ones that are included in the submission are people who live in one of our residential services and they have very high and complex care needs. In the submission we put in the date that these applications were submitted to PADP. Most people have been waiting over a year and some people a few months. The first one in the submission has been waiting since May 2007 for specialised seating. They are people with conditions such as muscular dystrophy and spina bifida so they have very complex seating needs.

CHAIR: Have they been told that their equipment is approved and they are on the waiting list, or is that just the time that the request has been put in?

Ms HALL: That is the time the request has been put in to PADP; at that time they are told that they will be on the waiting list. The therapist who prescribes the equipment is told that the client's equipment needs will be put on the waiting list. Then after that the therapist just continually tries to contact PADP. So it is a very time-consuming process. It takes a lot of the therapist's time because sometimes it is difficult to contact anyone at the local office because of how it is now constituted.

CHAIR: Do you think that the centralisation that is planned by Enable New South Wales will alleviate a lot of those problems?

Ms HALL: We are hoping that it will, and the therapists are certainly very optimistic that that will alleviate some of the problems, as long as there are enough staff to respond to calls in an efficient way, responding to the requests and inquiries.

CHAIR: With the waiting list, you mentioned the therapists often do not bother applying for things because they think it will take too long or be refused. We are aware that waiting lists therefore might be skewed because people are not applying for things. Has that been your experience?

Ms HALL: Particularly with regard to assistive technology equipment, a lot of those requests are not put to PADP. Sometimes they are put to PADP but the therapists know that they will not get it approved or funded so they go to one of the charities like Variety or one of those organisations.

CHAIR: Can you explain to the Committee—I note you talk about the eligibility requirements issue that Northcott has with orthotics?

Ms HALL: What happens is that we have orthotists and people who do specialised seating assessments. What they have been told—and other therapists have told me the same thing—that when we have a seating assessment that is done by a Northcott seating specialist, they are not allowed to submit the request to PADP for the seating to be funded because it is seen as a conflict of interest, but there are not many seating specialists in the State. Northcote has probably one of the few seating specialists in the State. A therapist then has to put in that request so it is a lot of duplication. Often in rural areas there are no therapists and there are very long waiting lists for therapists so they had to wait additional time to get a therapist to do the assessment. So it is a lot of doubling up and duplication of services.

Mr IAN COHEN: In terms of seating specialists, are they always separate from PADP or is there a connect between the seating specialists and PADP?

Ms HALL: Northcott has a seating specialist who does specialised seating assessments, and I think there is a statewide one as well with the statewide spinal injuries service, but I am not sure about any other specialists. There are not many in the State. Our seating specialists and orthotists do clinics in Dubbo, Tamworth, Wagga Wagga and Coffs Harbour.

CHAIR: In your submission you also talk about—we will clarify that about the seating specialists issue later—and increased loan pool and how you would like to see that be available. Can you expand on that?

Ms HALL: I think that was more with regard to the assistive technology equipment. Often people do not have access to a loan pool. We have a small loan pool at Northcott and I know some other services have small loan pools but it is restricted to the people who are clients of Northcott. So people from outside cannot actually access our assistive technology equipment, and because it is so expensive sometimes it just gets lost to us as well.

The Hon. MARIE FICARRA: Can you explain the assistive technologies? Are you talking about communication? I notice that in your submission you make strong points about the ability to communicate and assistance. What sort of technologies are you talking about?

Ms HALL: I would probably have to checked a bit more with the people who work with the computer assisted technology service because it is not my specialty area. I know they have voice technology and switches so that they can turn on equipment and remote access.

Miss PHILLIPS: And they have the technology to assist people who use computers and things like that for school, also environment modification in terms of putting switches on someone's wheelchair or something like that, environmental control.

The Hon. MARIE FICARRA: I would imagine that that is fairly important to enable a person to be productive and be a part of society and their self-esteem, their work, their productivity, everything. Is that not currently available through PADP, or do you have to wait so long that it is impossible? What is the situation?

Ms HALL: The information I was given is that it is a very low priority for PADP and it is often not considered a priority. The more basic needs like mobility and equipment for showering and personal care are seen as a priority. It is not always seen as a priority by the Department of Education and Training either.

The Hon. MARIE FICARRA: I guess if they have a limited budget, but ideally it would be good to have that funding.

Ms HALL: For some people the only way they can communicate or access the community is to have assistive technology.

Mr IAN COHEN: Drawing on your experience of Katy in your submission, can you just outline for the Committee what children requiring this technology are missing out on in terms of social skills and development and the long-term costs to society by the long waiting lists for this type of technology?

Ms HALL: I think that children of that age group—I think Katy is 15 but even younger children—are not able to access services or community activities and events. Even stuck in their home, they are not able to access them because they cannot communicate appropriately with people. So they are missing out on their development.

Mr IAN COHEN: How does that impact on long-term costs? Can you give an example to the Committee of how missing out on that type of assistance might impact when those children reach maturity?

Miss PHILLIPS: I think it contributes to social isolation, which is a problem as people become older, and also difficulty in accessing the curriculum at school, being able to learn and develop through the education system, being able to communicate with people, and being able to access tertiary education, employment and all of those kinds as things as they grow into adults.

CHAIR: In your submission you talk about the funding increase and how you found out about that through the press release but you have not been made aware of how the rollout is going to happen. Has there been no communication with organisations such as yours? Yours is a significant organisation in this sector.

Ms HALL: There has not been a lot of communication to date. We just are aware that there was an enhancement. I know that some of the therapists went to a PADP committee meeting the other day in Western Sydney and they said that even the PADP coordinator was not aware of what was actually happening with the rollout of the enhancement funding.

The Hon. CHRISTINE ROBERTSON: So the money has not been divvied out yet?

Ms HALL: That has not been communicated to us.

CHAIR: Do you expect that now your clients know there is an increase in the budget more people will apply for PADP-supplied equipment?

Ms HALL: I do not think they will do that because they think there is more money but because they have a need for equipment.

CHAIR: Okay, so you do not think it will affect that.

Ms HALL: No.

CHAIR: Do you have a view about what sort of figure might be appropriate for ongoing funding?

Ms HALL: I am not sure about the figure that is appropriate but I think there could be some projections about equipment needs in the future because a lot of people, particularly those with congenital disabilities, have ongoing equipment needs. Among the comments that are made to therapists by people who are currently PADP coordinators are, "You're always asking for equipment." Of course we are always asking for equipment because a lot of people have degenerative conditions, so they have ongoing equipment needs. Equipment wears out and as people degenerate their equipment also needs to be changed so they are frequently being re-assessed and their equipment needs to be updated. Just as we need new cars and new shoes, they need new equipment as well. Sometimes they are discriminated against, I think.

Miss PHILLIPS: Obviously children's needs change quite significantly as they grow and during transition periods in their life, going from preschool to school, so they regularly need different types of equipment to be able to access their environment.

The Hon. MARIE FICARRA: In your submission you mention a maintenance schedule for equipment. Is that because in your experience that is not really taken into account?

Ms HALL: Sometimes people have to wait on a waiting list to have their equipment maintained. If they get their equipment through another funding source, PADP often does not take responsibility for maintenance. Sometimes that is what parents weigh up: If we get equipment funded through a charity, who is going to maintain the equipment for us? Often it is very costly replacing and maintaining equipment.

The Hon. MARIE FICARRA: It is obviously a big need. You mention the Victorian Government has a scheme for motor vehicle adjustments and so forth. Can you elaborate on what sort of need there would be and do you know whether the scheme is operating well? Obviously you would like it implemented in New South Wales.

Ms HALL: We would like it implemented in New South Wales. I am not sure how it is operating; Rebecca probably knows. I know that people who have electric wheelchairs, in particular, always need a vehicle to transport the wheelchair. If they cannot afford taxis, which are quite costly for families and individuals, they need a modified vehicle. As children get older they need to have some sort of hoist to get them in and out of vehicles because it is too difficult for parents and they often end up with shoulder and back injuries, which we have mentioned in the submission. Then that has an impact on their health and how they can care for their child. It is very expensive to purchase a vehicle and modifications are very expensive as well.

Miss PHILLIPS: The Victorian scheme is very recent. We saw the information as we were preparing the submission, so it is new and we do not really have any more information about that, but they are offering it to people.

The Hon. MARIE FICARRA: Are any other States doing it or is it just Victoria?

Ms HALL: I do not know about other States, only Victoria, because there was a press release from Victoria that someone forwarded to us.

The Hon. MARIE FICARRA: It would be costly upfront but then there would be spin-offs in terms of quality of life and their ability to socialise and development and participate in society. That would have an equalling positive benefit.

Ms HALL: They usually have to get a vehicle that has a high roof, so the vehicles are quite expensive and most people probably would not pay that much for their family vehicle, and then the modifications are very expensive.

Mr IAN COHEN: You state that many PADP centres and services do not provide email addresses and do not respond to emails and you have raised this matter with the Department of Health and the relevant area health services or Enable New South Wales. What is the impact on your organisation and your clients of this lack of communication or lack of accessibility?

Ms HALL: It is very difficult for therapists. We have long waiting lists for therapy in our organisation and some of our services, such as the school-age services, have up to eight-month waiting lists for therapy services, which is a long time in the life of a child. Because they are meant to follow up on the applications, if therapists keep almost harassing the local PADP offices it seems to help with the approval process—if they continue to maintain contact. They also need to keep the clients informed. I think that sometimes the clients feel that we are not doing our job well because we cannot get information or feedback for them. It is also an additional job that they do not need because they already have long waiting lists and that is a big pressure for staff as well.

Mr IAN COHEN: In terms of that process and the lobbying you have to do, is that consistent across the board with PADP offices or do you find quite significant differences in ability to cut through the red tape and get results? Is it different in different areas or with different issues?

Ms HALL: I think it is consistent across the board but it depends on individuals and their relationships. Some therapists have good working relationships with PADP offices so they seem to get better responses. I guess it is ways of working with people. We are hoping that will be eliminated with the centralised process.

Mr IAN COHEN: So there are not specific areas or types of equipment that are much harder to get or that have longer waiting lists than other types of equipment?

Ms HALL: I think adults have a much harder time getting equipment. That is why we submitted that table. Children's therapy services say that at the moment their waiting list is not too bad, but it is still quite lengthy for small children, in comparison.

Mr IAN COHEN: You list a number of items requested by clients that have equipment currently outstanding, some longer than 12 months. Is that typical or is that exceptional?

Ms HALL: It is typical of that particular service. That is one service with 16 clients that has all those outstanding pieces of equipment.

The Hon. CHRISTINE ROBERTSON: Is it one geographic area?

Ms HALL: It is one accommodation service that has 16 clients with all those outstanding pieces of equipment. For some clients it would mean they could not go out and access their normal activities.

Mr IAN COHEN: Obviously it has quite a catastrophic impact on clients over a long period of time. It is understandable that there is a long waiting list on power drive wheelchairs, but are orthopaedic boots and mobile shower commodes also as much a problem—

Ms HALL: Yes.

Mr IAN COHEN: —or is it just the big-ticket items?

Ms HALL: The boots are actually quite expensive too. They are about $3,000. They are not a cheap item otherwise families would fund them themselves. Those boots are specially handmade, so they are quite expensive at times.

Mr IAN COHEN: Do you feel the centralisation of the organisation and the processes will assist? Is it just that PADP centres are vastly overworked currently and stretched beyond their capability or are there other fundamental problems in the system?

Ms HALL: They just tell our staff when they ring that they have no funds. All these applications have been before the local PADP committee and we are told they have no funds to provide the equipment.

Mr IAN COHEN: Are you aware of the extra funding that the Government has put up alleviating the situation or is that earmarked for other purposes? Are you aware of the direction to which that extra $11 million is going?

Ms HALL: No, we are not aware of that although I do know that one of these items has been supplied recently.

Miss PHILLIPS: I think there are also inconsistencies between the centres around procedural things—the way you apply, the response you get, all that kind of thing. Consistent procedures would be helpful.

CHAIR: You are saying that different lodgement centres have different systems and you might get a different response from one lodgement centre to another to a request for a piece of equipment.

Ms HALL: Yes.

CHAIR: Is that because of the committee that is involved in the process or is it just that different lodgement centres have different focuses?

Ms HALL: It is all meant to go before the committee so I think it is partly because of the committee but also sometimes partly because of the coordinators and staff in the lodgement centre.

The Hon. CHRISTINE ROBERTSON: You gave us the example of the long time for the seating order to come through for the wheelchair. Does this mean that a new prescription is needed and the whole process will have to occur again?

Ms HALL: Yes, definitely.

The Hon. CHRISTINE ROBERTSON: Because the person's needs have changed?

Ms HALL: Yes. That is very time consuming and it increases our waiting list because it is a priority to get that assessment done. The equipment has to be re-trialled, so it not only increases our workload but the equipment company's as well because we have to get them to come and re-trial the equipment. As you are aware, children grow very quickly so even if they wait a few months it is too long because they have outgrown the original prescription.

The Hon. CHRISTINE ROBERTSON: I would like to talk to you about the loan pool. You run a loan pool and you talked about the difficulties with the PADP program's loan pool. Do you think if the local pool becomes statewide and is more comprehensive and they are able to track where stuff goes after it is finished with that will improve the process?

Ms HALL: I am sure there is equipment, especially for children because they do not use it for a long time, that could be re-used for other children. In particular, with regard to the assistive and augmentative technology I am sure other children could use that equipment as well. I know that schools often say they have storerooms full of equipment that has been prescribed for children who have moved on. So, I think a statewide loan pool would be really useful.

The Hon. CHRISTINE ROBERTSON: So, right across the State, there are probably bits of equipment in that position—the ones that have gone to garage sales it is a bit sad about, and they have gone. Have you any ideas on the best way to collect a comprehensive list of this stuff and get it back into circulation?

Ms HALL: I do not know that even local PADP offices have loan pools—

The Hon. CHRISTINE ROBERTSON: That is where the problem started.

Ms HALL: Even now.

The Hon. CHRISTINE ROBERTSON: They do not?

Ms HALL: I know one of the disability services in South Australia, Evita, has a statewide loan pool that is funded by the State and it is very comprehensive, a very good loan pool. I know it is a smaller State than New South Wales but it is a very good model.

The Hon. CHRISTINE ROBERTSON: They have told us they are proposing to do it, but the time factor we are worrying about.

Ms HALL: Yes.

The Hon. CHRISTINE ROBERTSON: Another issue brought up this morning was in relation to technological equipment, and I am not using the nice word you used. Have you any ideas how you could increase the priority of that equipment on the criteria list?

Ms HALL: At the moment it is not really a priority at all.

The Hon. CHRISTINE ROBERTSON: But it needs to be put in.

Ms HALL: Yes, I think it does need to be put in, in particular if children are accessing the curriculum, students for education and people to go to work as well.

The Hon. CHRISTINE ROBERTSON: They are telling us they are going to set clinical priorities for the future of the program while we are going through this change time. The work of getting this issue on the agenda along with all the others—of course, persons proceed with the most important. Have you any ideas about increasing its priority? We have seen a lot of witnesses who it would be advantageous to. We are not saying it is not an issue, but getting it put up on the political agenda?

Ms HALL: I think they have had some clinical task force and Enable has had a clinical task force over the past couple of years looking at assistive technology. So, it is on Enable's agenda but how we make that a priority, I think it is about funding because people's most basic needs need to be met first. So, it is about adjusting our priorities and maybe it is about increasing funding.

The Hon. CHRISTINE ROBERTSON: The orthotist issue, the chair-fitting issue, has either of you had time to look at the pilot project with Lifetime Care and Support that puts out prescriber qualifications and experience guidelines that are quite fierce?

Ms HALL: I think they are joint guidelines with Enable and Lifetime Care and Support.

The Hon. CHRISTINE ROBERTSON: They are.

Ms HALL: Yes, we have looked at those.

The Hon. CHRISTINE ROBERTSON: Do you think they have the potential to address the issues for this is not very available skill?

Ms HALL: I do not think so. I think there is a real shortage of orthotists.

The Hon. CHRISTINE ROBERTSON: I realise that. But your orthotist being ignored at one of the—

Ms HALL: I think that was more about it being a conflict of interest, that we were the prescriber and the supplier, and they were saying that—

The Hon. CHRISTINE ROBERTSON: I understand what you said, but if the person is a qualified prescriber and approves, and fits into the description that they are working with as a pilot at the moment, it is a different story, is it not?

Ms HALL: He is on that expert advisory committee. So, he is eligible to prescribe.

Miss PHILLIPS: And he has been involved in that committee for the lifetime care. But I think it would be beneficial to have some kind of approval for therapists, because there are also therapists that prescribe, maybe, the wrong equipment, which is also costly.

The Hon. CHRISTINE ROBERTSON: And damaging?

Miss PHILLIPS: Yes, that is right.

The Hon. CHRISTINE ROBERTSON: So, in your minds do you have a perception that if they standardise the prescribing processes, the ordering processes, the priorities for equipment, as they are saying will happen, then some of your issues will be resolved?

Ms HALL: I guess in some ways some of our issues will be resolved but it will create other issues for us.

The Hon. CHRISTINE ROBERTSON: Can you give us some examples?

Ms HALL: Some of the issues it will create for us are that we have a shortage of therapists. So, to prescribe some of the equipment, you need a lot of experience and a supervisor. We do not always have that available. We are struggling to employ enough therapists for our services now, particularly therapists with that specific experience. That is one of the concerns of the therapists, and we do not have a lot of senior therapists who are available to support the more junior therapists.

The Hon. CHRISTINE ROBERTSON: That is an Australia-wide issue.

Ms HALL: I think it is an international one.

The Hon. CHRISTINE ROBERTSON: The other issue, and we have not had a copy of the Victorian plan, and the Committee is not as informed as you are on this issue, but does it remedy issues such as Victoria only gives 44 per cent of the cost of a motorised wheelchair, whereas we deliver 99 per cent? It would be dreadful if we raced off to Victoria and made things worse.

Miss PHILLIPS: We only identified that because of the need to support people with wheelchair accessible—I am not sure about the rest.

The Hon. TONY CATANZARITI: You did answer partly the therapist issue. I was going to ask you what therapists do you have and what sort of ratio is there?

Ms HALL: I think we have around 38 full-time equivalent therapists. Obviously, a lot of them work part-time hours. We have 38 full-time equivalent therapists. Most of them are based in the metropolitan area. Therapists who visit the regions do clinics in the regions. The computer-assisted technology service and orthotics clinics do clinics in the regions and we have a paediatric spinal outreach service that does outreach across the State and consultancy.

The Hon. TONY CATANZARITI: The shortage of therapists, would that mean the rural areas would be even further delayed?

Miss PHILLIPS: Yes. It is really hard to attract therapists to rural areas as well.

The Hon. TONY CATANZARITI: I understand the PADP only has two in the metropolitan area for some 1,300 people. Do you think that is anywhere near enough?

Ms HALL: I am not sure of the numbers they have in consultancy, PADP or Enable now. No, it is probably not. If the service is centralised, there will be a lot of inquiries and lot of issues around prescribing equipment, and therapists will need to consult with those therapists at Enable to ensure they are meeting the guidelines as well. We do not have a sufficient level of expertise in our organisation to meet the guidelines of some of the prescribing guidelines that PADP are suggesting.

The Hon. CHRISTINE ROBERTSON: Have you had any contributions to the structuring of the lodgement centres?

Ms HALL: I have been on the PADP advisory committee for the past three years. We had representation on all of the advisory committees.

The Hon. CHRISTINE ROBERTSON: What are you hearing is going to happen with the lodgement centres?

Ms HALL: I understand it is going to decentralise.

The Hon. CHRISTINE ROBERTSON: You do not know how many skills are going to be put there?

Ms HALL: No.

The Hon. TONY CATANZARITI: Have you witnessed any delays because of the shortage of therapists?

Ms HALL: Not so much the shortage of therapists within PADP but a shortage of therapists in our own service and in particular in the regional areas.

The Hon. TONY CATANZARITI: What I am getting at is, when the assessment is done there is a lengthy waiting time?

Ms HALL: At the moment our therapists do the assessment and the prescribing of the equipment and then the application, at the moment, goes to the local PADP office. So, there is no therapist from PADP involved in that. But our therapists can contact Enable at the moment and ask for advice when prescribing equipment.

The Hon. TONY CATANZARITI: So, you do not need them to authorise the equipment?

Ms HALL: No, not at the moment.

The Hon. TONY CATANZARITI: With this centralised system, what do you expect to happen? You expect there may be an answering service or people on the other end? Have you had any communications on that?

Ms HALL: I have seen a flow chart of what is meant to happen, and there is meant to be an 1800 number that people can access. I do not know how many people will be available to respond to calls and if people will be put on long call waiting times.

The Hon. CHRISTINE ROBERTSON: Did you know that number is already there?

Ms HALL: Yes, I do know that number is already there.

The Hon. TONY CATANZARITI: There has been no communication as to what sort of system it will be?

Ms HALL: I think Enable is trying to get out and inform people, going to local therapy meetings. There is a spot on a meeting that they go to and they are trying to get information out to people. A lot of therapists are communicating information as well.

CHAIR: Knowing that that communication exists now, can you see any reason why it is going to take until, apparently, 2010 to roll out the centralisation? I am just astounded it is going to take so long. I wonder, with your involvement, whether you have any understanding as to why that would be?

Ms HALL: No, I have no idea why that would be. Because the PADP review was a couple of years ago now, with all its recommendations, and everyone I have spoken to was pleased with the recommendations and the outcome of the review.

