REPORT OF PROCEEDINGS BEFORE

GENERAL PURPOSE STANDING COMMITTEE No. 2

INQUIRY INTO THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE

Uncorrected transcript

At Sydney on Wednesday 1 October 2008

The Committee met at 9.30 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

CHAIR: This is the first public hearing of the inquiry into the Program for Appliances for Disabled People [PADP]. This is a great opportunity to review the program. I hope I speak on behalf of all members of General Purpose Standing Committee No. 2 in saying that our Committee takes a great deal of care and attention with its reviews. We see it as a very important part of our role as Legislative Council representatives. This program affects a great many people whose lives are challenged in many ways. It is a great responsibility of ours to make sure that the program that we are reviewing comes up with the best outcomes for disabled people, their carers, parents, professionals in the health and allied field and also those who are providing equipment.

The reference has come to this Committee because there are a number of concerns about the PADP and we are looking forward to examining those concerns in depth and making recommendations. I thank everyone for their participation. The Committee has now received approximately 77 submissions, which are very well written and concise and address the terms of reference of this Committee. In my experience that has been the case of people with a disability and their carers who have to fight for so many things that many of us take for granted. They are used to writing submissions and they are very valuable. Today we will hear from NSW Health, several community organisations as well as consumers and carers. A second hearing will be held tomorrow and copies of the hearing schedule for both days are at the back of the room.

In relation to procedural matters, the Committee has resolved to authorise the media to broadcast sound and video excerpts of public proceedings. In accordance with these guidelines members of the Committee and witnesses may be filmed or recorded but people in the public gallery should not be the primary focus of filming or photographs. In reporting these proceedings the media must take responsibility for what they publish, or what interpretation is placed on anything that is said before this Committee. Committee hearings are not intended to provide a forum for people to make adverse reflections about individuals. The protection afforded to Committee witnesses under parliamentary privilege should not be abused during these hearings and I therefore request that witnesses avoid the mention of individuals unless it is essential to the terms of reference.

If people wish to pass messages to staff or witnesses would you please do that through Committee staff. I acknowledge our secretariat staff. This Committee is blessed to have terrific support. I ask that people turn off mobile phones, particularly those that are in range of Hansard and recording equipment because we get nasty feedback through the system.

RICHARD JOHN MATTHEWS, Deputy Director General, Strategic Development, NSW Health, 73 Miller Street, North Sydney,

CATHRINE MAY LYNCH, Director, Primary Health and Community Partnerships, NSW Health, 73 Miller Street, North Sydney, and

BRONWYN RUTH SCOTT, Director, EnableNSW, P.O. Box 1770 Chatswood 2027, affirmed and examined:

CHAIR: Do you wish to make an opening statement?

Dr MATTHEWS: Yes, just a short one if I may. I thank the Committee for an opportunity to give an overview of the Program of Appliances for Disabled People [PADP]. PADP plays a key role in supporting people with a disability by providing essential equipment to assist with mobility, self-care and communication. It is one of a number of NSW Health programs which provide equipment for people with disability. The others include the artificial limb services, the home oxygen services, the ventilator-dependent quadriplegia program and the children's home ventilation program as well as the new specialist equipment fund for people with catastrophic injury to assist in their discharge from hospital.

It provides an important source of funding for essential equipment, which, in spite of the difficulties inherent in the current program, which we will acknowledge as part of this process, provides 14,000 clients with more 41,000 items of equipment in a financial year. As outlined in our submission the current recurrent budget for PADP in 2008-09 financial year is $25.6 million which is an increase of 147 per cent over the 1999-2000 budget. In addition, the recent joint State and Commonwealth one-off funding boost of $11 million will go a long way to help people across New South Wales living with long-term disabilities through the provision of that essential equipment such as wheelchairs, adjustable beds, ventilators. We estimate that that money will assist about 5,000 people. So that significant one-off will increase this year's budget to $36.6, and will, we believe, fully address the current PADP waiting list, bearing in mind that many pieces of equipment take some time to manufacture and so the actual time that the person comes off the waiting list is when they are delivered their particular equipment.

At the moment about 80 per cent of the budget is spent on equipment and about 20 per cent goes on administration. Through the reforms, it is our aim to increase the component which goes to equipment to at least 84 per cent and we will outline some of that. As the Committee is aware, a former Minister for Health, Morris Iemma, when Minister for Health, approved a major review. The review was conducted by PriceWaterhouseCoopers and was released in late 2007. It identified a number of significant issues with the program's fairness, efficiency and quality and made 30 recommendations. A majority of those recommendations have been accepted and a copy of the Government's response was provided to the Committee as part of our submission. Of the 30, the Government did not support two. They were recommendation nine, which related to the establishment of a statewide steering committee with a smaller membership, a focus on governance, rather than advisory responsibility, whose role is to review the planning and performance of PADP. The other was recommendation 30, changing the program name to Program of Aids for People with Disability.

The Government also referred another recommendation regarding fees and eligibility policy for further work due to concerns that the recommendation, if implemented, could create some hardship for some people with a disability. We recognise that this program needs to provide a fairer service. We acknowledge that the processes for assessing assistance needs to be simpler and clearer, and we appreciate the need to provide clinicians with better support to assist them with the critical task of assessing and prescribing equipment. We also agree the program needs to use its budget more efficiently to make sure we assist as many people as possible, and we have embarked on a major project of systematic reform.

These reforms are even more important in view of the expected ongoing and increasing demand for assistance through the program as a result of lifestyle related disability, such as type two diabetes related to obesity, an ageing population and improved survival rates from catastrophic injury. I will give an example of that. I think members are familiar from other inquiries into the neonatal ventilated assistance program, and the phenomenon of neonates—children being born being ventilator assisted—and needing to be discharged home is a very new one in Health. These are children who, not many years ago, would not have survived. We have had to commence that program because we found ourselves in the situation where there were children who had nowhere to go beyond the intensive care unit at Westmead kids, and Sydney kids, and that was unacceptable.

In order to make these efficiencies, and positioning the program, in August 2007 we established EnableNSW and appointed a very able person to be its head. Enable comprise expert clinicians and business reform staff who are tasked with implementing the recommendations. Enable is only one year old, but it has already made significant progress in implementing the recommendations of the review, and those were all outlined in our submission, but they include: the development of new prescription processes in consultation with groups of expert clinicians, and the piloting of those processes at two major PADP centres; the establishment of a 1800 number to provide clients and clinicians with ready access to advice and assistance; publication of a quarterly newsletter to inform stakeholders of changes; and because of the recognition that those who suffer catastrophic injury with multiple disability have special and particular needs in transitioning from the hospital to their home, $1.8 million recurrent was put towards a specialist equipment fund to support safe, timely and effective discharge out of hospital into the home with disability appropriately supported. Over the next 12 months Enable will roll-out the new PADP prescription processes across the State and transition the first PADP lodgement centres to Enable.

I should point out that that interim process has commenced already. Historically we used to have up to 36 lodgement centres that represented the geography and means of communication available at the time. Through some amalgamations they have reduced to 22. It is our view that modern information and communication technology means that we can centralise the process, make it more efficient with more money going to the assistants without disadvantaging any clients.

We are going to implement Certificate 3 and 4 customer contact training for all staff; implement a new information system; develop a web recycling page and system to facilitate the reuse of equipment returned in good condition—one of the inefficiencies we have identified is lost and not returned equipment, much of which is perfectly able to be reused; develop procurement options taking into account equipment service and supply needs in all areas of New South Wales as well as best-unit price—in other words, bundle the buying in order to get a better price; launch a new website to provide consumers and clinicians with up-to-date information about the program; establish appeals committees to consider cases of special needs; develop facts sheets for clients and clinicians; and work to strengthen links between the equipment loan pools and PADP. As I said, we hope to see the total budget spent on equipment increased from $80,000 to at least $84,000.