Mr IAN COHEN: My understanding is that one of the reasons given was to minimise disruption to clients and services, particularly to clients in general, over that time. Do you have any information from that point of view?

Ms HALL: Obviously PADP has a lot more clients than we are aware of because we only have a pretty small client group in comparison with the rest of the State. I do not think our clients would be too disrupted by the centralisation as long as there was some way, particularly for people in the rural areas, that they could have their equipment delivered and access services on a local level.

CHAIR: So you think the sooner it is rolled out the better?

Ms HALL: Yes.

Mr IAN COHEN: I would not expect you to have seen this report to New South Wales Health that highlights quite significant inconsistencies with a number of the PADP centres where, for example, the use of therapeutic air from Health is charged to PADP. Are you aware of any of those sorts of problems and anomalies in the way the finances are being directed in PADP programs?

Ms HALL: I only know from my involvement with the PADP advisory committee, and there were reports tabled at that committee about inconsistencies.

Mr IAN COHEN: Has that been referred to the Government from your organisation?

Ms HALL: In the past we have had meetings regarding the problem.

Mr IAN COHEN: I am just citing air as an issue. My understanding is it should be paid by the Department of Health and it is charged to PADP. Do you have any other examples of what may be charged to PADP possibly inappropriately, cost shifting in that way between those departments?

Ms HALL: Not really, but I know that in some area health services the provision of home oxygen and home ventilation is separate from PADP now. So they have a separate department.

Reverend the Hon. Dr GORDON MOYES: Put on the area health service?

Ms HALL: Yes.

Reverend the Hon. Dr GORDON MOYES: You may have answered this question before I came in. I was concerned about the number of inquiries you have to see whether you can help with car modifications, the installing of a lift or the purchase of a larger vehicle to allow a child to travel either in normal seating but requiring extra space or in provisions for, say, a motorised wheelchair. Do you have much call for support for vehicle modification?

Ms HALL: We have a lot of calls for support on vehicle modification and also the purchase of vehicles. A lot of families—

Reverend the Hon. Dr GORDON MOYES: Cannot afford the big vehicles?

Ms HALL: No, cannot afford the vehicles to accommodate children.

Reverend the Hon. Dr GORDON MOYES: Have you any comment about that or suggestions?

Ms HALL: My comment is I think it would be good if families could receive some assistance to purchase the vehicles, because sometimes it compromises the whole family because they can only have one vehicle and that is the vehicle the chair goes in, the modified vehicle, and if they have other family members, sometimes they cannot go out together, they have to go out separately.

Reverend the Hon. Dr GORDON MOYES: They cannot afford to get a specialist cab?

Ms HALL: No. So it is very costly. Transport is a really big issue for families. Sometimes we have to approach several charities because they have a limit of how much they can donate to each family.

The Hon. CHRISTINE ROBERTSON: Do you know a lot about how well your clients are able to access the Community Transport System across the State?

Ms HALL: Our clients are able to access the Community Transport System but sometimes it is not very adequate to meet their needs.

The Hon. CHRISTINE ROBERTSON: Would you provide some details?

Ms HALL: Sometimes they have to wait around a long time so that if they go to an appointment sometimes they are sitting there a whole day before they get picked up and taken home. So it does not always meet their needs.

The Hon. CHRISTINE ROBERTSON: Is that consistent across the State or is it worse in some areas than in others?

Ms HALL: It is different in different areas. I know that a lot of our clients do not like accessing community transport because of the length of time that it takes them to get to appointments and then get back home again. In rural areas, Community Transport is often not an option anyway because they live so far. Some of them live so far from anywhere.

The Hon. CHRISTINE ROBERTSON: What sorts of areas in the country do not have community transport?

Ms HALL: I think they have community transport but it is not available to go out to a property and pick people up and bring them back. The same thing happens for school transport as well.

Reverend the Hon. Dr GORDON MOYES: They are flat out taking people to licensed clubs to pay the pokies.

The Hon. MARIE FICARRA: And do the shopping, sometimes.

The Hon. CHRISTINE ROBERTSON: I understand the waiting problems.

Ms HALL: Yes, it is a big issue.

Miss PHILLIPS: I understand there is also a restriction about what they will take people to. I am not sure whether they take them to medical appointments or regular appointments. I am not sure exactly of the detail but there are restrictions.

The Hon. CHRISTINE ROBERTSON: Some criteria?

Miss PHILLIPS: Yes.

Mr IAN COHEN: Does your organisation have specific issues or focus or problems with non-English speaking people in the community? Do you have to exercise the available resources of your organisation in relation to that matter? What are the problems?

Ms HALL: Yes, we have a lot of people from a non-English speaking background. It is an area in which we have to utilise resources for interpreters and translators for information.

Mr IAN COHEN: Do you get extra assistance for those specific problems?

Miss PHILLIPS: Through the Translation Interpreting Service [TIS]. I am not sure through which government department it is funded—I think it is federally funded—but we are able to access translation interpreters.

Mr IAN COHEN: Is that adequate for you to function?

Miss PHILLIPS: No, it has a cut off as to how much it can provide. Recently somebody requested an Arabic speaking translator and it said it had its limit for Arabic speaking interpreters for that month, so it is not always adequate.

Mr IAN COHEN: So you could not get an Arabic speaking interpreter service for someone that needed your services?

Miss PHILLIPS: Not for free.

Ms HALL: So then we have to put that in our budgets and apply for funding to pay for translating or interpreting services. Particularly, the Translating and Interpreting Service there is always a charge for that.

The Hon. MARIE FICARRA: What do you do in such circumstances? Do you encourage them to bring a family member or a friend?

Ms HALL: We try to avoid using family members and friends. Some people from non-English speaking communities actually prefer not to use interpreters so we have to bargain with them a bit and say "I will have to bring an interpreter every six months, and then you can use a family member in between." Some communities are quite small and they are concerned about confidentiality. In a lot of communities there is a taboo around disability so they do not want other community members know they have a family member with a disability as well. We often reach a compromise.

CHAIR: We could ask many more questions. The Committee may ask for further clarification. Thank you for your presentation today and for your submission, which has provided the Committee with valuable information that has raised a number of other questions that will be investigated further. Thank you for what you are doing on a daily basis for your clients, carers, parents and those users of the ADP. We hope this inquiry will prompt the Government to take some further action.

(The witnesses withdrew)

PETER TALBOT, Clinical Lead Dietetics and Nutrition, Dietitians Association of Australia, Sydney West Area Health Service, 1/8 Phipps Close, Deakin, Australian Capital Territory, and

JANET BELL, Head Dietitian, Dietitians Association of Australia, Central Hospital Network, South East Sydney Illawarra Area Health Service, sworn and examined:

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

Mr TALBOT: Clinical Lead Dietetics and Nutrition.

Ms BELL: Head Dietitian.

CHAIR: Thank you for your submission, which is very useful to the Committee.

Mr TALBOT: There are a number of submissions that are interrelated. There is the GMCT, Home Enteral Nutrition, so that is one. There are some others from the Cancer Council, GC as well, and others from companies that all relate to this.

CHAIR: Do you want to make an opening statement?

Mr TALBOT: The Dietitians Association of Australia is the national association of the nutrition and dietetic profession and is a leader in nutrition and advocates for better food, better health and better living for all. We represent accredited practising dieticians [APD] who are recognised professionals with the qualifications and skills to provide expert nutrition and dietary advice. APDs play an important role in the management of people who require tube feeding and nutritional oral supplements as well—people who are suffering from malnutrition.

Who needs home enteral nutrition [HEN]? HEN patients include those who cannot swallow so problems with their oesophageus or neurological problems such as strokes, multiple sclerosis, Parkinson's disease, motor neurone diseases, all the different types of cancer, including head and neck cancers, people who cannot meet their nutritional requirements, such as people with cystic fibrosis who may be able to eat but might need tube feeding at night to build up their calories, failure to thrive in children as well, young kids with congenital diseases and young kids born with cerebral palsy. What are aids to nutrition? Tube equipment such as feed sets, feeding containers and things like that. They might have a tube down their nose and after four weeks it is usually changed to a tube into their stomach. This connects to the tube in the stomach and they need a container as well to feed through.

There is also a Greater Metropolitan Clinical Taskforce [GMCT] HEN network of about 15-20 clinical specialties who are looking after these patients. We report directly to the Director-General of Health or the New South Wales Minister for Health. So the HEN network represents about 250 health professionals working in more than 100 New South Wales public health care facilities. We try to advocate for home enteral nutrition and try to make it ethical across the State.

Looking at the terms of reference, we are looking at adequacy of funding for present and projected program demand. At the moment in the recent review the Program for Appliances for Disabled People [PADP] accounted for about 3 per cent of the budget for aids to nutrition, so about $300,000. That is sort of inadequate and only covers about 300 patients whereas we estimate there are about 3,600 tube fed patients in this State at the moment, which is increasing by 20 per cent every year mainly because patients are being sent from the hospitals into the home quite quickly. Also in relation to the impact on client waiting lists, a lot of people were not aware of PADP so we are covering about 300, and you can see there is a shortfall of about 3,300 patients who are not being supported by PADP.

Centralising PADP—at the moment GMCT HEN is working with Enable NSW, the Department of Commerce and the Department of Health and we would like to see it centralised. We are hoping to wind out the provision of containers and giving sets and tubes for the supply of feeds to all patients across New South Wales. We are working towards trying to set that up in six to either month's time.

The Hon. CHRISTINE ROBERTSON: In conjunction with the current Enable program?

Mr TALBOT: In the future, yes.

Ms BELL: Looking at the appropriateness and the equity of eligibility requirements, there are issues around the criteria of permanency because a lot of patients really need a tube into the stomach after three months for a long time. A lot of patients, for example, head and neck oncology patients, need a tube for six to 12 months so they are not eligible for that criteria and it ends up costing them up to $300 per month just for the equipment, not for the actual feed, so it is very expensive. At the moment HEN formula is paid for by the patients. There is a New South Wales Government contract now that enables patients to purchase formula at contract prices but other States in Australia have subsidy models or co-payment models or they are fully subsidised. So that is something we would like considered. We have recommended that NSW Health consider a co-payment model to support those who cannot afford the cost of HEN. A single co-payment across PADP would simplify the process rather than multiple co-payments because we know a lot of the patients also have other expenses.

Overall the recommendation really is for equity and access for all patients for consumables that require tube feeding across New South Wales and a co-ordinated system to administer the supply and delivery of tube feeding consumables. The other thing is that patients who require tube feeding have access to one given set a day because at the moment the Therapeutic Goods Administration guidelines have recommended single use devices. That means one of those tubes, one a day. At the moment the PADP covers costs for two a week, so it does not cover the costs. Obviously, as we all know, access to nutrition is a basic right for all human beings.

CHAIR: Are those who are not on the PADP system self-funded or using service clubs to support their needs?

Ms BELL: There is no other access. There is no access through private health insurance or anything like that. Only the Department of Veterans' Affairs is the other way, really.

Mr TALBOT: They are self-funded mostly. Some charities will support them. I think the Lions Club is supporting the Cystic Fibrosis Association up to a point, but I think that was reduced in the past two years. Some other charities might support individuals from different area health services, but there are a lot out there who are self-funded. Some people are just waiting from six to 12 months to get onto the PADP list as well.

CHAIR: The data you have regarding the numbers of people who actually require your feeding systems does not seem to exist within New South Wales Health. Do you have that data at your fingertips?

Mr TALBOT: Yes.

CHAIR: Do you have projections as well?

Mr TALBOT: Yes. So, GMCT HEN started collecting that data in 2005. They did a report in 2006 and that was sent to the Department of Health.

CHAIR: So the department is aware of your projections and your current needs?

Mr TALBOT: Yes. We will be presenting a report to the senior executives in the Department of Health in September. So they are all the chief executive officers [CEOs].

CHAIR: What has been the response when you have given them that information and the projections that the numbers are increasing at that rate?

Mr TALBOT: They read the report. It took over a year to get it back. In the end we are working with the Department of Commerce and Department of Health to try to set up a good system for these patients, but because they have said they have no money we have to work out a way to fund it.

CHAIR: What do you mean?

The Hon. CHRISTINE ROBERTSON: From your current budget?

Ms BELL: Within current resources.

CHAIR: So you have not been given any assurances that with the supplementary funding you are likely to get an increase?

Mr TALBOT: We are waiting to look at the PADP report review to see what they have arranged for co-payments, but at the moment we have to work out a system where, if we can, we will try to get Enable New South Wales to handle both the giving sets and the feeds. Then by the volume of patients in the State we may be able to reduce the price of the feeds. Also, we are trying to fund the clinical coordinators in each area health service to look after these patients as well because a lot of them get lost to follow-up. They do not get followed up by clinicians; they drop out of the system. That is the other concern.

The Hon. MARIE FICARRA: What happens to those who need assistance at home and they drop out of the system?

Mr TALBOT: The carers look after them. They are set up in the system to receive, say, a discounted feed price. They may be paying for the giving sets, for the containers themselves.

The Hon. MARIE FICARRA: You said that currently you are funded for two feeding sets per week when in actual fact hygiene requires one set per day.

Ms BELL: Yes.

The Hon. MARIE FICARRA: For how long has this been going on?

Ms BELL: Forever.

The Hon. MARIE FICARRA: You have brought this to the attention not only of PADP heads but also New South Wales Health? They have known about this?

Mr TALBOT: It is contained in the report. The report is on our GMCT HEN website.

The Hon. MARIE FICARRA: Could you supply that report to the Committee?

Mr TALBOT: Yes.

The Hon. MARIE FICARRA: You mentioned also the report where you estimated the number of people currently not being serviced. Is that figure something like 300,000?

Ms BELL: No, 3,300.

The Hon. MARIE FICARRA: Even 3,000 is terrible. Would you tell the Committee again where those statistics can be found and how current they are?

Mr TALBOT: These are figures for 2005-06. So you need to project 20 per cent on top of that over the past two years. So, that is 20 per cent and then another 20 per cent.

The Hon. MARIE FICARRA: Those figures went to whom in the Government?

Mr TALBOT: They went to New South Wales Health.

The Hon. MARIE FICARRA: Can you table that also for the Committee?

Mr TALBOT: Yes, certainly.

The Hon. MARIE FICARRA: It seems extraordinary that this is pretty basic stuff, yet it is not being catered for. Would you explain further how the formula co-payment system will work for the consumer?

Ms BELL: Peter could probably explain this better. Obviously, there is a levy of affordability looking at the level of how much people are earning, that is, their wage, and then for people who cannot afford, they pay an extra co-payment on top of that. They have used that from looking at the amount of the cost of normal food and taking that away, leaving the difference, if that makes sense.

The Hon. MARIE FICARRA: To explain that for the inexperienced: If you use a case study of a person who needs formula, what sort of costs are we looking at per annum for that person?

Ms BELL: For the giving sets alone it is $300 a month and at the moment through PADP they are getting $65 a month for two a week. For feeds it is probably up to $30 a month.

Mr TALBOT: Yes, about $4 a day.

CHAIR: Is the $30 a month what they get back?

Ms BELL: No, that is what it costs them for the feed, the actual liquid they are putting through the tube.

The Hon. MARIE FICARRA: Do they get anything back?

Ms BELL: No, nothing.

The Hon. MARIE FICARRA: So what you are talking about is introducing a co-payment?

Ms BELL: A co-payment for better access for people who need it.

The Hon. MARIE FICARRA: To be means tested?

Ms BELL: Yes, exactly. The problem is that many of these patients have disabilities and have a lot of other expenses as well and it is a lot more expensive than food and, as I said, it is a fundamental.

The Hon. MARIE FICARRA: It is a nutritional basis of life?

Ms BELL: Yes.

The Hon. MARIE FICARRA: Has your organisation or the network you were talking about put in a submission to New South Wales Health on that?

Mr TALBOT: We put in a submission to this Committee.

The Hon. MARIE FICARRA: Has it gone anywhere else? Just to this Committee? It is good that it has come to this Committee.

Mr IAN COHEN: We have received a submission and I wonder whether it is typical of country areas. The people are stating that there 2½-year-old child has failure to thrive and chronic reflux, uses feeding tubes four times a day for his formula and milk bags also four times daily. Tamworth PADP only supplies two tubes, I think it says here, every six months. Would that be correct? Is this off the planet?

Mr TALBOT: Yes.

Mr IAN COHEN: And supplies bags every three months. They are writing a complaint to this Committee. Is this sort of thing typical in country areas? You said it is bad when it is every two weeks instead of daily.

Mr TALBOT: Yes. It is dependent on the centre and what other costs they have. So, the funds for nutrition might be put at the back of other things that are taking priority.

Mr IAN COHEN: Do you have any information in regard to supply to various areas? I imagine there would be a certain consistency of need in smaller population areas like Tamworth, but there must be a certain consistent percentage that requires these types of assistances?

Mr TALBOT: We got the figures from PADP when they did that review. So our figures came from there. We could certainly do another survey, but some of that information is contained in our report as well.

Mr IAN COHEN: Are you saying there is no consistency?

Mr TALBOT: No.

Mr IAN COHEN: In the way PADP or PADP local offices prioritise the equipment they supply?

Mr TALBOT: Exactly. It varies from centre to centre. Our one in Sydney west will give two containers and four giving sets per month, but that is different to your example. It is different from each lodgement centre.

CHAIR: That would seem to be totally absurd. Is it your understanding that when the system is centralised that will be standardised or have you no information about that?

Mr TALBOT: We are working towards that but, of course, some people are concerned that if they maintain this service, that would be awful for the patient. So, we need to make sure we have consistency. That is the idea if you centralise it; you have guidelines saying this is what patients need.

Ms BELL: So you can assess their need and prioritise the right equipment to the right people.

Mr IAN COHEN: In your experience, given that you are experts in the field, what will these people do? How do they deal with the situation? They have a severely disabled child who needs to be fed, obviously. Are they just reusing the old equipment?

Ms BELL: They would be washing it up in the sink with dishwashing liquid, pretty much I would say, and probably hanging it in the sun to dry.

Mr IAN COHEN: That sounds pretty stark. You supply the you-beaut supposedly once-off equipment. Is there any backup or any education about the proper process of dealing with the equipment or is that outside your purview because you are not allowed even to advise these people given their situation?

Mr TALBOT: The TGA put out a thing saying health officials are not allowed to advise on the cleaning of this equipment. They do not advise it because it is single use. So they put us in a bit of a dilemma. These patients then would contact their dietitians and the nursing staff of the local hospital to try to see what they could do about this situation. If it were not resolved, they would probably lobby the member of Parliament or contact GMCT HEN and we would try to look into that situation.

Mr IAN COHEN: How typical is this, particularly in country areas?

Ms BELL: Very typical.

Mr IAN COHEN: You said there were 3,300 people on the books through PADP. How many of these would you estimate are actually in the community suffering third world conditions?

Ms BELL: It is only 300 under PADP. So it would be the rest.

Mr IAN COHEN: I got the figures wrong. So you are saying there are 300 under PADP who are covered?

Ms BELL: Yes.

The Hon. CHRISTINE ROBERTSON: It is 3,000 who are self-funded.

The Hon. TONY CATANZARITI: And that would vary from area health service to area health service?

Mr TALBOT: Yes, depending on what services are set up. That is where the inequity is.

Mr IAN COHEN: Obviously you see these situations. Do you have any information or evidence of specific health problems that could be shafted back to lack of proper sterile equipment and such like? Is a common problem with these issues things like gastric problems with disabled kids and people?

Mr TALBOT: We have not got figures for that. We have presentations to emergency departments, but that is more to do with peak tubes. Probably out of 700, one in four present to emergency departments.

Mr IAN COHEN: With a localised infection?

Mr TALBOT: Yes, or a displacement.

Mr IAN COHEN: But would localised infections be through overuse of a product, bacteria build-up, that sort of thing? Is that what they are dealing with?

Ms BELL: It could be, but it is sometimes hard to ascertain if that is the primary cause. It is difficult, that is why we have had trouble in being able to extract that data.

Mr IAN COHEN: How would you describe the situation from your professional perspective?

Ms BELL: Dire.

Mr IAN COHEN: How serious is it throughout New South Wales? To me this is just one example and we will be receiving other material. How critical is it? How disastrous or potentially disastrous is it?

Mr TALBOT: It is dire and needs action.

Ms BELL: I agree.

Mr TALBOT: It is very concerning. That is why a whole lot of clinicians have got together to try to change the situation.

Mr IAN COHEN: From your point of view, where is the breakdown? What can relieve the situation? The Department of Veterans' Affairs uses the universal eligibility model. Is that the model we desperately need?

Mr TALBOT: I understand that you have to have the wisdom of Solomon to decide on who gets treated out of this huge number of patients. Basically, nutritionists would love to see this funded.

Ms BELL: To me the gold standard would be that everyone is funded.

Mr TALBOT: It is funded in other countries.

Mr IAN COHEN: Where, for example?

Ms BELL: In England and in Victoria.

Mr IAN COHEN: There is universal health coverage in England.

Ms BELL: Through the National Health Service [NHS] all patients get subsidised, and in other countries they do as well. For example, in Victoria tube-fed patients are fully funded.

The Hon. CHRISTINE ROBERTSON: But they do not get full funding for their wheelchairs.

Ms BELL: Exactly, there are inequities.

CHAIR: In your estimation what would be full funding per patient?

Ms BELL: I think all up it is $3 million.

Mr TALBOT: For the tube-fed patients and for nutritional supplements and drinking you are looking at $15 million, which is a lot of money.

CHAIR: It depends. Would you see that as your number one priority?

Mr TALBOT: Certainly.

The Hon. MARIE FICARRA: You said earlier that there was a funding shortfall of $15 million. What is the funding level at the moment?

Mr TALBOT: Around $300,000.

The Hon. MARIE FICARRA: So it is $300,000 verses $15 million?

Ms BELL: If it were for the consumables alone, or all the equipment, it would be $3 million. Is that right?

Mr TALBOT: Yes.

The Hon. MARIE FICARRA: So it is $3 million plus a co-payment?

Ms BELL: For everyone to be subsidised fully for feed and equipment it is $15 million. That includes oral supplementation for people and not tube feed.

The Hon. CHRISTINE ROBERTSON: The proportion you got last time was analysed at about 2 per cent, so $15 million would send it up to 50 per cent.

Mr TALBOT: That would probably cover all patients.

Ms BELL: It would cover all patients.

The Hon. CHRISTINE ROBERTSON: Fifty per cent of current PADP funding?

Ms BELL: Yes.

The Hon. CHRISTINE ROBERTSON: I know that this is an important issue. Many people come to the Committee with incredibly important issues. You are also arguing on behalf of the committees that are setting the structure for priorities, so I wanted to put that into perspective. Obviously that figure of 2 per cent is not high enough for nutrition, but 50 per cent is an enormous amount?

Ms BELL: Yes.

The Hon. CHRISTINE ROBERTSON: I was not seeking to discredit your statement. You referred earlier to the lifetime care and support structure and to long-term access to feeding. The PADP pays for that but it is difficult for short-term clients who are not getting covered.

Ms BELL: Yes.

The Hon. CHRISTINE ROBERTSON: Both structures are different for a reason. What sorts of arguments can you put forward to support those who require feeding, in particular, post-cancer patients? As treatment is getting so good, feeding for six months will become more common.

Ms BELL: Yes.

The Hon. CHRISTINE ROBERTSON: What sorts of arguments can you put forward to show that that important priority should be put on the PADP agenda so we can deal with that issue?

Ms BELL: That could change in the future as treatments are improving. As dieticians we assess these issues. I work with oncology patients and I assess certain criteria. I know what treatment certain patients will get. A lot of them are now getting more aggressive radiotherapy treatment. We know that they will automatically have a tube put into their stomachs prior to treatment and we know that that will be for at least six months.

The Hon. CHRISTINE ROBERTSON: You are aware of those facts but what sorts of arguments should we put forward to ensure that this issue has priority in the program? I am putting it on the agenda to ensure the implementation of such a priority in the community to treat cancer successfully.

Ms BELL: Maybe there needs to be a criterion for a six-month cut off, or something like that.

The Hon. CHRISTINE ROBERTSON: A six-month review?

Ms BELL: A six-month review, yes. To be eligible a patient must have had treatment for six months.

Mr TALBOT: The argument is that you are keeping people out of hospital by treating them in the community, and you are saving a lot of costs as long as you also set up good clinical care for those patients.

The Hon. CHRISTINE ROBERTSON: Are you arguing these cases for the committees setting the criteria priorities?

Mr TALBOT: Which committees?

The Hon. CHRISTINE ROBERTSON: You told us earlier that you were working with committees.

Mr TALBOT: That is right. We are working with the New South Wales Department of Health and Department of Commerce.

The Hon. CHRISTINE ROBERTSON: I refer to the co-payment issue and to current departmental guidelines for eligibility and payments. The current cut-off is low compared with the average wage. Have you given a lot of thought to the co-payment program and the issues that you want to implement, or have you been involved in discussions about it?

Mr TALBOT: Originally we were waiting for the PADP review to come out to see what co-payments would be set. We were waiting for it to come out with its figures so that we could work with it.

The Hon. CHRISTINE ROBERTSON: We were told yesterday that it was going to put out a discussion paper.

Mr TALBOT: Okay.

Ms BELL: We have looked out a lot of other models around the world and within Australia and we have made our recommendations. However, as I said, we are just waiting for the PADP.

The Hon. CHRISTINE ROBERTSON: Tell us.

Mr TALBOT: We put those recommendations in our first report and we left them out of our second report because we wanted to say that they were the true figures that needed to be subsidised. That is what is in our last report. Some people take into account the cost of food. Queensland Health was using around $60 to $70 for the cost of food and then it was using half of that for concessions, for example, $30 for people on pensions and things like that. Those are some models that were put in the report.

Ms BELL: I have information available from other States and from England if you are interested in seeing it.

The Hon. CHRISTINE ROBERTSON: That would be useful.

CHAIR: Yes please, Ms Bell. Could you table it so that all Committee members have a copy of it?

The Hon. GREG DONNELLY: Could you explain for the benefit of the Committee the discussions that take place between the national body and the Commonwealth Government on improvement of funding as opposed to state-level discussions that are taking place so we have a picture of the whole dynamic between the States and the Commonwealth?

Mr TALBOT: A submission came from all the different feeding companies and I think that went to the Council of Australian Governments [COAG] about two years ago. Apart from that, the Dietitians Association of Australia [DAA] held a workshop on this at its last conference and it is putting together a report to try to lobby COAG. That is as far as it has gone.

The Hon. GREG DONNELLY: There are no ongoing discussions with the Commonwealth Department of Health?

Mr TALBOT: Not that I am aware of.

The Hon. GREG DONNELLY: Essentially, your discussions on these issues are at the state level with respective State health departments?

Mr TALBOT: Yes, but we are working with dieticians in each State and nationally to try to lobby the Federal Government. It gets bounced between the two governments—State and Federal. We are happy no matter where the money comes from, as long as our patients get assistance.

The Hon. GREG DONNELLY: Sure. Is there any sympathy at a Federal level to improve funding available to the States to deal with this?

Mr TALBOT: There certainly is sympathy. From my understanding there was lobbying of some of the parliamentarians about this issue, so there is sympathy.

The Hon. GREG DONNELLY: Lobbying of Commonwealth members of Parliament?

Mr TALBOT: Yes.

The Hon. GREG DONNELLY: Just so that I understand, did that lobbying occur via the Dietitians Association?

Mr TALBOT: I think it might have been by the companies that supply the feeds.

Reverend the Hon. Dr GORDON MOYES: I was concerned about the cost of consumables to which you referred earlier, as it is a big issue for parents. On my last check alimentary canals had both an entry point and an exit point. You are involved in the entry point, and what comes in also goes out, which involves high-cost consumables. Do you have any view on that?

Mr TALBOT: Are you talking about colostomy bags?

Reverend the Hon. Dr GORDON MOYES: I am talking about colostomy bags, all kinds of faeces, urine, and so on.

Mr TALBOT: We would support any assistance to our patients, if that were needed.

Reverend the Hon. Dr GORDON MOYES: Incontinence pads?

Mr TALBOT: Yes, certainly. We did not cost that into our report at the time, but it is certainly an issue.

Ms BELL: Yes, definitely.

The Hon. MARIE FICARRA: You said earlier that suppliers of the equipment had lobbied the Federal Government. Would it not be more advisable for you to have a central professional spokesperson or a group from the professional organisations rather than the commercial interests of the suppliers?

Mr TALBOT: Certainly, and we are working towards that. At our last conference we chaired a workshop to work with all the States in looking at inadequacies across all States. We are certainly working towards that.

The Hon. MARIE FICARRA: I think it would be better received; there would be less conflict of interest. Their interest is with the consumer.

Mr TALBOT: Certainly.

Ms BELL: It is interesting to see all the differences within each State. That is why we are looking to establish one group.

CHAIR: Thank you for your presentation today. We learned a great deal. We will take into consideration the issues that you raised today. Thank you for presenting additional information.

Mr TALBOT: Many thanks.

Ms BELL: Thank you for having us.

(**The witnesses withdrew**)

(**Short adjournment**)

CHRISTOPHER PAUL SPARKS, Executive Officer, Independent Rehabilitation Suppliers Association of New South Wales, and

GREGORY THOMAS KLINE, Owner, GTK Rehab, sworn and examined, and

SHAUN JENKINSON, General Manager, Invacare Australia, affirmed and examined:

CHAIR: Thank you for your organisations' submissions and for appearing as part of a panel today. There will be questions asked, which any of you may answer.

Mr SPARKS: Madam Chair, may we make an opening statement?

CHAIR: Yes, if you have a brief opening statement?

Mr SPARKS: Yes.

CHAIR: If it is something lengthy, it can be tabled.

Mr SPARKS: Thank you. Firstly, thank you for the opportunity to provide evidence to the inquiry. We represent the individuals and businesses who design, manufacture, import, distribute, sell, rent and service equipment for people with disabilities. Without us, there would not be any equipment—might save the Government a few bob. The member businesses of the Independent Rehabilitation Suppliers Association [IRSA] simply try to make a living out of providing expertise, equipment and service to people with disabilities and the elderly in much the same way as occupational therapists, PADP staff, those who work for Enable NSW, et cetera. Suppliers—mostly small businesses—build an ongoing and supportive relationship with their customers. Long after the occupational therapist has moved on and the PADP funding has been allocated and spent, the supplier continues to play an important role in supporting the end user.

We are a major stakeholder and critical part of the entire equipment supply process, yet until now we have been effectively shut out of any debate with little chance to contribute in formation of policy. Frankly, we were stunned when we were not properly consulted in any way in the formation of the PricewaterhouseCoopers report. In our view this report is fundamentally flawed due to its abject failure to consult with equipment suppliers, yet this report has become the basis of the Government's reform agenda.

Yesterday's evidence from the New South Wales Department of Health leaves us unconvinced that Enable NSW has the necessary capacity and capability to deliver reforms in a timely manner. What is needed is evidence of a committed project plan that will instil confidence in the ability of them to actually make progress to deliver real outcomes for people with disabilities in New South Wales. One has to wonder about the goal of increasing available equipment expenditure from 80 to 84 per cent of the $25.6 million recurrent budget via centralisation. This will deliver a net benefit of just over a million dollars annually, yet it is going to take until 2010 or 2011 to achieve it. However, every year $4 million is wasted by government and business on client reassessments due to funding delays and this does not take into account the dreadful frustration and pain this causes to people with disability and their devoted carers. Imagine going to see your optometrist to get a glasses prescription today knowing full well you are not going to order them for 18 months or more. It is simply absurd.

Yesterday's evidence from carers and people with disabilities highlighted the damage caused by the unwillingly inefficient and overly bureaucratic PADP application and assessment process. Far too often the potential joy of receiving greater mobility, independence, comfort and dignity becomes a frustrating and personally debilitating process. This is too often the desperately sad reality for people with disabilities as an outcome of the PADP process. As a community we should be hanging our heads in shame. There has to be a better way.

There is also an alarmingly growing trend to try to procure imagined savings through large-scale centralised procurement contracts. This may work for simple items, but is a recipe for disaster when supplying complex rehab equipment. The evidence in other States is that the costs to government increase while service levels to people with disabilities decline. There is an enormous risk of wiping out small regional suppliers and therefore any hope of quality service to our country customers with a disability on the doctrine of lowest price per widget is pursued above all else. We believe good government should be about regional sustainability and excellence in service delivery.

Finally, there needs to be an understanding of the unique challenges associated with the supply of complex rehabilitation equipment. Wheelchairs ain't wheelchairs. In reality, the knowledge of complex rehab products and equipment prescription lies mainly with suppliers, not with occupational therapists. Those who require complex equipment are often the most disadvantaged and physically challenged members of our community and also those with the most to gain from access to the right equipment. Our association stands ready to work with the Government and all stakeholders to deliver a better PADP system.

CHAIR: Is that on behalf of all three?

Mr JENKINSON: Yes.

Mr KLINE: Could I throw one more thing in that Chris has not covered: The viability of our industry at the moment is at risk because of government payment record. I am happy to table my debtors to the Committee. It has improved. Three weeks ago I had over $300,000 out over 90 days. I am a small business. We cannot carry that sort of debt.

CHAIR: Your overdraft is funding the Government?

Mr KLINE: Funding the New South Wales Government.

The Hon. CHRISTINE ROBERTSON: By "improved" do you mean they have paid what they owe you at the moment?

Mr KLINE: Currently we are down to only $100,000 owed over 90 days.

The Hon. CHRISTINE ROBERTSON: So some was paid three weeks ago?

Mr KLINE: Some was paid.

Reverend the Hon. Dr GORDON MOYES: They do not go beyond, say, 120 days?

Mr KLINE: Most of that is out over 120 days.

CHAIR: Do you ever get anything paid within the standard 30 days?

Mr KLINE: The closest we get to getting paid in 30 days would be 45, and there is only one PADP who normally meets that criteria and that is Newcastle. I have spent a lot of my time over the last month trying to go up the chain to get payment, but the excuses I am getting are just not acceptable, such as, "Yes, I can pay you this week." I said, "How much?" They said, "I can't tell you that." I said, "Why not?" They said, "Well, I've got to pay my wages tomorrow and after I've paid my wages you can have what is left."

CHAIR: Who is telling you that?

Mr KLINE: The finance department within area health.

The Hon. MARIE FICARRA: Is it commonly reoffending area health services? You said you have outstanding over 120 days probably the majority of the $100,000 that you are down to. Do certain area health services continue to offend or is it across the board?

Mr KLINE: One just cleared its—

The Hon. MARIE FICARRA: So we will not mention them.

Mr KLINE: But normally, other than Newcastle, it is across the board.

CHAIR: When you say Newcastle, are you talking about Hunter New England as a total, not just Newcastle?

Mr KLINE: No, Hunter New England.

Reverend the Hon. Dr GORDON MOYES: Has there been any accumulation from all of the suppliers of how much is outstanding?

Mr SPARKS: I would hate to think. I go in to bat regularly on behalf of our members and the senior finance staff of the Department of Health have been extremely responsive, but it has been almost a weekly occurrence. Particularly it seems to have got worse in the past three months where I have to go to the top level of the department to get a small family business in northern New South Wales paid so they can pay their staff next week.

Mr JENKINSON: The other thing to add is that the impact it has on the end user when our only recourse with small business is to put them on stop credit and maybe then to do the same to the health department is that you are sitting with a piece of equipment somebody really needs, and the emotional strain of saying, "We can't provide this equipment because we don't know if we are going to get paid" means that it is very emotive when you have a user at the end who really desperately needs that equipment.

Mr IAN COHEN: Mr Jenkinson, in paragraph 3 you state that when money is released bolus-style there is often a rush and the resultant bottleneck leads to reduced service levels for the user.

Mr JENKINSON: Absolutely.

Mr IAN COHEN: Is this current one-off injection of funding of $11 million creating this problem, or how do we resolve the problem?

Mr JENKINSON: I will certainly talk a little about that and Greg might want to comment as well because I think we always welcome that sort of injection of funding because it is going to release equipment for people who really need it, but these businesses often run on staffing levels that they can afford based on their cash flow and all of a sudden, if you release something that is nearly 50 per cent of the national funding, if Greg has three therapists they can only deal with their capacity and all of a sudden there is a rush to get equipment through, so what is going to happen is that it will just delay the speed at which they can get the equipment. The money is welcome, but the capacity is not there to manage it, and more constant workflow would be significantly improved for the whole industry.

Mr KLINE: Could I make a comment on that because this happened this week in our office: One of the PADPs is spending this money and they rang and said, "We must have an updated quote today." We have five quotes to update. This is a particularly complicated one. We first quoted it in December 2006. We requoted it in May 2007.

CHAIR: What sort of equipment is it?

Mr KLINE: It is a very highly complex powered wheelchair with a head control. This chair is going to a young cerebral palsy man who currently is doing his higher school certificate, I have been informed. He is in a manual wheelchair that he cannot self-propel, so he is being pushed around. He has been waiting two years for this chair to give him independence. It has now come to the top of the pile, but several things have happened. The chair itself has been discontinued. The therapist is no longer there—she has gone. We have had to requote for this chair, which we have done, without seeing the client for two years. Obviously we will go out and see the client.

CHAIR: He has probably grown.

Mr KLINE: Well, he has grown; he may have changed. Is the equipment still suitable for him? We do not know. But that is what this delayed process—and here is a young boy of 17 who should have been out there independently in the community, who has been in a manual wheelchair with someone pushing him.

CHAIR: We have heard evidence that there is another step in the chain that causes a huge amount of problems, that is, basic servicing of equipment such as a wheelchair. There was an example given yesterday of a foot plate being broken and the need to go to the occupational therapist for assessment as to whether it needed to be fixed or replaced and then to PADP—months going by when it is clear that the person has a wheelchair, needs the wheelchair and needs it to be functioning. Once they have it, it would seem that they should get it fixed and just put an invoice in to PADP. Do you see that link in the chain being necessary?

Mr SPARKS: I believe in some areas it is becoming more and more bureaucratic. Greg's company is probably one of the largest rehab suppliers in Australia and he has an extensive service team because he has to be highly responsive. If your electric wheelchair breaks down, you have no option. There are those PADP regions that historically have had great relationships with suppliers, and they will get on the phone and say, "Greg, Bill Smith's chair has broken down, can you sort it out?" They will go out there and fix it. "If it is going to be expensive, please ring us, but if it is a few hundred dollars just get the job done and invoice us." My impression from our members is that that is becoming less commonly the case with the bureaucracy in controlling increases. Mr Kline could probably comment further on that.

Mr KLINE: We have had a couple of PADPs recently that have asked us to go out and quote on the job—not fix it.

CHAIR: So that costs you money then to go out, take your repair person out to quote?

Mr KLINE: We charge them for that. We get an order number to go and quote, which to me is a total waste of resource. If we are there, we should fix it.

CHAIR: I guess ongoing maintenance also becomes an issue.

Mr KLINE: It is a huge issue in that PADP currently does not fund regular maintenance on any of the equipment. If we did that to our cars we would void our warranty. The first we hear from the PADP is when the chair is broken down. For instance, electric motors on wheelchairs have brushes; it is like in your car. If you drive around with no brake pads you will damage the disc and it will cost you a lot more money. Wheelchairs are no different. If you do preventative maintenance your overall costs in the long run will be cheaper. But currently PADP will not fund preventative maintenance.

CHAIR: These things cost more in many cases than in cars, do they not?

Mr KLINE: You can pay up to $20,000 or $30,000 for a powered wheelchair.

CHAIR: How will centralisation, as proposed as a response to the PWC review, although that will not take place until 2010-11, affect your services?

Mr SPARKS: We are optimistic about centralisation. It clearly makes good business sense. It puts the back office functions under one roof, derive some efficiencies from it. We have been given indications that issues such as invoicing and payment will be smoother, order placement will be more consistent, which will definitely make our lives easier and take cost out of the whole process. So we are optimistic about centralisation. I suppose the alarm bell rings in my head, as somebody who has been involved fairly extensively in mergers and acquisitions, is often achieving these goals and objectives. They are a major undertaking in themselves. When I hear dates of 2010 and 2011 and "we hope" and "aspire", and one wonders if Enable New South Wales, which has some outstanding people in it, is adequately resourced to deliver the objective of the project.

CHAIR: We have heard from a number of people about the resourcing of the PADP, that the top-up funding is claimed by the departmental representatives to get rid of the backlog or waiting list. Do you have a view about what the recurrent funding should be?

Mr SPARKS: I do not know it is industry's place to tell government what it should be dishing out to those in need. You have just got to do the simple math: If we needed $11 million this year to wipe out the waiting list, then year on year the waiting list will recur so clearly it is underfunded. To what degree? I think it is substantial. I have never applied for PADP. I have been a wheelchair user for 40 years. Why? Because I have a job. All my pressure care and mobility, I fund. So where I sit in the definition of "need" is an interesting question. Yesterday one of the members posed the question about the fairly harsh means test limits on the system. The fob off was, "Yes but 98 per cent of our people are on Commonwealth benefits." I do not understand. Clearly if the means test was higher maybe some poor Joe who earns $35,000 a year could get funding for his $13,000 power chair.

CHAIR: As you are aware, we had examples yesterday of people self funding. As businesses you would have data about how many people are coming directly to you for supplies of their equipment, et cetera, because either they are not bothering to go to the PADP because they do not think they will be funded or it takes too long or they have other means of funding their equipment. Do you have that sort of data?

Mr KLINE: We do. We track everything we do and we break it up into whether it is a charitable donation.

CHAIR: So you know where your equipment has gone. It seems that the department does not know where equipment is or does not seem to have that data on a consolidated basis.

Mr KLINE: No. There is a lot of equipment out there, as was stated yesterday, that just gets sold or tipped. People ring us trying to sell us back PADP chairs.

Reverend the Hon. Dr GORDON MOYES: It is a way of getting the bills paid.

Mr JENKINSON: There are discussions around a central loan pool. Many of us would welcome reuse and effective use of equipment because it will not lessen the expenditure per se. That will just go to the unmet need. So an efficient use of that would be great. You only have to go to PADP areas around the State to see the effective bone yard of equipment sitting outside, unused, un-maintained and wasted, which is hugely inefficient. So to understand what is the real need for financing is difficult because the current resources are not used efficiently.

The Hon. CHRISTINE ROBERTSON: What sort of maintenance contract would you set up for that to function well? Obviously between clients you will have to cover full maintenance.

Mr KLINE: In every product we sell, if it is a powered wheelchair there is a maintenance schedule for six monthly, 12 monthly and 18 months servicing.

The Hon. CHRISTINE ROBERTSON: But are you moving it from one client to another?

Mr KLINE: Some of the PADPs do recycle well. They will call us. Again, I use Newcastle as an example.

Mr IAN COHEN: It seems like the only one.

Mr KLINE: I think they are the only one.

Mr IAN COHEN: What is constantly coming up is the efficiency.