CHAIR: Dr Matthews, before you continue, if the remainder of your opening statement is a few more pages, perhaps you might like to table it?

Dr MATTHEWS: I would like to deal with the audit, if I may, because I know that is a topic of some interest to the Committee, and I will conclude with that. In 2007 we engaged Oakton, formerly Acumen Alliance, to conduct financial and compliance audits of all area health services. A copy of that report will be provided to the Committee in response to an order for papers put forward by Mr Ian Cohen. Acknowledging that I am here and the report is to be tabled today, I place on the record that I am very happy to return, if you wish, to answer specific questions about the audit. There has been some criticism about its timing. In conclusion I will say that we commenced it in May 2007, the auditors finished in May 2008. There was then a usual process of checking the facts, which all auditors allow, and that involved the auditors talking to all the area health services. We received the final report last Wednesday and we are tabling it today. In the interests of time and your questions, I will leave the rest of my opening statement.

CHAIR: Thank you. No doubt some of the remainder of your statement will be addressed in response to questions. I am sure you would agree that timely provision of equipment is essential for better outcomes and better life opportunities for people with a disability. What is the time frame for actually implementing the EnableNSW PADP rollout and recommendations from the PWC review.

Dr MATTHEWS: I will ask Bronwyn to describe the rollout from here.

Ms SCOTT: We are already commencing with the process of implementing some key reforms, which will improve processes and systems. We are doing that with the lodgement centres as they are in place currently. Those reforms will be expected to achieve efficiencies: for example, in the prescription processes, they will be rolled out over the next 12 months. Certainly they will speed up the processes around consideration of applications, advice to clients, and will improve the quality of prescriptions. The actual transition of each of the offices will not be completed until the end of 2010, early 2011. The reason for us taking time with that and being very careful is to make sure that we do not disrupt services for clients, that we take into consideration all of the local issues and that the actual process of transition is very smooth for clients. We want it to be really seamless for them. Whilst they will have a different telephone number to ring, their services will not be interrupted. That is a somewhat lengthy process, but the actual other reforms to the program around prescription processes, policies around what is supplied and how it is supplied, and our financial management systems will be implemented before the last lodgement centre is transitioned.

CHAIR: From the completion of the PWC report, which was 2007, you do not anticipate the completion of your response to the recommendations until the end of 2009, is that right?

Ms SCOTT: 2010 and 2011 in actual movements of all of the individual offices, but many of the other reforms will be in place.

CHAIR: Is centralisation additional to that?

Dr MATTHEWS: That is part of the centralisation process but, ultimately, there will be only one lodgement centre. There will be electronic lodgement and there will be a standardised process to eliminate variations in clinical practice outside the evidence-based acceptable limits.

CHAIR: With the governance of the PADP and the policies and guidelines with EnableNSW and Health NSW being consistent, why is it that across the State there is such a variation in outcomes with requesting equipment, getting delivery of equipment et cetera?

Dr MATTHEWS: To some extent that is historical. You would be aware that over time we moved from hospital-based services with hospital boards to 17 area health services and now to 8 geographic area health services. Many of the budgets are historically based. So, one of the things that the review and the audit has determined is that there are quite different waiting times in different areas. The centralisation will mean that those inequities, which are partly based on historic area health service budgets, will be eliminated and, ultimately, the criteria beyond the standard criteria will be clinical needs and capacity to pay with equity across the State.

CHAIR: We have received many submissions about the $100 co-payment. Do you plan to eliminate that co-payment?

Dr MATTHEWS: We planned to review it. I have to say that that is a difficult and vexing question. On the one hand, many people with a disability require assistance and have a capacity to pay, and there are very large numbers of people who do not. It is administratively burdensome and requires additional transactional time and costs. If it is to be done away with, it removes a contribution towards the program. I have a similar issue at the moment with IPTAS where the co-payment covers 15 per cent of the cost. There are powerful arguments to remove it; there are also arguments to keep it. We are going to review it and we will try to balance need capacity to pay and the inevitable fact that budgets will always be tight.