The Hon. CHRISTINE ROBERTSON: That is Hunter-New England.

Mr KLINE: Yes, they are terrific to deal with. They will call us and our service technician will go and do a safety maintenance check on the chair. These days most chairs are flexible enough to grow in different dimensions so we reconfigure it for the new individual and it goes out again. We think that is a great use of resources.

Mr IAN COHEN: From your position in terms of being in the business of supplying, why are we seeing such efficiency out of Hunter and the Hunter only? It seems like it is working well, yet we are hearing other areas' lack of follow-through, just lack of awareness of what equipment is where and things like that. Can you comment on that?

Mr JENKINSON: To be successful in any area you need to have a combination of the right people, the right process and the right tools. If you do not bring those together in the system that works, then you will not have a successful organisation. I think the combination is that with good people actually applying the process well and probably measuring and monitoring it with tools around loan equipment, so it is really just about normal good business practice, removing waste and being organised and structured.

Mr IAN COHEN: Earlier mention was made of the one-off funding of $11 million. Again from your business perspective, how much is that just throwing waste after waste in terms of it getting to effective areas other than the Hunter? It seems like there is a graveyard of wheelchairs and things like that.

Mr SPARKS: It provides some very unique challenges. When it was announced we contacted Enable New South Wales as the industry organisation to try to get information on how this would be rolled out so that our members could be prepared. Enable had a very pragmatic view of it. They said that it has got to be over time because Enable simply does not have the administrative resources to place the orders, to process this, to check priorities so it will take them time to get their house in order, which is understandable. They knew that it would take the suppliers time. Understand that that $11 million was, I believe, specifically targeted at the backlog—that backlog of people that companies like Mr Kline's went and saw 18 months, two years, three years ago. So now Mr Kline has got his therapist back in the truck, back with the trial equipment, back out to the client's house, do a whole new reassessment, come back in, do a requote. That is an incredibly laborious and costly task.

The Hon. MARIE FICARRA: I think you mentioned you have done an estimation of $4 million of Government money being wasted on this reassessment process.

Mr SPARKS: Just to clarify, that is government and business.

The Hon. MARIE FICARRA: Government and business. You mentioned before you sent out your technician and you got there and had to do the quote, and that obviously is billed to the Government. What would be far better? Hopefully this reassessment thing will be improved so that we can get some cost efficiencies into the system. In terms of doing a repair is it possible that a quote can be faxed and immediately a decision made so the technician is there and can be given the go-ahead and just do it?

Mr KLINE: The majority of PADPs we deal with, we have been dealing with a long time. They ring us and say, "Fix it. I'll come back to you with an order number." Some can raise it straight away but apparently it is very difficult now for a PADP to raise their own orders like they used to, so it has to go through purchasing. The majority are focussed on keeping people mobile. We respond—our worst-case scenario is the next day for a break down. We try to get the same day.

The Hon. MARIE FICARRA: So it would be a limited number of lodgement centres that have been asking you to quote—

Mr KLINE: It is only one or two.

The Hon. MARIE FICARRA: —and hopefully in the centralised system that they are advocating that waste will be eliminated?

Mr KLINE: I would hope so.

The Hon. MARIE FICARRA: You were not consulted as a body when the PricewaterhouseCoopers review occurred?

Mr KLINE: Not consulted.

Mr SPARKS: One of our great frustrations is the PWC review shows $1 million cost to the Government in reassessments. You have heard people give evidence in the past two days that we do not have enough OTs. We need desperately to change the assessment model. You heard yesterday a client talk about a $200 rail to help her child learn toilet training. To get that, we had to get a therapist to go out and look at it. The therapist then wrote a report, PADP review and say "Yes but you will get the money in 18 months." That is insane. I firmly believe—and I have been agitating with Enable New South Wales—that we need a working committee that includes stuff like this, to say, "Let's change the assessment. Let us look at a quicker, more expedient situation for low-cost urgent items and deal with that one way." Let us also move to the model that worked extremely successfully in one western area health service some years ago where, instead of dragging an OT and three different suppliers out to see a person in need, they did an on-the-phone assessment. Billy Smith has cerebral palsy and needs a padded chair through seating. What will that cost? It will cost somewhere around $15,000. Great! Let us put in a funding application for $15,000 today. Eighteen months later Billy Smith's application reaches the top of the pile and he is now eligible to get his chair. We then despatch the therapist, we contact the two or three suppliers, we assess Billy, the order is issued a week later once the chair of choice is selected and the chair is delivered—no more assessments. We just saved the Government $1 million.

The Hon. MARIE FICARRA: This is sensible in running any business. Why have they not noticed this before and implemented it?

Mr SPARKS: Enable New South Wales was unaware that its own western area health service had done this some years ago, although there was a presentation done for the OT association as to what a successful model it was and how much cost and time wastage it took out. When we made them aware of this they embraced it. At one of the professional training events we conduct for therapists, a representative of Enable said that they were very keen to move towards this. In meetings with them, they are not quite sure how to kick-start it, resources, pilot schemes. For us it is incredibly frustrating, because we estimate it would save business somewhere in the order of $3 million a year and save Government in excess of $1 million in New South Wales. The client is better off because they are not being dragged through a lengthy assessment only to be not given anything for 18 months and for it all to be done again.

The Hon. MARIE FICARRA: And your organisation would be prepared to be on a working party with government to implement—

Mr SPARKS: I would stand on bended wheel to get onto the working party!

The Hon. CHRISTINE ROBERTSON: I refer to the process of contracting. I have not heard during the inquiry from the Health people that they are looking at sole contractors for individual requirements, so how would you anticipate being involved in the process to set up the structures for the central contracting?

Mr SPARKS: I believe mention was made yesterday morning about the costing efficiencies of letting a supply contract out. We endorse that; we are not against that at all. Experience interstate and overseas has shown two things: Firstly, you must not include complex rehab technology in these contracts. Costs for government will go through the roof. Secondly, these contracts should only apply to supply within the larger metropolitan areas. The reason for that is there are smaller rural dealers and they feed their families by selling half a dozen rollators, a couple of standard wheelchairs and the odd scooter and perhaps a slightly complex power chair once a month. All of a sudden you say you are going to buy all your standard products from company X based in Sydney. That guy says, "Wow, my business isn't viable. I'm going to go back to painting houses or be a panel beater." That business collapses and next thing the disabled people in that community have no access to local service. Just recently in America there has been a giant competitive bidding strategy to try to get the price of equipment down. They have learnt there are two things you cannot do: One is put complex rehab technology out to competitive bidding; the second is you cannot apply it to small rural areas. You will destroy service levels.

The Hon. CHRISTINE ROBERTSON: A lot of us are from the country and we do understand this issue. Perhaps something like geographic base needs to be considered because in some small rural areas you cannot get any service whatsoever unless there is a contractual obligation. I understand regional centres like Tamworth and Wagga have medical supply centres but there are many centres that do not. You still need to know that you are covering the district level-type towns that do not necessarily have a supplier. You still have to have a contract that forces people to cover those.

Mr SPARKS: Absolutely. It is one of the things that we are very strong on.

The Hon. CHRISTINE ROBERTSON: Perhaps some of the Sydney ones might cover those. I am trying to envisage how they would structure that.

Mr SPARKS: In any tender or contract that Enable New South Wales puts out for supply of equipment service levels for people with disabilities must be maintained. There must be key performance indicators for that. In terms of servicing equipment in small rural areas, the best person to speak about that would be Greg who has probably a fleet of thousands of wheelchairs out there all over New South Wales.

Mr KLINE: We have established a network in rural areas, normally an auto electrician, who services all our power mobility in the country, and we have been dealing with some of these people for 10 or 15 years. Motors and gearboxes are basic everyday items to them.

The Hon. CHRISTINE ROBERTSON: But you are a Sydney-based company supplying a statewide service. Is that right?

Mr KLINE: We cover all of New South Wales.

The Hon. CHRISTINE ROBERTSON: It makes for much complexity when you are trying to work up a contract that ensures supply. Sorry to add a complication.

Mr IAN COHEN: Ensuring backup, you mean?

The Hon. CHRISTINE ROBERTSON: Yes, supply and maintenance.

Mr IAN COHEN: We need a disability NRMA!

The Hon. CHRISTINE ROBERTSON: Another issue is the assessment discussion you just had. One of the major issues that have come up in the inquiries is the lack of standardisation, and the geographic differences in prescription writing and delivery of supply. For obvious reasons an emphasis is being put on repairing the problems so that everybody gets an equitable service. I guess what you are asking for is to be at the table when the prescription criteria for practitioners who can write prescriptions are considered. Is that what you are actually asking for with your story?

Mr SPARKS: Indeed.

The Hon. CHRISTINE ROBERTSON: Because the story actually said that what they are doing is good but you want to be at the table. Is that right?

Mr SPARKS: I will get Greg to speak to the detail of this, but the fourth appendix in our submission is a typical script form, for a complex power wheelchair. I challenge any of you to run your eyes over it. Therapists with years of experience struggle to get that right.

The Hon. CHRISTINE ROBERTSON: Yes, they need assistance to work with you people, the suppliers, in order to deliver.

Mr KLINE: From my experience, and I have been employing occupational therapists in a sales role for the last five or six years—

The Hon. CHRISTINE ROBERTSON: Is that why we cannot get any in the health service?

Mr KLINE: There are a few of them from the Spastic Centre. From when a therapist joins me it takes 12 to 18 months before they are both confident and competent to do the job of prescribing complex rehab equipment. That is doing it four days a week for 18 months. My concern about the prescriber guidelines is that if you do five prescriptions you are qualified to prescribe at that level.

The Hon. CHRISTINE ROBERTSON: So you want to participate in the prescriber process. We had another example from Northcott about conflict of interest in relation to prescribing, and I understand that. How can that be addressed in order that your services can be used more appropriately at prescriber level?

Mr KLINE: I am not the only supplier who employs therapists—

The Hon. CHRISTINE ROBERTSON: Not you personally. I am talking about your general group.

Mr SPARKS: That is happening today on a daily basis and again it makes a mockery of one of the comments in the PWC report, which suggested that suppliers should have no role in the selection of equipment. If that happened tomorrow, the errors would compound.

The Hon. CHRISTINE ROBERTSON: There are rules about conflict of interest in the public sector so we have to try to work it through. I am trying to be positive here, not negative. Somehow there has to be some working-through process so that the skill base within the supplier organisations—I am a recipient of the skill base in supplier organisations so I am not bagging it, but I do understand why they have to address issues like conflict of interest. You cannot have the suppliers taking over the program.

Mr SPARKS: Absolutely not.

The Hon. CHRISTINE ROBERTSON: I am trying to look for some help here.

Mr SPARKS: We are helping to suggest appropriate solutions to complex needs. The therapists are the gatekeepers of what we propose.

The Hon. CHRISTINE ROBERTSON: So how do we write that down?

Mr SPARKS: I do not think it is that complex. It is happening every day. We work in concert with general purpose therapists day in, day out providing solutions. Another spin-off of the sort of assessment program we are presenting is you would have guidelines for typical costs associated with equipment. Alarm bells could be rung where a piece of equipment is clearly outside those guidelines. That is not to say you should not get that piece of equipment, but if a typical power chair for little Johnny is $13,000 and all of a sudden we have a quote for $22,000, enable New South Wales and its expert panel can investigate to see whether it is a genuine need or not.

The Hon. CHRISTINE ROBERTSON: Okay. The payment issues are quite relevant of course. Do you perceive that the central payment model will improve that situation?

Mr SPARKS: We hope so. We have been given assurances by Enable New South Wales that it will improve.

The Hon. CHRISTINE ROBERTSON: Have you actually been told there will be sole provider contracts?

Mr SPARKS: At a presentation hosted by Enable New South Wales to suppliers early this year one of the department's procurement experts spoke on this topic. I raised the issue of service levels in rural areas and the damage that could be caused to business. The response was, "There is always some collateral damage when these contracts are let."

The Hon. CHRISTINE ROBERTSON: Being from the country we understand this language.

Mr SPARKS: I found it totally unacceptable.

Mr JENKINSON: The service component is important and has to be delivered at a local level. My experience over 20 years in dealing with these businesses in health care, pharmaceuticals, medical diagnostic equipment and nutrition—the dietitians spoke before about that—and now in this marketplace, is that I can confidently say that of all those marketplaces this one runs on the lowest margins of any of those businesses and the service component is probably higher than any other. To remove that local service—the viability of some of these people is very small, so that has to be considered when we set up these programs.

The Hon. CHRISTINE ROBERTSON: Is there a way when the contracts are being drawn up for the maintenance and repair programs to be structured in?

Mr KLINE: Maintenance, yes. I do not see a problem with a maintenance contract at all. Again, you would have one or two suppliers for Sydney but each regional area would have their own—

The Hon. CHRISTINE ROBERTSON: Contractor for the region.

Mr KLINE: Yes. I would think so.

The Hon. TONY CATANZARITI: Mr Kline, could you give us a brief overview of how you service country areas?

Mr KLINE: From a sales point of view?

The Hon. TONY CATANZARITI: Yes, from both the therapists' point of view and the sales point of view.

Mr KLINE: We employ four occupational therapists and three salespeople. We cover the majority of New South Wales. We go up to Ballina, down to Bega, and to Tamworth, Armidale, Canberra, and Wagga on a three-monthly cycle. Because of the delay in PADP funding it is not critical that we are there next week because they go onto a waiting list anyway. That works well for the people out in the rural areas. There are some local suppliers that people use, but we tend to operate in this high-end, complex area. As I said, the therapists we have on board are highly skilled. We are not the prescribing therapists. We make that quite clear to everyone we deal with. We have therapists but they are in a sales consultant role. They have just got a therapy background for them to help the therapist make the best choice for the client.

The Hon. CHRISTINE ROBERTSON: You want it to stay that way?

Mr KLINE: Yes, I do. I have always felt that therapists belong in this role.

The Hon. TONY CATANZARITI: How closely do you work with the therapists from PADP?

Mr KLINE: Enable has three therapists but we do not have a lot of contact with them at this point. They are more for therapists to go to them—I know rural therapists at the moment are sending scripts to them to go over and check because rural therapists who might do a power chair a year are not going to have the skill level to prescribe a complex piece of equipment and never will have. The fact that Enable has these therapists is a good thing.

The Hon. CHRISTINE ROBERTSON: Specialty therapists.

Mr KLINE: Yes.

Mr SPARKS: PADP is not the major therapeutic body; it is the funding body. The majority of therapists that companies like Greg's will deal with are from DADHC or groups such as the Northcott Society and the Spastic Centre.

The Hon. CHRISTINE ROBERTSON: And the health services.

Mr SPARKS: Yes.

The Hon. GREG DONNELLY: Can I ask a question about other jurisdictions in Australia? What is your knowledge or insight into how they do some of these things that you have raised as your key concerns, and are they better than in New South Wales? Do you have any comments to make about that?

Mr IAN COHEN: Can I just add to that? You raised the issue, Mr Kline, of approval funding. Did Enable New South Wales state anything in relation to the process that is operating in South Australia specifically?

Mr KLINE: I passed on to Enable the names of the two people I spoke to in South Australia who are running the scheme. I do not know what they have done with those details. They have been running quite successfully for the last 18 years on pre-approved funding.

Mr SPARKS: Mr Donnelly, we are doing some work at the moment for the Federal Government to try to put together a picture of the different State schemes, so my knowledge right now is incomplete. One of the things I applaud the New South Wales Government and the Health Department for is the lack of caps. We see in other States caps that frankly are absurdly low. Governments inevitably do not want to index things like income tax rates or entitlements so they set a cap in 1986 because a power chair back then cost $5,700 and, blow me down, in Queensland it is still $5,700 20 years later. That is a major philosophical step that New South Wales is taking and as a person with a disability I applaud that. In administrative efficiencies, we have seen tremendous upheaval in Victoria, where they attempted a central brokerage type, and costs went through the roof. They have now disbanded that and they have embargoed complex rehab technologies, as I mentioned earlier.

CHAIR: Do you have a view about DADHC versus Department of Health? Currently you are under the Department of Health for PADP. Do you think DADHC would manage it better?

Mr SPARKS: I think that is a hard call for industry to make. We deal with budgets. One of our members gets funding through the AIDAS program, which is Aids for Individuals Living in DADHC Accommodation Services, and is administered by DADHC. It is funding for children in group homes. Specifically you have to be within a group home conducted by DADHC, and DADHC contributes to PADP. As a person with a disability I constantly make the case I have a disability, I am not sick. If I am sick I go to the Department of Health. Who would do it better? That is not within my knowledge.

CHAIR: And others would say I do not have a disability, I am sick.

Mr SPARKS: True.

(The witnesses withdrew)

DAVID PETER JACK, Chief Executive Officer, Muscular Dystrophy Association of New South Wales, Locked Bag 1005, Rosebery, sworn and examined:

CHAIR: Would you like to make a brief opening statement?

Mr JACK: Yes. I have a couple of slides, which will guide some of the conversation. Firstly, on behalf of my organisation I welcome the inquiry and express appreciation for the initiative that has been taken. It is perhaps long overdue, and certainly our members have expressed to us significant appreciation for their capacity to find a voice and to have a voice and to be able to express and tell their story. I would also preface the conversation by saying that our recognition is that there are systemic issues and funding issues that have restricted the capacity for PADP to deliver to our clients in the most effective way. Certainly, my comments do not reflect on individuals. We work with many people in PADP who have been extremely helpful and who have probably been as frustrated as we have been over the years.

I would like very briefly to tell one or two stories, if I may, which might frame some of the key issues for our client groups. The first case is a person who applied to PADP for an electric wheelchair. PADP declined the request. A letter of appeal was sent to PADP stating that our organisation, MDANSW, would reconsider if approval were not given following the letter of appeal. Unfortunately our client passed away, aged 56, without ever hearing back from PADP. To the best of our knowledge there was never a response from PADP.

CHAIR: What time frame did that process take? How long was it from when they applied to when they passed away?

Mr JACK: I believe this was eight months.

CHAIR: Was there an explanation as to why they declined?

Mr JACK: At the time I do not believe there was. I think it was just declined. All these cases I will be presenting occurred in the past five-year period. I have been with the organisation for five months, so I cannot necessarily give every detail of every case.

The Hon. MARIE FICARRA: Perhaps for the benefit of people who do not understand muscular dystrophy or the rate at which it can move and be critical; I did my honours on Duchenne muscular dystrophy through Prince of Wales, and I understand it. Maybe others do not.

Mr JACK: I was going to point you to a later slide that gave a little bit of that. Muscular dystrophy is a disease that degenerates the muscles. There are certain forms. Duchenne muscular dystrophy, whereby the average age of diagnosis is three years 10 months; by the age of seven the child, typically boys, will find themselves in a wheelchair and in late teens and early 20s they will probably die. That is the typical cycle for Duchenne muscular dystrophy, which is one of the most prominent forms of muscular dystrophy. There are many other forms, some of which result in our clients requiring various pieces of equipment, including wheelchairs, hoists, et cetera.

So, for some of these people that we are telling the stories of, to wait for 18 months or two years can be a very significant portion of their lives, particularly for a child. The growth between the ages of seven and 12—at which point they need a new chair and are put on a two-year waiting list—puts them in an almost impossible situation from the perspective of quality of life, access and an ability to function as a normal human being. In the second case there was application to PADP for a wheelchair for a 13-year-old. PADP approved it as a low priority. A letter of appeal was sent to PADP. There was no response. A letter of appeal was sent to the health Minister with no response. Ultimately MDANSW fully funded the wheelchair to ensure that our client had a quality of life going forward.

Mr IAN COHEN: Which office or site PADP was that appeal sent to?

Mr JACK: If you are interested in that, I will need to go back and go through the records.

Mr IAN COHEN: Perhaps you can take it on notice.

Mr JACK: I will make a note of that and clarify it. We are building a picture. I have tried to select examples that highlight the different kinds of issues. Certainly that is an appropriate response issue, even a common courtesy issue. In the third case there was an application to PADP for a replacement ventilator. The ventilator was seven years old. It was recommended by the health professional that the individual was working with that there was a requirement for replacement because at some point it would fail. PADP replied that the ventilator must fail before the replacement could be considered. In response to the client's question, what if it failed during the night, the client was told PADP replied go to the hospital like everyone else. Going to a hospital for a person with muscular dystrophy and who is in a wheelchair is extraordinarily difficult. You cannot get the wheelchairs into the ambulance, and the ambulance beds, and so on, are not structured to accommodate a person with muscular dystrophy.

Mr IAN COHEN: Just on that, how close to a life-support system is the ventilator? Is this just to allow sleeping?

Mr JACK: The ventilator will determine a life-and-death scenario in the event power fails.

Mr IAN COHEN: How does one get from home to hospital without a ventilator, or do they have a mobile device?

Mr JACK: There are some mobile devices but we had another client who had a battery backup system, which was supposedly in good working order. The power failed, the backup system failed and the client died. So, it is a critical piece of equipment. Obviously there is difficulty in getting an ambulance. The only other option is to drag your carer out of bed, wherever they may be, and use the vehicle that is available to you. Alternatively, if there is no vehicle, you call a taxi that has the ability to transport a wheelchair. At 3.00 a.m. that might be difficult, and, clearly, the client's life could be at risk. There are another small collection of issues around ventilators, and we would clearly insist at the point where health professionals are recommending a replacement that that be provided and that there be an overlap period, which is one of the real challenges.

The fourth case was an application to PADP for a replacement battery for a wheelchair. The battery was dead. PADP replied that the supplier did not have stock, and the client waited 10 days for a battery. We would not wait 10 minutes for a battery for the car. Keep in mind, this is not their motor car, this is their legs, this is their ability and capacity to access services, to live a quality life and engage in the normal activities of life—to go shopping, to go to work and to receive education. Incidentally a manual wheelchair for this client was not an option unfortunately—again, an inappropriate response restricts mobility access and choice for the client.

My last brief story, PADP approved as a high priority a commode shower chair. There were no PADP funds available after eight months and MDA NSW sent a letter requesting an urgent review, which ultimately resulted in PADP providing the funding. That story is told over and over again by our client groups. To give you an idea, just to now step back and profile. These are the equipment needs typically for a person with a serious form of muscular dystrophy. Clearly a young person who is not going to make it beyond their late teens, early twenties, will not require three or four sets of equipment. I was talking to one family who said goodbye to their 11-year-old. They ran through the costs and not all of the costs have been included in it. There are still vehicle modification costs to buy a suitable vehicle and to put what is required into the vehicle can be a $50,000, $60,000 or $70,000 activity if you have any other children you need to accommodate in the vehicle. You add that on and it becomes exorbitant. Muscular dystrophy goes through every aspect of our community. It is not confined to people who have the financial capacity to deal with these costs.

As a summary, of the 57 requests that came to us during this five year period for equipment funding—remembering not all of our clients come to us; some get funding from PADP, some have their own funds available and do not like to ask and some do fundraising—75 per cent were fully funded by our organisation and PADP contributed nothing. Remember, our assessment requirements or our criteria for funding is the same as PADP. We require an OT assessment. We have the same requirements. We would typically believe that all of those should have been funded by PADP. Twelve per cent of the 75 per cent had PADP approval but the wait time was too long—very significant. Sixteen per cent of the 75 per cent came to us following a clear PADP rejection. Of the 57, 16 per cent waited on PADP for a significant period of time, and I will give you a breakdown of some of those timeframes in a moment, and 21 per cent were share funded by MD NSW and PADP. I can provide a view of the inequitable distribution of funds from case to case which, because our clients get together, they share their experiences. Some come back scratching and say "How come that person had a chair 90 per cent funded by PADP and mine was 7 per cent funded? That does not make sense" which is a fair comment to make.

Then you can see the breakdown of the age groupings and, of course, there is a more significant group in the younger age groups, and as Becker and Duchenne muscular dystrophies claim the lives of our clients it tapers down beyond that. The waiting periods vary—20 months, three months. An extensive wait was what PADP indicated to one client. It could not put a timeframe on it and just said there will be an extensive wait. One client waited 3½ years, at the end of which they were advised it would be another 12 months. We funded that client. Finally it was desperate. In some cases no time frame is given by PADP and we often will step in and fully fund those situations—two years, eight months, at the end of which no funds were provided by PADP. So there was a promise of eight months, we funded that situation. These are taken from real cases and just give you a sample of the spread of waiting period.

I have already provided a background into Duchenne and some of the timing of events in the life of a person with Duchenne muscular dystrophy. This slide really just expands on that and acknowledges that not only the delays create discomfort and inability to access life, but also in some case they result in a dangerous situation. One of the roles that we play in addition to the provision of equipment and support, information and so on is advocacy. I have referred numbers of times to letters written to PADP or indeed to the Health Minister. This gives us a view into how that advocacy has been responded to. It is a little disappointing that of 17 cases where we did provide advocacy 35 per cent resulted in PADP funding which is terrific but when I have looked at letters that have gone in we have not given any new information, all we have done is insist. You step back and wonder why PADP could not have drawn the conclusion first time round? Is it the squeaky wheel? What about people who do not have good strong advocates that can get them the result? Of the 35 per cent, 12.5 per cent ultimately results in the direct Ministerial intervention, which we appreciate and acknowledge. However, it has not been able to address the broad situation?

Mr IAN COHEN: Which Minister?

Mr JACK: It goes across a number of periods.

Reverend the Hon. Dr GORDON MOYES: Disability Services?

CHAIR: Health?

Mr JACK: Health. I thought you wanted the name?

The Hon. CHRISTINE ROBERTSON: No.

Mr JACK: Of the 17 cases, 30 per cent resulted in a PADP rejection and ultimately the clients were fully funded by MDA NSW. Remember, we are a small organisation. Our budget is under $1 million. We have a full spectrum of activities, including research and equipment is a very substantial cost. When you look at some of those costs I put up earlier there is a lot of money involved.

CHAIR: Are you funded through fundraising and bequests? Do you get government funding?

Mr JACK: Yes, we get a very small amount of government funding. We get $84,000 a year for NSW Health to run a Carer Support Program so it is quite restricted to that purpose. It is a terrific program. It is reaping a lot of great results in terms of supporting carers, which is a very important part of this discussion. Outside of that there is a flexi-respite program but, again, those funds go directly to clients. They do not support our organisation but it is does provide flexible respite care. Outside of that we fundraise. So the bulk of our funds are raised funds.

The Hon. MARIE FICARRA: Most fundraising is directed towards research. When you have heart rendering cases and the short life span of mainly young men who come to you, do you direct some of those research funds into providing much-needed equipment?

Mr JACK: There is no doubt at the moment that we need to carefully consider our portfolio of activities, and that has meant recently a scaling back of the research program.

Mr IAN COHEN: With the PADP clinical priorities, is it the banding and failure to ascribe to adequate urgency, or is it inefficiencies within its system? Is it the way it is set up for the problems of your organisation? Is it a breakdown of process?

Mr JACK: I would think that there is breakdown of process. Where there is a lack of funding you cannot use your eligibility criteria as the framework to fund, you have to move beyond that and identify other criteria that will enable you to meet the presenting need that does meet the criteria. In many cases where we have advocated—this is for clients who meet the criteria—that has been fully expressed in the original application but other criteria have had to be used to ensure that PADP can deal with its funding situation. Now the difficulty is that those extra criteria, whatever they are, and it seems it is very ad hoc from our experience, do result in inequitable scenarios. As our clients begin to talk and share their stories back to us you can see that it just does not work. I think PADP has been in an extremely difficult position where it has had to make very difficult decisions about clients, all of whom fit within the criteria but some cannot be funded. I think that is probably a significant thing.

Of course, you have the PADP staff person trying to dialogue with a client, trying to help a client understand why they cannot be funded and you can appreciate that at the point where they acknowledge "You do not meet our criteria" where do you go? What do you say to somebody at the point? It is very easy to get yourself tangled up, and I have become involved in a couple of cases personally since joining the organisation and, clearly, PADP staff members got themselves tangled up because our client met their criteria; they had to argue not to fund the client because there is not the money available, and things start not to add up. It creates confusion and frustration.

The Hon. CHRISTINE ROBERTSON: They are very legitimate issues and have been found in the PriceWaterhouseCoopers review process. Will the proposed changes, albeit their implementation too lengthy, make a difference to the process as far as your organisation is concerned? Are you operating quite well with the local toing and froing.

Mr JACK: It is interesting because one of the things I would suggest and recommend is that organisations such as ours have a key person to whom we can talk who we work with closely within PADP, develop a relationship, but more important than that is let us develop a partnership whereby we acknowledge that organisations such as ours bring something to the table. We are happy to bring some funds to the table. We are happy to bring our expertise but let us work in partnership, but you need a relationship. Let us look at the banking sector. They have moved into the relationship/manager framework—whether it is good, bad or whether it works. I think there is a principle there that we could bring back in. Let us build a stronger relationship. Let us have a key point of contact and let us acknowledge that if we work together we might get better outcomes.

The Hon. CHRISTINE ROBERTSON: You also refer to the future procurement policies. You said that you do not have single suppliers. Will you expand on that?

Mr JACK: Clearly numerous suppliers, for instance, in terms of electric wheelchairs, bring different types and styles of wheelchairs to the table for our clients. They would like to continue to have that choice available to them. If that is centralised and the suppliers still then supply to the middle person who then supplies on, and in relation to the middle person, first, they need to make some money out of the situation and, second, they do not have the expertise across the full range of wheelchairs. Our clients and our staff would like to be able to talk directly with the people who manufacture and have the expertise. I think that is quite a significant issue.

The Hon. TONY CATANZARITI: It surprises me that you do not have a contact person to whom all the organisations contact.

Mr JACK: With changing personnel both in our organisation and within PADP there is not an identified person with whom we can make contact. I have discovered someone who is fantastic. I ring her now on everything. But what if she moves sideways? I have to find another person, create a relationship and test the relationship.

The Hon. CHRISTINE ROBERTSON: So you are saying it has to be a position?

Mr JACK: I believe so.

CHAIR: We heard yesterday from the Motor Neurone Association, which undertakes for its clients similar things to what you are doing. It has a pool of equipment that it seems to be able to manage, track where it is, retrieve it, send it out and get it serviced. I assume you have the same sort of process: you know how much equipment you have out there and you have a capacity to keep track of it, is that right?

Mr JACK: Not exactly. We have gone through a number of different situations in regards to equipment. There was a time when we did purchase and supply on a loan situation, but now we do not. We do not own equipment; we give the equipment. The individual owns the piece of equipment. But whichever way you do it, there are significant issues around repair and maintenance, and who is responsible. One of the reasons we stepped back is that there are all kinds of occupational health and safety issues. Can we sustain the repair and maintenance requirements around a piece of equipment? Can we accept the liability to replace the item of equipment in a timely fashion?

The Hon. CHRISTINE ROBERTSON: The legal liability?

Mr JACK: Yes. So now we give it. But the repair and maintenance issue is significant.

CHAIR: The client then covers those costs or do you assist further?

Mr JACK: We certainly will assist. The first port of call is that we always ask the client to apply to PADP, keep us in the loop. If we can be helpful at any point in time, we are here for that.

CHAIR: But PADP will not service equipment that you have supplied?

Mr JACK: Well, the battery, for instance, for a wheelchair is provided.

The Hon. MARIE FICARRA: What is your budget?

Mr JACK: Under a million dollars. The whole organisation runs on probably $600,000 to $700,000 a year, which employs four staff, our research program et cetera. We are getting serious about repositioning our organisation and looking to grow the organisation. There are significant and substantial needs that we have not been able to meet. So we want to move forward. We would anticipate that possibly as an outcome of this inquiry there will be a little less pressure on some parts of our funding, and clearly where there is no money available we can invest in other areas of the life of our client group.

The Hon. MARIE FICARRA: Have you ever calculated the amount of time you are spending on chasing up all of these applications, assessments and everything that should be happening? How much time do you spend and people who have donated to your organisation to research this horrible disease? How much time are you spending chasing up the Government inefficiencies?

Mr JACK: That is a good question. We have not been tracking it, but keeping it to a personal experience, I have been with the organisation for two weeks. A request came in. It was a challenging situation with PADP funding that was not available. I said to my staff, "Let me handle this one for my own benefit to get an understanding of how this works." I spent days on it. I finally got a great outcome, but I did spend days. The outcome was outside any funding allocation formula that had been used before. It was quite out of the ordinary, but we got a great outcome that worked for the client and worked for us. We put money into it though, a couple of thousand dollars, but it took days. It took a lot of my time. It was worthwhile for the client and it helped me understand, but it took days.

The Hon. CHRISTINE ROBERTSON: It was personal negotiation?

Mr JACK: Yes, talking to individuals and PADP, going back to the OT, trying to seek a reinterpretation of certain documents—backwards and forwards.

The Hon. MARIE FICARRA: Surely your time could have been better spent?

Mr JACK: Of course.

The Hon. MARIE FICARRA: It would have been nicer not to have to do that?

Mr JACK: I did it for a reason as chief executive officer to gain an understanding, but I do not want my staff spending that much time. There are other things that we should be doing.

CHAIR: I am sorry that we have interrupted you all the way through. Thank you so much for your presentation. You have provided useful information for our inquiry.

Mr JACK: There is other information, and there are lists of concerns. We did come with some ideas. We are not here simply to say it is all bad. There are some things that could be done that we think would be extremely valuable. I think one of the key questions is the rights and responsibilities. Do our clients have a right to certain things and does PADP have a clearly defined responsibility regardless of issues such as funding? How do those two elements kind of play out in the life of our clients who, at times, believe they do not have a right and someone does not have a responsibility? Together we need to care for these people. Thank you, I really appreciate the time and opportunity.

CHAIR: Thank you. Your recommendations are very useful. Your summary, which we did not quite reach today, we have in hard copy and certainly will incorporate those recommendations as we move forward. The secretariat staff may contact you for clarification on any point. Hopefully your recommendations will help your clients once we put pressure on the various funding organisations.

Mr JACK: Thank you. I really appreciate it.

(The witness withdrew)

(Luncheon adjournment)

JAMES STEPHEN MacWHINNIE, Senior Seating Technician, PADP Seating Clinic, Bathurst Base Hospital,

MELANIE TERESE TOBIN, Manager, PADP and PADP Seating Clinic, Bathurst Base Hospital, and

CATHERINE NOWLAN, Operations Manager, Eastern Cluster, Greater Western Area Health Service, Orange Base Hospital, affirmed and examined:

CHAIR: If any or all of you would like to make a brief opening statement you are welcome to do so, otherwise we will go straight to questions. As I understand it, we did not receive a submission from you, so you might want to give us a bit of background.

Ms TOBIN: I have an opening statement. Thank you for the opportunity to appear today. I have an information package for each Committee member, which I will hand out. Honourable members of the Committee, the Program of Appliances for Disabled People [PADP] was introduced by the Federal Government as an initiative during the International Year of the Disabled in 1981 to support the chronically disabled. The role of the PADP is to assist eligible residents of New South Wales, who have a permanent or long-term disability, to live and participate within their community by providing appropriate equipment, aids and appliances.

There are three PADP lodgement centres within the Greater Western Area Health Service. They are located at Bathurst, Dubbo and Broken Hill. The Bathurst Lodgement Centre, which includes the PADP Seating Clinic, is currently located in the old Macquarie Care Hall, Gorman's Hill Road, Bathurst, and services the geographical area of the former Mid Western Area Health Service. The seating clinic began operation in 1986 following the increase in demand of specialised seating services in the Central West. The service of Jim MacWhinnie was utilised from the Bathurst District Hospital maintenance department to repair and fit matrix seating systems for PADP clients and for the maintenance of all equipment in the PADP loan pool. The cost of his services was wholly absorbed by the maintenance department of Bathurst hospital.

In September 1985 the Department of Health, Central West Region, agreed to fund six eight-hour seating and maintenance sessions per annum from PADP funds. In 1986 demand increased further and Jim MacWhinnie was appointed full time to PADP. Funding for this position was made available from PADP commencing in the 1987-88 financial year. An occupational therapist was also employed by PADP 15 hours a week for the prescription of wheelchairs and seating systems. This was the beginning of the full-time clinic at Bathurst. The clinic was initially set up for 40 ongoing clients and other one-off seating appointments. The clinic was, and is, the only public health clinic of its kind west of the Blue Mountains, accepting referrals from community occupational therapists, clients and their families, as well as referrals from the Spastic Centre and the Northcott Society.

Today the seating clinic services approximately 220 ongoing clients. Fifteen of those clients have been serviced by the seating clinic since it began in 1985. The increase in clients was due to a change in PADP policy in 2001, giving universal access to all children under the age of 16. Prior to 2001 parents were subject to a means test. As per policy, the seating clinic endeavours to prescribe the most economical option to meet the client's clinical needs, using both off-the-shelf seating systems and custom-made seating moulds where no off-the-shelf alternative is available to meet the client's individual needs. These seating moulds are used for clients with profound fixed deformities. You will find photographs of them in your information packages.

Unlike other seating clinics in New South Wales, the Bathurst clinic provides for PADP eligible clients with every form and degree of disability from paediatric to geriatric. The clinic has offered a continuity of service and is currently staffed by one full-time seating technician and two occupational therapists sharing 30 hours a week. The current seating technician has worked for 23 years in the clinic and one of the occupational therapists has worked at the clinic since 1995. The seating clinic provides assessment and fabrication of both off-the-shelf and custom-made seating requirements; prescription of mobility and seating equipment, such as manual and power wheelchairs, commodes and strollers; modification of appropriate equipment to meet the client's daily functions and complex needs; pressure mapping for people experiencing skin breakdowns and pressure issues; maintenance services for mobility and seating equipment; an open door policy to allow emergency breakdown repairs; and servicing and assessment of clients in their homes within the region where the client is unable to attend the clinic.

The seating clinic is also available for telephone advice relating to seating and equipment issues for regional therapists and their parents or carers. We are extremely dedicated to our clients and we are passionate about the services that we provide. There is an element of uncertainty about the ongoing funding for this service following the centralisation of PADP lodgement centres to Sydney. The impact on our clients and the consequences to their lifestyle is uncertain. These people are already severely disadvantaged. I ask you to consider carefully any action that will further add to their disabilities.

CHAIR: When you said that you had some concerns about centralisation, are you more concerned about the back office component of being centralised? What are your concerns about that issue?

Ms TOBIN: We are concerned about the ongoing funding of the seating clinic.

Mr IAN COHEN: Clause 19.5 of the PADP policy directive requires that prior to approval high-cost items over $800 be considered by a local advisory committee. I refer to finding 2.3 in the Oakton audit about this lodgement centre, which states that the acting manager was approving, as I understand it, items up to $3,000. Can you explain that divergence from PADP policy?

Ms TOBIN: We present all applications over $800 to the high-cost allocations committee.

Mr IAN COHEN: Was everything referred to that committee?

Ms TOBIN: No.

Mr IAN COHEN: I understand from the report to which I referred that items up to $3,000 were not referred.

Ms NOWLAN: Not in the time that we have managed the service. We have a committee and—

Mr IAN COHEN: How long has the committee been in place for that service?

Mr MacWHINNIE: Since the beginning of the PADP. We were one of the first clinics to introduce it as a full-time means of providing members of the community with a say on what was happening.

Mr IAN COHEN: Who are the members of that committee?

Mr MacWHINNIE: At the moment we have a local social worker, the head of the occupational therapy department from Bathurst Base Hospital, and aged care.

Ms TOBIN: Catherine Nowlan and I are also members.

Mr IAN COHEN: Are any user groups represented?

Mr MacWHINNIE: Over the years they have been.

Mr IAN COHEN: When you say "over the years" how long has that committee been in place?

Mr MacWHINNIE: From the beginning.

Mr IAN COHEN: What year?

Mr MacWHINNIE: From 1985.

Mr IAN COHEN: Finding 2.4 of the Oakton audit of Bathurst lodgement centres states:

> Bathurst does not have a consumer client representative on the advisory committee.

During this period did any clients approach the PADP and nominate themselves for this position?

Ms TOBIN: Not that we are aware of.

Mr IAN COHEN: No-one approached you?

Mr MacWHINNIE: Recently, no.

Mr IAN COHEN: At any time?

Mr MacWHINNIE: We have had a representative from the community, but not in recent years. We have not been contacted.

Mr IAN COHEN: Who was that representative?

Mr MacWHINNIE: There have been a number of people. At one stage the committee did not want to have the same person year after year. We had a number of different people who represented the aged. We have had power wheelchair users, manual wheelchair users, a carer, and a parent from the seating clinic. A number of people were involved in it.

Mr IAN COHEN: Would you take that question on notice and provide the Committee with a list of the people who were on that committee over that period?

Mr MacWHINNIE: Yes.

Mr IAN COHEN: At that time did any clients approach the PADP and nominate themselves for the position?

Mr MacWHINNIE: No, not to my knowledge.

Mr IAN COHEN: In relation to finding 2.5 of the audit report, why is it that no formal letter is sent to clients updating them on progress on the waiting list for enhancement funding?

Ms TOBIN: That may have been in the past, but we have endeavoured since my time to inform all clients of their applications going to the committee and after the committee straightaway, an update if they are on the waiting list or they are to be ordered straight away.

Mr IAN COHEN: When would that process have commenced? It was highlighted in this audit report.

Ms TOBIN: Is this the audit that covers 2006-07?

Mr IAN COHEN: Yes, 2006-07.

Ms TOBIN: I began in this position in February 2006 and it was not long after that that the audit was done, but I can assure you that I do send out letters to all clients.

Mr IAN COHEN: Could you give the Committee an indication of how often you do that? Is there a set period of time in which you inform clients who are on waiting lists as to where things are at? Is it a regular process?

Ms TOBIN: We have a meeting every month, on the third Thursday of every month. As soon as an application over $800 is received a letter goes to the client to say that their application is being presented to the committee and within a week post the meeting they are informed of the decision.

Mr IAN COHEN: So you actually send a formal letter?

Ms TOBIN: Yes, I do.

Mr IAN COHEN: According to this report no formal letters had been sent.

Ms NOWLAN: And that is obviously true at the time of that report, but, since Melanie has managed the service, that has been rectified.

Mr IAN COHEN: Does Bathurst Lodgement Centre make purchases from suppliers that are not on the approved supplier list, or has it done so historically?

Ms TOBIN: As far as I am aware, there is no list. I contacted Enable NSW and there is not an actual list of suppliers.

Mr IAN COHEN: No list of approved suppliers?

Ms TOBIN: Yes.

Mr IAN COHEN: So it is up to you to choose suppliers?

Ms TOBIN: We actually receive quotes from therapists and we choose the most economical. For applications over $800 we ask for a minimum of two quotes.

Mr IAN COHEN: So you always get a minimum of two quotes?

Ms TOBIN: If they are over $3,000 we ask for three quotes. They have to be comparable quotes and all have to meet the client's clinical need, and PADP policy is to provide the most economical item to meet the client's needs, so we will choose the most economical.

Mr IAN COHEN: Mr MacWhinnie, as a result of those quotes you are working on seating for particular wheelchairs, for example?

Mr MacWHINNIE: Yes.

Mr IAN COHEN: Could you indicate to the Committee generally, in the last five years, what brand of wheelchair you have recommended for purchase through this process?

Mr MacWHINNIE: Just a quick jump back in relation to if it is on the list or not on the list, depending on the individual, a piece of equipment may have to be purchased and there may only be one company that sells that piece of equipment.

Mr IAN COHEN: If that is the case, that is quite acceptable. Do you have a preferred company?

Mr MacWHINNIE: No, I have preferred suppliers, and they are suppliers who will come to the country because there seems to be a sandstone wall when you get to the Blue Mountains.

Mr IAN COHEN: So who do you have that comes to the country?

Mr MacWHINNIE: GTK, Specialised Wheelchair Company, AMS, Able Rehab, Lifehealthcare.

Mr IAN COHEN: Who produces the Glide wheelchair?

Mr MacWHINNIE: Who produces it?

Mr IAN COHEN: Glide is supplied by which company?

Mr MacWHINNIE: Two companies, Specialised and AMS.

Mr IAN COHEN: Have Glide wheelchairs been the major—

Mr MacWHINNIE: It has been one of the major ones. It meets our price, it meets our quality and it meets the fact that we have clients in isolated areas and enables me to have stock in place, so that if there is a breakdown, breakdowns can be minimised and these people can be put back on the road.

Mr IAN COHEN: So you go with Glide because you have the backup?

Mr MacWHINNIE: And with Roller Chair.

Mr IAN COHEN: Roller Chair is not operating any more, is it?

Mr MacWHINNIE: Roller is not, but we still have a lot of them out there and they have only recently stopped manufacturing under that name. We still deal with Quickie, we still deal with some of the Invacare brands, so we have a lot of chairs that are prescribed in Sydney and sent to the country and therefore we have to deal with any issues.

The Hon. MARIE FICARRA: It seems that the seating clinic is doing a unique thing in western New South Wales. What is the catchment area that you service?

Mr MacWHINNIE: There is a map in the folder that you have. It is the old area health service region.

Ms TOBIN: Mid Western area health service.

The Hon. MARIE FICARRA: The service you provide is fantastic, but what happens to people in other rural and remote areas?

Ms TOBIN: If I can just refer to my notes, in Broken Hill they only have a handful of clients that require specialised seating services. They have Novita travelling from South Australia every three months. Novita is part of the Northcott Society. I spoke to Broken Hill yesterday and unfortunately with these clients, if nothing can be done at that time, they have to wait three months until Novita visit again or they have to travel 500 kilometres to the Hampstead rehabilitation centre in Adelaide or 800 kilometres to the Frederick centre in Melbourne. The reason why we do not service the Broken Hill area is that there is a distance of nearly 1,000 kilometres between Bathurst and Broken Hill. In Dubbo they are serviced by the Spastic Centre—mainly children with cerebral palsy. They have the Northcott Society, which comes every eight weeks, and they also have Assistive Technology visit every three months. They have 60 to 70 clients with specialised seating needs.

The Hon. MARIE FICARRA: I know it is very expensive to service these outer areas. Is there a way that we could do better than waiting one to three months for a repeat visit? In your experience west of the Blue Mountains, is there any way that we could do better utilising services of New South Wales Health in these areas—combined services?

Mr MacWHINNIE: Well, combined services. All we can base this on is what we have done in Bathurst. We have a very large region. If I drive to see a client at the edge of our region it gives me a very small amount of time to do what I have to do. We are on the edge of a very large region, but the one thing we have shown is to be able to centre a clinic without having to have a million people working for it—small, dedicated, to the point, utilising private industry for the purchase of equipment—and then to be able to customise it and individualise it to the person in their home or in the clinic, and then the continual follow-on. I think it is a bloody good model and should be looked at.

The Hon. MARIE FICARRA: Your model would be able to be set up in three, four or five regional areas to do what you are currently doing?

Mr MacWHINNIE: Yes.

The Hon. MARIE FICARRA: Otherwise what do people have to do? Do they have to fly to Sydney or Melbourne?

Mr MacWHINNIE: They deform.

Ms NOWLAN: Actually they receive services. As we have said, we rang Broken Hill and that is how they get their service.

The Hon. MARIE FICARRA: It is a long time to wait.

Ms TOBIN: It is a long wait.

The Hon. MARIE FICARRA: Mr MacWhinnie, did you say they deform?

Mr MacWHINNIE: Well, unless it is done and it is covered, and as far as we understand it is being done to the best of the ability of the services that are doing it, but I have been in this for a long time. We see people and, as stated in our opening statement, we are still seeing people that we saw in the first year of our starting, so we have people turning 21 and 23 and we are still seeing the same clients. When you take on a client it is not a one-off, you do not just build a wheelchair and say, "Right, next one in". They continue. There are people in regional areas where the service I feel could be better enhanced with a quicker follow-up.

The Hon. MARIE FICARRA: With the centralisation that is being proposed, we get the impression that administration will be done centrally, but services will be still delivered on a regional or rural basis. Is that your understanding or have you not had too much information as to how it is going to be rolled out?

Ms TOBIN: We have not been given much information. We are uncertain of the continuing funding for the seating clinic.

Ms NOWLAN: We are very clear about the lodgement centres and we actually support the lodgement centre centralisation. We think there are efficiencies that can be made with centralisation of lodgement and back-end administration services. I think that Mel's point was that we are uncertain about the PADP seating clinic having information in relation to funding. It is funded under PADP. The letters go back to 1985, and we have managed to source those for you, which evidence that we have a funding body and we are unsure about what happens.

CHAIR: We will attempt to clarify that on your behalf when we have an opportunity.

The Hon. MARIE FICARRA: Other than the seating clinic and the resources and staff needed to run the seating clinic, what resources and staffing do you have for a local lodgement centre? I am trying to get an idea of what you currently have in Bathurst to serve that region.

Ms TOBIN: Apart from the seating clinic there is myself and two part-time PADP clerks, and we have a maintenance man 16 hours a week.

The Hon. MARIE FICARRA: If you wanted to maintain the clinic, what would be required, other than there being Mr MacWhinnie? Who else would be required to maintain that clinic?

Ms TOBIN: I think an occupational therapist, which is essential for the prescription of the wheelchairs and the seating systems; administration services.

The Hon. CHRISTINE ROBERTSON: All on this Committee understand the incredible importance of seating, especially long-term, for many persons in New South Wales. The funding for the seating clinic that you operate comes from your general PADP budget?

Mr MacWHINNIE: Yes.

The Hon. CHRISTINE ROBERTSON: So you set up a specialty service within your PADP processes?

Mr MacWHINNIE: Yes.

The Hon. CHRISTINE ROBERTSON: How are you managing to deliver the broad range of demands on services on PADP that actually occur as well as seating issues?

Mr MacWHINNIE: I think the comment that we are passionate and dedicated to what we are doing.

The Hon. CHRISTINE ROBERTSON: I am not questioning your work.

Ms TOBIN: The administration just has one office, they are located in one office, so all the resources are shared. There are no overheads that are duplicated. There is one photocopier and one fax. These people are all located in one office and at the bottom of the stairs they have all their equipment, so there is no duplication of those resources.

The Hon. CHRISTINE ROBERTSON: I assume that because you have set up a specialty seating clinic, within your geographic area you have excellent seating service provision, so that is on the table and not being questioned by any of the Committee. We understand that the PADP project has had great difficulty with funding for a very long period of time. How has your area health service provided generalist PADP services within the budget when you are operating a specialty service within your budget?

Mr MacWHINNIE: In a lot of cases you look at the client. Our guidelines are to supply the most cost-effective, clinically appropriate piece of equipment. At any given time that we look at a client I can have a piece of equipment, for instance, that cost $1,000 and I can give you another piece of equipment that is exactly the same clinical piece of gear and it costs $10,000. So it is a matter of being able to say $10,000 or $1,000, they do the same, they are both quality products and they both clinically do what you want—we go with that one.

The Hon. CHRISTINE ROBERTSON: So you are managing your seating facility in a frugal fashion?

Mr MacWHINNIE: Yes.

Mr McWHINNIE: We look at it from every individual point of view.

The Hon. CHRISTINE ROBERTSON: You are operating as a prescriber and a clinician, are you not?

Mr McWHINNIE: I am a fitter and turner. I am a seating technician but I work with a team in conjunction with an occupational therapist.

The Hon. CHRISTINE ROBERTSON: So the OT is still the prescriber.

Ms NOWLAN: Absolutely.

Ms TOBIN: That is right.

Mr McWHINNIE: Yes.

Ms TOBIN: Any equipment, aids or appliances that are required for seating clinic clients are applied for through the PADP scheme, the same way that an outside community, occupational therapist, the Spastic Centre or the Northcott society apply to PADP for funding. All applications are sent to the committee for prioritisation, waiting list.

The Hon. CHRISTINE ROBERTSON: So you are saying your processes are still exactly the same.

Ms TOBIN: Yes, the processes are exactly the same.

The Hon. CHRISTINE ROBERTSON: So centralising the lodgement service, you are actually supplying an on-hand service in the field. That is not part of the lodgement service. You are concerned that centralising the lodgement service will disrupt the service to the people you serve. That is what you are saying?

Mr McWHINNIE: Regional, isolated people. Nothing has changed from the reason why this was set up.

The Hon. CHRISTINE ROBERTSON: How will it disrupt your job?

Ms NOWLAN: We are aware of the lodgement centre centralisation and we are not overly concerned about it. Obviously there are sufficiencies. We have been fully informed about that from Enable support services. What we have expressed concern about is the PADP clinic ongoing.

The Hon. CHRISTINE ROBERTSON: The seating clinic.

Ms NOWLAN: Yes, the PADP seating clinic ongoing.

The Hon. CHRISTINE ROBERTSON: A speciality clinic, so it is a different sort of issue to the whole bolus.

Ms NOWLAN: That is exactly right.

The Hon. GREG DONNELLY: What about other parts of the State in terms of how they deal with these specialist seating needs for people with disabilities? How does it work in other area health service jurisdictions?

Ms TOBIN: Within our Greater Western Area Health Service?

The Hon. GREG DONNELLY: We are talking about a specific service provided, and you have taken us through that. Just for the Committee's information, elsewhere in the State do they have a particular service like you operate, dealing with clients who have disabilities that require this sort of service?

Mr McWHINNIE: To our knowledge, there was one started up in Wollongong, which was based on our model. It was hoping to set up but the support fell through for whatever reasons. In the Hunter region and other regions, they use—for instance, the Northcott has a service that can be utilised. The Spastic Centre—there is a whole stack of companies in Sydney that service that particular style of seating, because it is a very specialised sort. We may have showed you in the thing that there are two different sorts; there is your plainer system and then there is a contour system. Contour systems are easier to supply. It is only when you get into the contour systems that it becomes incredibly expensive and the follow-up is more. But there are companies doing it. It is the tyranny of distance for the country, people living in our areas. We are still the only clinic up here. Nobody else has set up. I think it has to say something. I wish somebody had set up, but nobody else has set up in the country to do this on a full-time basis.

The Hon. GREG DONNELLY: Are you the only clinic of your sort in the State?

Mr McWHINNIE: Yes.

Reverend the Hon. Dr GORDON MOYES: I commend the seating clinic. I think it is absolutely marvellous. I do have a question about moulded seating for sleep time, having had a young brother who was put into a wooden frame every night and hung on the wall with only a sheepskin to help him—

Mr McWHINNIE: We do that.

Reverend the Hon. Dr GORDON MOYES: I just wonder whether you did moulded night time products.

Mr McWHINNIE: Yes. Based on our moulding that we do especially for people with profound deformities, we have found that that same mould then can be used, with a few modifications, as a sleep mould. We have been able to increase their endurance and durability for during the day, so we get happier people.

Ms NOWLAN: In relation to the questioning by the Hon. Christine Robertson about funding, in the letters you have been provided it shows that there was funding sent across. We are not taking out of. So the seating clinic was seen to be as part of our PADP budget.

The Hon. CHRISTINE ROBERTSON: As you reported it, or you were given extra in your PADP RDF specifically for your seating clinic? Thank you, that is my question.

Mr IAN COHEN: Mr McWhinnie, I take it that you have been doing this for quite a long time.

Mr McWHINNIE: Yes I have.

Mr IAN COHEN: And you have been pretty innovative in your processes. It must be pretty frustrating sometimes to deal with red tape while you are trying to forge ahead?

Mr McWHINNIE: They do this. They leave me to do what I want to do where needed.

Mr IAN COHEN: If you have that independence, what do you draw from the conclusion from the PWC report recommended 16, which states, "The role and function of the Bathurst seating clinic should be reviewed by a competent professional or team who are able to form a judgement as to the appropriateness and safety of the continued practice of this clinic in undertaking its own modification and construction of mobility equipment."? Is this just out-of-touch bureaucracy or something dealing with the situation?

Mr McWHINNIE: Your words say it all.

Mr IAN COHEN: It points towards potential safety features and things like that, so that is a real concern.

Mr McWHINNIE: It was old information. Whoever and whatever it was based on, it was based on old information. When it was brought to our attention that the TGA we ceased; we used to construct our own sports-type wheelchairs and manual wheelchairs for clients who needed something customised. It was brought to our attention that this no longer could happen and we ceased doing it and have not done it since 2000.

Mr IAN COHEN: As a public service, is the seating service open to all people with a disability or are there restrictions on this?

Mr McWHINNIE: They have to be eligible for PADP.

Mr IAN COHEN: So it has to be through PADP. Is there are situation that you can recall at all where major items have had only one quote?

Ms TOBIN: No. We always ask for two or more quotes. In my time, in the last 2½ years, I always ask for two or more quotes. Previous to my time that may have been true. Just going back to the safety of items with the seating clinic, I just want to say that from the information gathered by the panel, there are no current regulations as to the custom-made seating devices and if required to in the future the seating clinic staff are prepared to comply and seek registration with the TGA.

Mr IAN COHEN: I would like to clarify one point regarding local PADP committees. I understand that consumers do not nominate and generally the area health service is meant to have a consumer representative and the area health service should seek or advertise for the position. So it is actually your responsibility to make sure that there is a consumer representative?

Ms NOWLAN: I will make sure there is a consumer representative.

Mr IAN COHEN: Has there been? What is the situation?

Mr McWHINNIE: In the past there has been, over the past two years.

Mr IAN COHEN: How long is it since there has been a consumer representative?

Mr McWHINNIE: I think two years. It is only a recollection but it would be two years. Up until then we always had a representative.

CHAIR: Ms Nowlan, you will undertake to have a look at that situation?

Ms NOWLAN: Absolutely.

(The witnesses withdrew)

LUISA FERONATO, National Program Manager, Equipment Solutions, Vision Australia, PO Box 176, Burwood, and

SUSAN ELIZABETH CRANE, Administration and Research Officer, Policy and Advocacy, Vision Australia, PO Box 176, Burwood, sworn and examined:

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

Ms CRANE: I am representing Vision Australia and also the clients who are blind or have low vision.

CHAIR: Do you have a brief opening statement?

Ms CRANE: Vision Australia appreciates the opportunity not only to appear before the Committee but also to make our views known about the PADP on behalf of our clients who are blind or have low vision. Vision Australia was created in the last few years through the merger of some of Australia's oldest and most respected blindness organisations, including the Royal Blind Society of New South Wales. We work in partnership with our clients to remove barriers to access and participation in the community for people who are blind or have low vision. We are a national organisation. It is important to note that it has only been recently, since 2004, that equipment relevant to people who are blind or have low vision has been funded by PADP. This was only after extensive advocacy by Vision Australia.

To comment directly on the terms of reference of the inquiry, firstly, the funding is not adequate. That is clear by the length of the waiting lists. Without accurate statistics on the use of the program being available, it is difficult to make predictions as to future funding needs. However, it is clear that the need for equipment, and therefore funding, will not decrease, particularly as we are an ageing population. We recommend that the collection of statistics and making this data available is a priority that comes out of this review. Secondly the impact of client waiting lists. Vision Australia strongly believes that the excessive length of waiting lists needs to be addressed by this inquiry. The impact of these waiting lists on individuals cannot be underestimated.

Our community is very much set up for people who are sighted. Much of the equipment for people who are blind or have low vision is for accessing information. Without this, a person who is blind or has low vision is inhibited from accessing and participating in the community. This is likely to lead to further social isolation as it also limits prospects of future potential employment. The knowledge and use of equipment and technology can contribute to the achievement of employment goals. That is vital when you consider that almost 70 per cent of people of working age who are blind or have low vision are currently unemployed.

Reverend the Hon. Dr GORDON MOYES: What was that percentage?

Ms CRANE: Almost 70 per cent. We consider it unreasonable that once equipment is identified that will aid a person's participation in the community that person is expected to wait sometimes up to two years for that equipment. The other issue with such a long waiting time is that with technology advancing so quickly, by the time the application is approved the equipment requested could well be superseded by a technology that better suits the person's needs.

Thirdly, the effects of centralising PADP lodgement centres: The complexity of the program should be improved by centralising PADP centres. It is currently difficult even to find out basic information about the program. It is a complex process and people have to jump through hoops to get their needs met. It is currently pretty much impossible for a person who is blind or has low vision to access the program independently as the information and the application forms are not accessible. In the past there has also been a lack of consistency and transparency in how the program is administered. Centralising PADP centres should lead to improved consistency and prioritisation and also PADP staff knowledge of equipment and its application in everyday life. Vision Australia recognises that Enable New South Wales is starting to make positive changes in how the program is administered and this includes the introduction of the centralised 1800 number.

Finally, eligibility requirements: PADP staff should be made better aware of equipment and technology relevant to people who are blind or have low vision and how it affects their lives. Lack of knowledge often sets up barriers in the first instance. Even before the client gets to the application stage they have often been deterred by PADP staff. These are just some of the priorities for our clients who are blind or have low vision that we would like the Committee to consider in the inquiry.

Ms FERRONATO: Just to add to Sue's statement, Vision Australia wanted to emphasise how important this is because in addition to providing living skills and training services we also provide an equipment solutions service, which is one of our core services. This is because the equipment and technology is an essential part of enabling independence and community participation for people who are blind or have low vision. That is why we provide an equipment service and assist people with their PADP applications. We want to see this inquiry result in positive change to the program.

CHAIR: So do we. Were you consulted as an organisation about the PWC review?

Ms FERRONATO: We were involved. I was a member of the PADP advisory committee during the PWC review so where the advisory committee was consulted we were involved in that aspect of the review.

CHAIR: Have you been consulted by Enable New South Wales about its establishment of centralisation so that it is user-friendly for people with vision impairment and the forms etc are able to be accessed by people with visual impairment?

Ms FERRONATO: We have certainly raised the issue with Enable New South Wales and they do recognise that the application process needs to be made more accessible, and that input was given to them by the PADP advisory committee process.

CHAIR: I have two questions about the statistical information. The equipment that your clients use is highly technical and no doubt expensive. Do you have doubts that there is the capacity within the PADP system at the moment to understand the equipment available and the necessity for it? Is that what you are saying? Is that not reflected also in the priorities?

Ms FERRONATO: The nature of the equipment and technology is not always complex. It is often seen as complex because of the small population size in the disability population. People who are blind or have low vision are not necessarily a large proportion of people in the disability community. I think there is capacity within the program for the staff to build their knowledge around understanding the nature of this equipment and technology and how it can contribute to people's lives. Vision Australia is certainly interested in contributing to that. What was the latter part of the question?

CHAIR: Data collection and that sort of thing. It sounds like you have more capacity to collect data and have that available. My understanding is the department does not seem to have that data at its fingertips. You seem to have much more ability to present that. I guess one of your strong issues is that there be a greater focus on data collection and statistical information.

Ms FERRONATO: Yes, definitely. As a result of our being a merged organisation we are implementing a new client data management system that will capture some of this information that will be relevant to PADP. It is important to keep in mind that Vision Australia is just one organisation that offers services to people who are blind or have low vision. There are other organisations out there that provide low vision blindness services. Certainly we have a vast range of experience and knowledge in the area, but we are not the only ones.

CHAIR: A number of people have suggested to us that the co-contribution ought to be dropped because of the administrative costs not really making it a financially viable system. What is your view on that?

Ms FERRONATO: We would agree with those views presented.

The Hon. MARIE FICARRA: How many blind or visually impaired persons would there be in New South Wales? Do you have data on that?

Ms FERRONATO: It is very difficult to get accurate information on the demographic and population data primarily because the census data calls it "sensory impairment", which includes hearing impairment. Estimates are around 300,000 Australians. We can find that out.

The Hon. MARIE FICARRA: Someone should know, should they not? We should have these sorts of statistics. Would they be accessing Medicare or health services? I am just wondering where we could get that accurate data. There are other organisations that cater for this client base as well. Are there many organisations?

Ms FERRONATO: Not many. Probably the next largest would be the Guide Dog Association. There are also various low vision clinic services that operate through different health services and other organisations.

The Hon. MARIE FICARRA: Do you cooperate in lobbying, communicating or information exchange with these organisations?

Ms FERRONATO: Yes, we work collaboratively and in partnership with these organisations and services.

The Hon. MARIE FICARRA: We have been informed by Enable New South Wales and New South Wales Health that the additional funding of the reform measures probably will not be implemented until 2010. Do you have any opinion on that time frame, seeing as the review took so long—2007 to 2010?

Ms FERRONATO: It adds to our frustration and will add to our clients' frustration.

The Hon. MARIE FICARRA: Have you been informed of any process that you would be invited to participate in in the rollout of this system?

Ms FERRONATO: We have been invited to apply to their newly established committee.

The Hon. MARIE FICARRA: You talk about lack of transparency in the eligibility criteria. Can you elaborate in terms of your client base? How does that lack of transparency affect you?

Ms FERRONATO: It is the lack of knowing the status of a person's application so they are not informed about where it is at in the process. A lot of the equipment is over the $800 mark that identifies it as high cost and therefore means that it has to go through the advisory committee process to determine approval and priority, so not a lot of information is given to clients about the status of their application within that process. Even once their application has been approved and they are placed on a waiting list clients are rarely given an indication of how long before the funding will be available to provide the equipment.

Reverend the Hon. Dr GORDON MOYES: I want to raise a couple of issues. I was quite concerned to read a couple of things in your report. Allowing that PADP is a specialised service for disabled people I was surprised to read that it is difficult for people with low vision or no vision to access information about them. It is not easy to contact the office and staff do not seem to be aware of means of communication for people who have low vision or no vision. Clients have stated that the required forms cannot be completed independently if they are blind or have low vision and yet they are given no assistance in completing those forms by PADP office staff. This seems to me to be absolutely a contradiction in terms for people who are working in a specialised disability office. Do you have a reflection on the training of staff?

Ms FERRONATO: Yes, I think it is an awareness issue in training—

Reverend the Hon. Dr GORDON MOYES: It is not just awareness, it is a lack of training. Do they have TTYS or forms of contacting people by Teletext or anything like that?

Ms FERRONATO: PADP? I doubt it very much.

Reverend the Hon. Dr GORDON MOYES: You would think this would be fairly basic, would you not?

Ms FERRONATO: Since the establishment of the 1800 number it has been easier for clients to get direct information and consistent information. However—

Reverend the Hon. Dr GORDON MOYES: As a rule, is this followed up by any other material being sent to them?

Ms FERRONATO: No. It is not available in alternate formats such as Braille or even electronically online. Application forms are still very much based—varied depending on where the lodgement centre is.

Reverend the Hon. Dr GORDON MOYES: This is not directly your field but if they do not have the awareness and training for visually impaired people would hearing impaired people have the same kind of experience?

Ms FERRONATO: I am not sure.

Reverend the Hon. Dr GORDON MOYES: That is where the telephone and the 1800 number may be of no use whatever.

Ms FERRONATO: I think they have the TTY number, but you would have to check with them.

Mr IAN COHEN: Are there instances in the vision-impaired area where the technology is superseded before the client receives the equipment? Is this an issue?

Ms FERRONATO: Yes.

Mr IAN COHEN: Could you perhaps elaborate on that? Is it a frequent situation? Is it the nature of the industry or are we dealing with inappropriate waiting periods that create the problem?

Ms FERRONATO: It depends on the category of equipment and technology. Certainly computer access and technology that enables computer access are changing more quickly than some of the hardware-type devices that are available, so in that area of the industry there are quite rapid developments in the technology. Often they can be in favour of PADP when the technology becomes less expensive and still maintains the same functionality. If you are waiting 12 to 24 months for developments, technology can certainly change and products can be obsolete that were originally applied for.

Reverend the Hon. Dr GORDON MOYES: No support, for example, for GPS on mobile phones, or linked as there are some linked with glasses and things like that? Nothing of that kind?

Ms FERRONATO: Nothing of that—sorry?

Reverend the Hon. Dr GORDON MOYES: GPS kind?

Ms FERRONATO: Yes, that also is a rapidly developing area, and mobile phone access.

Reverend the Hon. Dr GORDON MOYES: My car drives itself home but if I were blind I would not get any help to get home?

Ms FERRONATO: Yes, and I guess that is one of the areas we also wanted to bring to your attention, that there are other technologies that may slip under the radar of PADP because there is this heavy focus on physical disability. With sensory disability, particularly blindness and low vision, access to information and communication aspects of our everyday life is difficult. There are other solutions, technological or equipment-based solutions, that PADP may not be aware of or consider because it is a bit left of field. The area of mobility is an example of that. There are aids to mobility that PADP may not feel that it is an area—

Reverend the Hon. Dr GORDON MOYES: I will ask them about white canes.

Ms FERRONATO: White canes and seeing-eye dogs, as well as GPS and the emerging technologies. They are devices.

The Hon. CHRISTINE ROBERTSON: You and the Northcott Society have both brought up this issue in relation to communication devices and their lack of priority. Theirs was more about the ability to communicate, yours is about reception.

Ms FERRONATO: Receiving.

The Hon. CHRISTINE ROBERTSON: This inquiry has been a bit difficult because we are getting individual priority groups saying put us on top, put us on top. I am not having a go at you, but that is what is happening. This issue in relation to electronic and technological communication issues, we might be able to deal with as a whole. What do you think about that? Rather than saying this one needs it and that one?

Ms FERRONATO: Our preference is for everyone to be on an equal playing field, to not compare apples with oranges. The impact of someone with a physical disability and their access to everyday life is just as difficult to someone who has a sensory disability but in different ways. The technology and equipment that is available to enable a better quality of life and better access to society.

The Hon. CHRISTINE ROBERTSON: That was my next question and it was to pick up quite deliberately the first paragraph in your document, which I will not read out now that you have articulated it so well. That comprehensively talks about each person's disability being assessed as its own self.

Ms FERRONATO: Yes, and I guess the challenge is standardised tools can sometimes be skewed to one particular disability and there needs to be more work in the area of capturing all relevance.

The Hon. CHRISTINE ROBERTSON: You did talk a bit about the complexity of some of the things that are not very complex at all. Would it be better for the lesser number of persons who were affected—the group you are representing are less than the group who have had strokes—remaining on the complexity list so their cases are dealt with in a more individual way rather than a formula way? Am I being clear? I am being a bit complicated because often your people's issues are far more complex because they are individual requirements not necessarily matching the fact that they need to be able to get to the toilet—not that that is not complex. Am I making sense?

Ms FERRONATO: I guess, if it makes access for our clients easier. You are suggesting that their needs may be more unique and therefore require unique attention?

The Hon. CHRISTINE ROBERTSON: There are fewer persons, so if they get tangled in the standardised prescription processes that are being structured to try to stop inappropriate prescriptions being written for people that cause more damage, there is potential in the standardisation process to remove the specific issues of smaller groups of persons, and it relates back to this technological requirement. Am I making sense? You are nodding at me and I do not trust nods.

Ms FERRONATO: I am listening. I am understanding, maybe, but not quite there. I think if it makes access as fair and equal and timely, then perhaps that is a process that could work.

The Hon. GREG DONNELLY: What struck me as we have had different NGOs coming over the course of today and yesterday, and other groups representing the interests of disabled people, is that within those organisations is a high level of expertise and knowledge. Very much they are at the cutting edge of understanding what are the new aids, tools, equipment and other things that are able to best assist people with disabilities. That knowledge seems to reside at quite a high level in those organisations. My question is, in the process that operates within New South Wales, are there channels to transmit that information up further so there is a collection and understanding of what are the new things that should be being looked at by the relevant government agencies, what is next down the track for people with particular types of disability? In other words, on behalf of the people you represent, do you advocate the types of new equipment to the Government or the government agencies so they can reflect on it in their decisions about whether or not these things should be on the list or not?

Ms FERRONATO: Yes, we do.

The Hon. GREG DONNELLY: And that is done as part of an ongoing dialogue with the government agency?

Ms FERRONATO: Yes, depending on the government agency and our relationship with them. The Department of Veterans Affairs is an example where it has taken us a long time to get through and to have a dialogue to share our knowledge and ensure it is aware of what is happening.

(The witnesses withdrew)

(Short adjournment)

MAX BOSOTTI, Chief Executive Officer, ParaQuad New South Wales, 6 Holker Street Newington, affirmed and examined, and

MARTIN GARDINER, General Manager, Corporate Services, ParaQuad New South Wales, 6 Holker Street Newington, sworn and examined:

CHAIR: Do you want to make an opening statement?

Mr BOSOTTI: Thank you for giving us the opportunity to expand upon our submission. For the past 47 years ParaQuad New South Wales has served the people and the community with programs following catastrophic injury. We have extensive knowledge and experience in providing equipment, products and services to people with a disability. We provide both government-funded and self-funded products and services to the community directly through ParaQuad and through our commercial arm, BrightSky Australia. Through ParaQuad we currently administer the Mobility and Functional Support [MFS] Program under the Rehabilitation Appliance Program for the Department of Veteran Affairs [DVA] which involves the provision of equipment to the end user following the termination of appropriate equipment by an authorised prescriber.

We have developed intellectual property to significantly streamline the processing of an order for equipment, including contract limit controls, placing the order with the supplier for delivery to the end user, and for concluding the financial settlement of that equipment. We successfully operate this contract under tight key performance indicators [KPIs]. We have been operating this contract in New South Wales for four years and understand that our share of this contract for more than 50 per cent of the State total is approximately $13 million. We have the capacity to extend this nationally, should the opportunity present itself. The MFS contract provides equipment similar, if not identical, to that required under the PADP.

Through our commercial arm, BrightSky Australia we have long been the provider of continence aids, enteral nutrition, respiratory and mobility support aids, along with specialist health care products and services. We have operated a New South Wales component of the Rehabilitation Appliance Program [RAP] continence contract for the DVA for many years and provide special clinical advice to customers regarding their needs. We are a brand-neutral organisation and as a result maintain a strong reputation within the community for this service. This powerful combination of expertise and systems as outline above would be difficult to replicate without significant expense. We believe that partnering with ParaQuad NSW would be a win-win for both the New South Wales Government and the spinal cord injured community because all profits that ParaQuad NSW derives from its commercial activities are ploughed back into empowering people after a catastrophic spinal cord injury. This naturally reduces the pressure on the Government to fund these much-need services. We believe that there is a strong case for the Department of Health to consider partnering with ParaQuad for the administration of PADP through the fulfilment of an order once prescribed.

ParaQuad NSW has already developed a proven fulfilment system to effectively manage equipment and mobility aids. It has the clinical expertise and experience to provide continence and other health product requirements and is an organisation extremely well equipped to deal with people with disability. ParaQuad is therefore able to deliver to the key features required under item three of the terms of reference of centralising lodgement and providing financial savings from efficient systems and processes.

The Hon. MARIE FICARRA: Will you explain how the commercial arm, BrightSky Australia, ploughs its profits back into providing services for your clients?

Mr BOSOTTI: BrightSky is the commercial operation that we started many years ago. It has been renamed. Many years ago we started a commercial operation to derive additional revenue which funds a portion of the community services which receive no government or little government funding. Those services are geared to providing services for people with a spinal cord injury that are members of the association.

The Hon. MARIE FICARRA: How do you make those profits through BrightSky?

Mr BOSOTTI: Because we sell continence and health products. We have a product range of about 5,000. By bidding for and winning contracts, as with the Department of Veterans Affairs continence contract which we have had for a number of years, and deriving a profit from it. So the profits that we generate from many of our activities—there is no shareholder, it is all ploughed back into ParaQuad.

Reverend the Hon. Dr GORDON MOYES: Do you get a full tax benefit for that?

Mr BOSOTTI: Yes, we do.

The Hon. MARIE FICARRA: How have the operations of PADP affected the running of your organisation?

Mr BOSOTTI: We are a party for PADP and have customers that will buy through ParaQuad to fulfil those PADP requirements. In my opening statement I was making the comparison that we already have a significant equipment and mobility contract that we administer and it seems logical to say that we could extend that and assist in the restructure of the current PADP proposals with essentially a viable operation that would require very little in terms of being able to extend that to PADP.

The Hon. MARIE FICARRA: Have you made your intentions to partner with them well known to Enable and NSW Health?

Mr BOSOTTI: Yes, we have. In fact, we are in the process of having a more detailed meeting with Enable further this month. Certainly from the health department I have met with the chief financial officer and made him aware of the fact that we have this capability and we would like to make sure that Enable and the rest of the department is aware of this possibility.

The Hon. MARIE FICARRA: How will your improved processes deliver services to people who need them—the disabled—more readily and in a more effective manner?

Mr BOSOTTI: I guess we already have a system in place for being able to take an order from a prescriber and effectively through the processes that we have developed over a number of years efficiently make sure that that product ends up with the client as quickly as possible. That is part of the KPIs that we currently adhere to in administering the MFS contract.

The Hon. MARIE FICARRA: What is wrong with the current system about which we hear so many criticisms that it is not working? We know the workers within PADP are well-intentioned but it seems that it is under-funded, overwhelmed and under-resourced and systems and processes are not working?

Mr BOSOTTI: I think perhaps an uninformed comment, because I do not have all the detail, it would appear that there are a number of layers in place and a number of areas that operate. What we are saying is a simplification would be if the prescribing system, as is planned, is enhanced and centralised then the next logical step would be to also then allocate the fulfilment of that prescriber order to someone that expertise and a track record to fulfil it. We are putting up our hand and saying "We can fulfil that role". I guess the benefit is that whatever revenue we generate out of performing that service is, in fact, not going into a commercial entity in that it is actually being ploughed back into what would otherwise be services that we have to put up our hand and say to government "This is additional funding that we require to continue to perform those services." That is why I said in the beginning I think it seems to me it is a win-win for the Government and certainly for ParaQuad.

CHAIR: Is it a win-win for current commercial operators who provide and plan to continue to provide, particularly in rural and regional areas, equipment and service it on a regular basis? If you were to take a greater role how would those commercial enterprises survive?

Mr BOSOTTI: I cannot answer the impact it would have on those rural or other suppliers. All I know is that I would not see the list of providers would change significantly from what it is currently.

Mr GARDINER: I can comment on that. Under the MFS program we have about 30 to 35 suppliers around the State now. We receive the order from the relevant prescriber and we actually then put the order back onto the supplier who is in the regional area. So there is half a dozen people from Port Macquarie up to the Tweed Heads area who supply all the products. They actually get the business. We are actually administering the program so that is where the efficiency gains can come in because we receive the order, we pass it on and they deliver it. We handle all the administration associated with that. They do not lose out of the business at all and I would imagine that they would still get the business. We will just facilitate the whole process.

CHAIR: Is it the same for the maintenance and repair of equipment?

Mr GARDINER: They do repairs as well under the current MFS program.

Reverend the Hon. Dr GORDON MOYES: In other words, you are like those big Lynfox trailers that pass me on the highway—integrate, supply, chain, solutions—you do all of those?

Mr GARDINER: Yes.

Reverend the Hon. Dr GORDON MOYES: Doing that so well, forget about the Commonwealth Government or the Department of Veteran Affairs, the Committee is concerned about prompt payment of accounts when you work with the State Government?

Mr GARDINER: I was going to say that one of the deficiencies that we experience under the current PADP is that payment terms by the various departments is atrociously slow and we need to do constant follow up of those departments. My experience would be anywhere from 60 to 120 days we are getting paid now in most cases. So, under the model that we would propose, we would hopefully find that that would be a totally streamlined process. We would be claiming payment from one location. We get different stories now where they say, "Send us the invoice to this department." Then we follow them up and they say, "No, no. You sent it to the wrong department. Send it to that department." So, we get the constant run-around in the process. So from an efficiency perspective for payment, we get the relevant order approved, we process, we claim from one location. Everything would be a lot cleaner for the hospitals as well.

Mr IAN COHEN: Do the cheques ever bounce?

Mr GARDINER: No. Not at the moment anyway.

Mr IAN COHEN: In your submission you talk about independent research conducted by your organisation investigating website access. Are there any lessons for the Department of Health and Enable New South Wales to learn from your research in that area?

Mr BOSOTTI: Nothing springs to mind apart from the fact that people experience difficulties in the design of websites. Not everyone is as PC literate as we assume they can be when websites are designed. I think more care needs to be taken in actually designing the accessibility for those websites.

Mr IAN COHEN: How broad is your organisation's coverage for fulfilment of disability appliances and other equipment? You mentioned the various contracts you have for small-scale pieces of equipment and a certain line of appropriate equipment—continence equipment et cetera—from the Department of Veterans' Affairs. Do you deal with the big-end equipment such as wheelchairs?

Mr GARDINER: That is the equipment we supply in the MFS program. That is where we would use a regional network of local suppliers who are the experts in equipment. They are the ones who would supply the equipment.

Mr IAN COHEN: So you are the agent?

Mr GARDINER: There is a local independent business in, say, Ballina. We place the order, they supply that bed, wheelchair or whatever.

Mr IAN COHEN: So the proposed centralisation will not make any difference to the processes that your organisation is going through?

Mr GARDINER: That is what we do now.

Mr IAN COHEN: The centralisation of government departments?

Reverend the Hon. Dr GORDON MOYES: If the Government centralised the process?

Mr GARDINER: I am sorry. No, I do not believe it would.

Reverend the Hon. Dr GORDON MOYES: I actually think it could cut you out because the Government would be doing the same sort of work.

Mr BOSOTTI: I think it is entirely possible for the Government to establish something that is similar, if not identical, to what we have. What we are saying is that there is already a sunk investment and intellectual property that we have developed and able to execute. It just seemed logical—

Reverend the Hon. Dr GORDON MOYES: For them to outsource it to you?

Mr BOSOTTI: Exactly.

Reverend the Hon. Dr GORDON MOYES: That is something we have to note. There are those who say they would much rather deal with one point of contact, which would be a government centralised service, which is being considered. My feeling is that that would cut you out because it would do exactly what you are doing. Therefore, the alternate view is that they outsource to you.

Mr BOSOTTI: Correct.

CHAIR: That is what you are lobbying for?

Mr BOSOTTI: That is right. We already have something that works, is established and it is pretty lean and mean because we need to be. That is the nature of the organisation. Can it be replicated? It certainly can. Most things can. I guess the question is: Will it come at a cost? I guess the answer is that I think we could do that much more effectively.

Reverend the Hon. Dr GORDON MOYES: The question to keep asking is: Do you think the Government would do it cheaper than you?

Mr BOSOTTI: I do not think so.

CHAIR: Does your organisation maintain a pool of equipment?

Mr BOSOTTI: No, we do not have a pool of equipment.

CHAIR: Do you keep data about your clients, what equipment goes out to them, what their needs are and project their forward needs as well?

Mr GARDINER: Under the continence side of things, yes, that information is something we are working through now in having repeat orders on the basis you will need so many pads on this cycle. We are actually building that into our processes now. On the MFS side, the equipment side, no, because it is actually coming directly from the prescriber saying this is what they need now.

CHAIR: Do you keep data about the enteral nutrition program?

Mr BOSOTTI: I am not sure what data we keep on the enteral nutrition program, but I think that would be much the same as the continence program.

Mr GARDINER: Our systems can capture all that information and then we can feed the data from that and develop repeat orders and whatever else we need from it.

The Hon. MARIE FICARRA: How many staff do you have? Where are you located? When did you develop the streamlining of service delivery? Would you give the Committee a bit of your history?

Mr BOSOTTI: We are probably about 400 strong in the number of employees. There is a mixture of part time and full time. The majority would be casuals because we have a large attendant care program, which is carers going out to look after the needs of those people with a spinal cord injury. We also have a facility at Ferguson Lodge, which has about 50 to 60 employees. The balance would be in our Newington premises, which is in the Silverwater precinct, the Olympic Park area, where we have three large warehouses, administration block and our computer systems. From a commercial operation it has probably been the better part of something like 15 years or more that we have been operating. So, I think we have a reasonable track record. We are talking about a significant number of clients. In the continence area we would probably have somewhere between 15,000 to 18,000 and in the MFS area we would have about 16,000 clients. We are not unfamiliar with dealing with large populations. We have two call centres, one for the MFS program and one for the health products and continence aids. I think we come pretty well equipped to be able to say with some confidence that it is something that incrementally we could handle, certainly for the MFS contractors. As I said in my opening statement, were the opportunity available to look at the whole national picture, we certainly are well equipped to be able to take that on.

The Hon. MARIE FICARRA: Obviously you receive government funding. What proportion do you receive? Where does your funding come from to run this large enterprise?

Mr GARDINER: The turnover of the organisation is roughly $30 million. Of that, actual pure non-fee-for-service type government funding is about $200,000. We receive government funding as in DVA or DADAHC funding, but it is all fee for service. If we do not deliver the service, we do not get paid the money. So it is very small from a government funding handout perspective.

The Hon. MARIE FICARRA: It is cost effective?

Mr GARDINER: Yes.

CHAIR: Thank you for your presentation today and your submission. We certainly will take on board your suggestions. As we proceed we perhaps may need clarification on some things raised today. The secretariat staff may be in contact with you.

Mr GARDINER: Thank you.

Mr BOSOTTI: Thank you for the opportunity.

(The witnesses withdrew)

DAMIAN GRIFFIS, Executive Officer, Aboriginal Disability Network, PO Box 666 Strawberry Hills, affirmed and examined:

CHAIR: If you would like to make an opening statement you are welcome to do so.

Mr GRIFFIS: That would be great. Aboriginal persons with a disability experience multiple and aggravated forms of discrimination, disadvantage and neglect across all areas of life, including in the provision of equipment, aids and appliances under the PADP. For Aboriginal people, the inability to obtain adequate or timely assistance from the PADP intensifies their impairment and disability, their social isolation, their inability to participate in education and the workforce, and it has a severe and negative impact on their physical and psychosocial wellbeing.

Lack of access to appropriate equipment, aids and appliances also contributes significantly to the disproportionately lower life expectancy of Aboriginal people, as compared to the general population. For example, the lack of equitable access to health monitoring equipment such as blood glucose and blood pressure monitors impacts negatively on the survival of Aboriginal persons and, as we know, there is a much higher incidence of diabetes and heart disease amongst Aboriginal people. Lack of access to essential aids and appliances such as appropriately customised wheelchairs and pressure cushions can result in pressure sores that can mean prolonged periods of hospitalisation. If not appropriately treated these pressure sores can result in life-threatening infection.

Lack of access to customised devices and posture supports can exacerbate skeletal and muscular conditions that compromise respiration and cause life-degrading discomfort and pain. Lack of access to the PADP is a major area of unmet need for Aboriginal people with disabilities across New South Wales.

CHAIR: When referring in your submission to Aboriginal people and their access to the PADP you included people in rural, regional and isolated areas. Has that been a problem? Do you think that centralisation would assist or hamper those issues?

Mr GRIFFIS: Regional, remote and isolated communities in New South Wales face particular disadvantage. It is not uncommon to meet Aboriginal people with disabilities who have never heard of the PADP program. They really have no idea what it is and they have not had any capacity to engage in the program. If they do it is more by chance; it is rarely by design. The problems are particularly acute in western New South Wales and even within Dubbo. Once you go beyond Dubbo it is particularly problematic. That is where we are most active. The northern rivers region and northern New South Wales are other areas of unmet need. I would not be confident with centralisation. I think a regional approach is the way to go, purely on a practical basis, so that people have a much more readily available and approachable option in their nearest location.

CHAIR: The centralisation proposal that will be rolled out in a couple of years looks at backend administration rather than at service delivery. Were you involved in the PricewaterhouseCoopers review?

Mr GRIFFIS: No, unfortunately not. One of the problems that we as an organisation face is our capacity. I am the only paid employee. We have a number of pressures and we get pulled into a number of different areas. That has been a real frustration for us. We believe that we are a viable Aboriginal-owned and Aboriginal-operated organisation that has not had a lot of success in getting the staff that it needs to deal with these important issues. We do not always get the opportunity to participate as much as we would like.

CHAIR: People with whom you deal with on a regular basis would not even be reflected in the data. I must say that there is limited data, but they would not be reflected on waiting lists because they are not there in the first place. You raised other issues and you talked about corrections health. Could you flesh that out a bit? We know that Aboriginal people are overrepresented in the correctional system and that there is tension about which department picks up some of those issues. Could you explain that?

Mr GRIFFIS: This is another area of major concern. There are a number of Aboriginal people with disabilities in the corrections system. There are people living with psychiatric disability, intellectual disability, brain injuries, or physical disability. Not a lot of attention has been paid to this area. It is another area where we realise that we need to do more work. I will give you anecdotal evidence about where the problem appears to be. If people have access to the PADP, or to aids and equipment within the criminal justice system, they have to hand them back before they return to the community. That is our understanding of how it operates.

The Hon. CHRISTINE ROBERTSON: Because it is a region in its own right.

Mr GRIFFIS: Yes. If a person with a physical disability is a wheelchair user and that person is released from gaol he or she still requires the use of that wheelchair. I understand that that is the way in which it operates. Someone should dig a bit deeper on that one. I understand that that is happening and, naturally, that has a serious impact on the lives of Aboriginal people.

CHAIR: We will do some work on your behalf and we will put pressure on different bodies to see what we can achieve.

Reverend the Hon. Dr GORDON MOYES: Damian, there is no reference in any of the other submissions to this lack of equipment portability. For example, if Aboriginal people happen to have a wheelchair or some mobility aid and they wish to visit their family over the border, they would have to relinquish whatever equipment they had.

The Hon. CHRISTINE ROBERTSON: If they move.

Reverend the Hon. Dr GORDON MOYES: If they shift or go over the border.

Mr GRIFFIS: Certainly, yes. That is a major problem.

Reverend the Hon. Dr GORDON MOYES: That is incredible. They hand that back, yet there is no centralised pool for the equipment to be passed on to someone else.

Mr GRIFFIS: Yes. It does not make a lot of sense.

CHAIR: There is a lot that does not make sense.

Mr GRIFFIS: The convention that we talk about in our submission—the new Convention on the Rights of People with Disability that the Australian Government recently ratified—provides some guidance in relation to these types of issues. The right to liberty is a fundamental right of all people with a disability. Surely liberty involves the right to move in between States to visit family and all those sorts of things. That is an issue that comes up for those people within the PADP system.

Reverend the Hon. Dr GORDON MOYES: The other aspect about it is that a large number of studies have been conducted into how aids of various kinds are cared for. If you own it you look after it.

Mr GRIFFIS: Sure.

Reverend the Hon. Dr GORDON MOYES: Whereas if it is just given to you, wherever you happen to be, there is a higher rate of lack of maintenance and so on.

Mr GRIFFIS: Yes.

Reverend the Hon. Dr GORDON MOYES: It is foolish not to grant ownership.

Mr GRIFFIS: Absolutely. I could not agree more.

Reverend the Hon. Dr GORDON MOYES: That just increases problems with maintenance and upkeep.

Mr GRIFFIS: Absolutely. Another problem is that if there is only one wheelchair in the community or there is only one aid or appliance, several people will often use them because there is no-one else with that equipment. That problem arises in Aboriginal communities; people share their aids and appliances. Again, that is not through any fault of theirs; that is indicative of unmet need.

CHAIR: Absolutely. Do you have issues relating to the servicing of that equipment, in particular, in isolated communities?

Mr GRIFFIS: Yes. That is not an easy thing to achieve.

Reverend the Hon. Dr GORDON MOYES: I imagine that it would be non-existent.

Mr GRIFFIS: Yes.

Reverend the Hon. Dr GORDON MOYES: Who wants to go out to Menindee to repair a wheelchair?

Mr GRIFFIS: That is exactly right. People wait for long periods to get access to aids and appliances. I am not sure what is the waiting list for repairs, but I am sure that it would be a long one. That is an issue.

The Hon. MARIE FICARRA: Damian, how do we collect accurate statistics to reflect the number of indigenous persons with disabilities in the community? How accurate are your figures?

Reverend the Hon. Dr GORDON MOYES: Take the figures of the white community and double them.

Mr GRIFFIS: That is the theory. A recent Commonwealth Government report entitled "Overcoming Indigenous Disadvantage" quantified disability as 37 per cent of Aboriginal people having some form of disability or long-term health condition. That doubles the non-Aboriginal rate of disability. What is really concerning about that is that it acknowledges that psychiatric disability is not included within it. That is even more alarming. You cannot necessarily go to the statistics on the disability support pension [DSP] either. We meet a number of Aboriginal people with disabilities who should be on the disability support pension and who are not. That data is not reliable. It is anecdotal to begin with but research is now starting to justify the "twice the rate" idea that has always been around.

The Hon. MARIE FICARRA: How can we give the indigenous community and, in particular, disabled persons who need these services, better access to what is available? What about the Aboriginal Medical Service? Who identifies these people and says, "Did you know that you have this, that and the other, and you are entitled to X, Y or Z?" How can we better identify them?

Mr GRIFFIS: There is much to do in this area and there is much to unpack around disability as it relates to Aboriginal communities. It is not always an easy conversation. Aboriginal people are not always likely to identify as having a disability, and that might be for a number of reasons. One of them might be as simple as, "Why would you want to take another label when you perhaps already experience discrimination because of your aboriginality?" There are some other factors. Historically, disability has been medicalised in the wider context. I am sure that, within the wider rights movement, many people talked about the social model of disability. But that problem is particularly acute in an Aboriginal context. We get situations where part of the job gets done.

An example with which I am a familiar might be an old fella who had some complications with diabetes, which is not uncommon. He left it too late to get treatment and he had to have his leg amputated. When he left the hospital that was the end of it. He returned to an inaccessible home and an inaccessible community and his quality of life was reduced and he will possibly pass away within a couple of years. There is no "closing the gap" for that person. That is indicative of how this operates. Unfortunately, even within the Aboriginal rights movement, there is much to understand.

I can give you another example. Recently, at the Closing the Gap events in Canberra, 200 of the most prominent Aboriginal leaders in the country were asked to do a parallel session on disability. We had only seven people in the room, so that is indicative of where disability sits within the Aboriginal rights movement. There is much to unpack and there is much to do. When half the population comprise people with disabilities it is pretty alarming and an area of urgent need.

The Hon. MARIE FICARRA: Is there a group within the indigenous service delivery groups, such as the Aboriginal Medical Service, that could be better resourced to give more attention to this issue?

Mr GRIFFIS: Absolutely. This must move forward by building a social movement of Aboriginal people with disabilities. Aboriginal people with disabilities must talk to Aboriginal medical centres and to Aboriginal people and communities about their needs. We think that is the first step. Our organisation is an organisation of and for Aboriginal people with disabilities. If you like, we are a self-advocacy group. We think that is the way to go first, but we need to be better resourced to be able to do that. Aboriginal medical services need some education. Some do this stuff fantastically well but others have a long way to go. Indicative of that is that the first Aboriginal Medical Centre in Redfern was not in an accessible building until a few years ago. That is indicative of where it has been sitting, which is kind of odd.

The Hon. MARIE FICARRA: Are glucose monitors not provided? Where do people get funding for glucose monitors? Diabetes and cardiac disease are extremely prevalent. Where do people get funding for that?

Mr GRIFFIS: I do not know.

The Hon. CHRISTINE ROBERTSON: Through the PADP.

The Hon. MARIE FICARRA: It is definitely underfunded.

Reverend the Hon. Dr GORDON MOYES: Something that did not occur to me until I read your submission is that these days every organisation wants to be politically correct. Every organisation wants to have the voice of Aboriginality on a committee. Therefore, I would expect, because of the health, educational and disability aspects, you receive demands and requests to go to various committees and organisations. You said that you had applied for additional funding because, after all, you are it.

Mr GRIFFIS: Yes.

Reverend the Hon. Dr GORDON MOYES: You are the only staff person.

Mr GRIFFIS: Yes.

Reverend the Hon. Dr GORDON MOYES: Yet you have not been able to get any funding to enable you to represent Aboriginal people in all these other areas where we want the voice of Aboriginality to be heard.

Mr GRIFFIS: Yes.

Reverend the Hon. Dr GORDON MOYES: It occurs to me that we ought to be making some specific recommendations in that field so that in order to do the right thing, that is, to have the voice of the indigenous community heard in other departments, there should be some specialised funding to allow the only bloke in the field to be that representative.

CHAIR: Who provides your funding?

Mr GRIFFIS: We have recently received some funds from the Commonwealth. We have never had much success getting funds from the New South Wales Government, I must say, so that has been a serious disappointment to us. The fact that the advocacy review has taken 10 years, for instance, is part of the reason why we have not had much success, but we have recently received some funding from the Commonwealth. We are now called upon to establish like networks around the country, so we are also now working around the country.

Reverend the Hon. Dr GORDON MOYES: You are going to be stretched.

Mr GRIFFIS: Yes, it is very difficult.

Reverend the Hon. Dr GORDON MOYES: That might be a recommendation we ought consider.

CHAIR: It might be.

Mr IAN COHEN: There has been a fair bit stated in the inquiry about barriers accessing PADP. Can you detail specific barriers? You have gone through some of the problems that indigenous people will have, be it centralisation, far-flung communities, and attitudes that might make it difficult for them to effectively access what might be available to them?

Mr GRIFFIS: Sure. I think it starts with information, but it has to be more than brochures. There is a bit of a thing that goes on where there are lots of brochures developed with nice Aboriginal motifs on them and that seems to be the end of it. It actually requires a concerted outreach strategy. It requires someone to be sitting down with people, having a yarn with them and telling them what the PADP program is, what people's rights are, and taking it from there. That is the absolutely critical point.

Mr IAN COHEN: So you are suggesting a PADP field officer of some sort?

Mr GRIFFIS: That would be fantastic, an Aboriginal PADP officer.

Mr IAN COHEN: What sort of numbers—just as a guesstimate—would benefit from having someone like a PADP indigenous field officer?

Mr GRIFFIS: If we take the figure of 37 per cent of Aboriginal people having some form of disability, it has incredible potential for a number of people to benefit. I could not give you an exact figure, but you can be pretty sure it would be a fair number of the Aboriginal community that would benefit.

Mr IAN COHEN: So currently indigenous people are in communities and towns throughout rural New South Wales and, of course, the biggest population is in Sydney, is it not?

Mr GRIFFIS: Yes.

Reverend the Hon. Dr GORDON MOYES: At Mt Druitt.

Mr GRIFFIS: Yes.

Mr IAN COHEN: I am thinking of isolated areas. Really it is a case of dealing with it as best you can in the community and in hospital. Is that the current situation?

Mr GRIFFIS: Absolutely, yes, and as I mentioned before I think people do not come across it through design, it is more by chance. Someone in the community might know someone else who has managed to access an aid and appliance. It sort of happens that way. It is rarely through a structured kind of understanding of what a person's rights are or how they can access PADP.

Mr IAN COHEN: Would it be fair to say that this would significantly add to lower life expectancy in terms of indigenous communities?

Mr GRIFFIS: Absolutely, and this is the thing that we need to be talking about. When we are talking about closing the gap, it needs to include Aboriginal people with disability. That conversation is not really happening, but it does need to happen because of that example I used earlier where the old fellow leaves hospital and goes back to an inaccessible home and inaccessible community. His quality of life will seriously diminish. We need to have more resources so that we can get disability on the closing gap agenda, so yes, absolutely.

Mr IAN COHEN: Have you come across any cases where PADP clients have had to relinquish items as they are moving around?

Mr GRIFFIS: I know it has happened, but I have not dealt with them personally. I know of people who have been in that situation, but I have not dealt with them personally.

The Hon. CHRISTINE ROBERTSON: In relation to interstate movement of equipment, it seems to me from the review process that one of the issues in relation to the program is that equipment goes off into mid-air—it may not be used, but does not go back in—so ownership of the equipment and keeping records in order for it to be recycled appropriately is a very big issue. Do you think it would be possible for individual discussion and consultation to go on so that people negotiate for interstate movement to occur? I realise why you say it should belong to them, but I understand the problems that programs have because people perceive ownership and, when it is finished with, it is gone.

Mr GRIFFIS: I can only answer that from a rights-based perspective. It is everyone's right, and according to the Convention Australia has just ratified the right to liberty, so the right to freedom of movement.

The Hon. CHRISTINE ROBERTSON: That is right, not to be chained by the chair to a town.

Mr GRIFFIS: That is right, and of course it is also a practical thing. People have to take the same wheelchair because it is probably fitted.

The Hon. CHRISTINE ROBERTSON: This is a different issue. This is about the equipment going with a person.

Mr GRIFFIS: Yes, so it is about ownership in the end. I mean to do that you need to be able to own the equipment in some way. If you do not own it, I think that is where the complication comes in.

The Hon. CHRISTINE ROBERTSON: I do not discount anything you have said about inequity in relation to the program for Aboriginal persons. It is a very real issue. I guess the issue for PADP is, despite the fact that it has gatekeepers who may stop a submission, many Aboriginal persons get no submission whatsoever, they get no prescription because the service providers do not perceive it is necessary because of all the other nasty things that happen in Health for Aboriginal people.

Mr GRIFFIS: Yes.

The Hon. CHRISTINE ROBERTSON: Would it be possible to structure a process so that there is a service provision component concentrating on issues of disability in Aboriginal persons rather than a PADP officer because you are just going to end up with another page ticker?

Mr GRIFFIS: Sure. I had not thought about that. That would be the ideal, absolutely—an Aboriginal owned and operated PADP service.

The Hon. CHRISTINE ROBERTSON: If we left out PADP and had disability service, you are dissociating the piece of equipment, it is ordered by powerful people who recognise need rather than having the equipment controlling the need, which is what has happened so far.

Mr GRIFFIS: I think that would be the ideal. I think we have a way to go in that area, though. Building the capacity of Aboriginal disability services is certainly an issue. Aboriginal health workers are a dime a dozen, but it is very hard to find Aboriginal people who have a professional background in disabilities. That is where we need to get, but I think there is a way to go yet, a while before that happens, and the onus needs to be on the non-Aboriginal service sector to start employing Aboriginal people so that they can be the conduits, I suppose.

Reverend the Hon. Dr GORDON MOYES: Skill base.

Mr GRIFFIS: Yes, absolutely. That has to run parallel to what we are doing. We are doing an advocacy-social movement sort of picture, but there needs to be a service capacity building side that comes along.

The Hon. CHRISTINE ROBERTSON: Aboriginal health workers now have multiple emphases on their job: "This is in crisis, go and do that." If you are saying that Aboriginal health workers should take this on, you are giving them another huge—

Mr GRIFFIS: I am not saying that. There need to be Aboriginal disability support workers, or whatever term you want to use.

CHAIR: Occupational therapists?

The Hon. CHRISTINE ROBERTSON: You will not get them.

Mr GRIFFIS: I would not know there to be too many, even in New South Wales. Someone might be able to determine that, but I would be very surprised if there were many Aboriginal occupational therapists across the country.

The Hon. CHRISTINE ROBERTSON: In relation to your story about the gentleman who was discharged from hospital, there is a process in New South Wales Health called discharge planning and nobody should have been discharged from hospital in a wheelchair to an inappropriate house—or without a wheelchair, did you say?

Mr GRIFFIS: They were wheeled out in a wheelchair, but the point was that their home was inaccessible and the community was inaccessible to them. They had a wheelchair, but they could not really use it.

The Hon. CHRISTINE ROBERTSON: They sat in the garden at the bottom of the steps?

Mr GRIFFIS: Yes, or they were stuck at home inside.

The Hon. CHRISTINE ROBERTSON: That is a very important issue. I recognise it is just a story, but it is a really important issue about equity and discharge planning and that also relates to this inquiry because it is a service provision issue, so the persons were not getting the appropriate prescriptions for their house to be modified. That is a very important equity issue.

CHAIR: It should be part of their discharge plan.

Mr GRIFFIS: Another area of major unmet need is housing modifications for Aboriginal people. It is a very confused area because there are different people that own and operate their housing and it is not easy to get modifications, but this is going to become an even greater issue over time. It is a major issue and when you think about how that happens in remote parts of New South Wales, people are waiting several years before they get a simple ramp to the front door.

The Hon. CHRISTINE ROBERTSON: But Health actually provides that process through PADP, so that is also an issue in relation to the referral and prescription process. It is not really about where they live. Across New England North West it does not matter where they live, house modification will occur if it is required. It is the referral for it to happen that is not happening.

Mr IAN COHEN: What would currently happen? Where would you or your organisation go? You have an elder out of hospital in a wheelchair, either stuck in a house or not able to get access without the whole family helping out.

Mr GRIFFIS: Yes.

Mr IAN COHEN: Forgetting the PADP for the moment, how would you access support at this point in time?

Mr GRIFFIS: We would try to engage with the system, but we know that people might wait for a year or two, or whatever, to get their housing modified. What invariably happens is that people do their own modifications, so people build their own ramps or pull down walls. That is really what happens out there, particularly in remote parts of the State, and I frankly could not discourage that because that is about access and if that is what people need to do then that is what they are going to end up doing, but we try to engage with the system.

Mr IAN COHEN: In the indigenous sector is there anywhere you can go to get some support for any of those activities, given there is a desperate need? Is there anywhere you can go? I am only thinking in terms of indigenous problems.

Mr GRIFFIS: Well, this is why we need an individual advocacy service for Aboriginal people with disability. We get calls regularly to us, but, as I said, we do not really have the resources to meet everyone's needs. There are issues like this all the time. They can be housing modification; they can be, "I need to have access to a wheelchair". There urgently needs to be a funded advocacy service for Aboriginal people with disability.

The Hon. MARIE FICARRA: A couple of us are on the Social Issues Committee looking at indigenous disadvantage. It would appear likely that the Aboriginal Housing Office will be empowered to better manage a lot of indigenous housing that might have been under the auspices of small unviable entities. Would it not be nice to think that the Aboriginal Housing Office could give some emphasis to working with indigenous disabled people and the PADP to better roll out these modifications for housing?

Mr GRIFFIS: Certainly. That would be exactly what is needed urgently, but again we go back to resourcing. The Aboriginal voice of and for Aboriginal people with disability needs to be resourced.

The Hon. CHRISTINE ROBERTSON: And the organisation that is responsible for delivery should not just be responsible for delivery to nice white fellows from the middle of Tamworth, they should be responsible for delivery right across New England North West. Giving them an out, like saying, "The Aboriginal housing authority will deliver for you" I do not think—and I do not know how you feel?

Mr GRIFFIS: No, I agree.

The Hon. CHRISTINE ROBERTSON: The PADP is responsible for providing housing modification.

Mr GRIFFIS: I agree with you. In the end what we want to do is create choice, so an Aboriginal person with a disability can access a non-Aboriginal service or an Aboriginal service if they want to.

The Hon. MARIE FICARRA: My point is that the Aboriginal Housing Office should better coordinate that for their clients as well. Government instrumentalities working together.

Mr IAN COHEN: The point is that we are dealing with a PADP situation that is not servicing adequately in many areas—

The Hon. CHRISTINE ROBERTSON: In relation to who is entitled to the service.

Mr GRIFFIS: Yes, absolutely.

CHAIR: And not adequately servicing a whole range of organisations—

Mr IAN COHEN: —such as yours. Where are you based?

Mr GRIFFIS: In Redfern.

(The witness withdrew)

(The Committee adjourned at 4.00 p.m.)