CHAIR: When do you plan to come up with a conclusion on that? Will you be making that publicly available?

Dr MATTHEWS: I think Enable has produced a discussion paper on that with a timeline to produce the discussion paper.

Ms SCOTT: We plan to have a discussion paper with some options for public consultation by June next year and hope to have finalised arrangements in place for the commencement of the following calendar year.

Dr MATTHEWS: It is one of those decisions where, in my view, there is not absolutely a right answer. There is a series of judgements to be made.

The Hon. MARIE FICARRA: Have you conducted an audit of the $100 co-payment to determine how much it is costing the Department of Health to administer? I imagine in your deliberations that you would have to examine cost. Is it worth the full cost of chasing it up from go to whoa individually? One would imagine that you would conduct your own cost analysis? On what basis are you going to be releasing a discussion paper?

Dr MATTHEWS: The cost of collection, of course, can only be estimated because it forms a small part of the duties of a large number of people. Whether across the system you would save overall one full-time equivalent position is arguable, but it will be included in the discussion paper.

The Hon. MARIE FICARRA: Have you considered means testing it at all? Is that not a way of making the system more efficient? I imagine that chasing $100 payments must be very time consuming for bureaucrats on high wages. I would not like to do it if I were running a business.

Ms SCOTT: I think that in preparing a discussion paper we would want to look at a range of options. Certainly we will want to take into consideration the administrative costs of collecting a $100 co-payment from every single person who accesses PADP. So, that certainly will be a consideration in preparing the options for eligibility and fees.

The Hon. MARIE FICARRA: Some of the submissions have made reference to income-based eligibility criteria that is applied currently. Is consideration being given to making that eligibility criteria realistic—in other words, eliminating the very high income earners? There are many grey areas where the comments are that the current means test is very unfair.

Dr MATTHEWS: I think something like 98 per cent of recipients are in receipt of a benefit. So, at the moment the program effectively is very largely confined to people who are in receipt of Commonwealth Government benefits, which means that their income is prescribed.

Ms SCOTT: The exception to that would be children who, as you are aware, have universal access. So, we actually do not even collect information about parental income.

Mr IAN COHEN: Dr Matthews, everyone, including your department, is aware of the waiting lists and also the widely recognised position that children have an automatic high priority for items under PADP. Could you explain the reason for the many instances of very long waiting times? A huge cause for concern in the community is that often people wait for over 18 months. We hear anecdotal stories also of children outgrowing their equipment before they receive it, and that it is not worth going to PADP, particularly in country areas, because you get better value out of just going to your local charity and raising funds for these people. It is my understanding that the waiting times at Liverpool Children's Hospital are extremely long compared, say, with the waiting times in the Hornsby area. People in the Bathurst area have made complaints about waiting lists, but they believe that they will lose their rights if they complain. That issue is evident throughout the system when people with disabilities, who are very sensitive, speak up and do not get their equipment. Could you address those issues?

Dr MATTHEWS: Sure. You asked three questions. The differences between Liverpool and Hornsby are acknowledged. That is one of the things that we want to eliminate by centralising it and doing away with historic budgets that have grown over time and that are not necessarily related to population need. Referring to the long waiting times, there are factors other than funding. They can be: incorrect prescriptions because of variable or poor practice, and we want to eliminate that; prescriptions sometimes of discretionary items; funding of equipment that is needed only for a relatively short period and that is then abandoned; variable pricing, which is another thing that we want to eliminate; efficient local business processes; and variation of what assistance is provided and how much between different lodgement centres. We hope that the new standardised prescription processes, the statewide procurement contracts, and all the new business and information processes will eliminate a lot of those inequalities and inefficiencies.

Mr IAN COHEN: Do you perceive this to be a Government problem? For example, people with a disability get a referral by their doctors and they then have to go through specific experts. There is a long time lag before they receive proper attention and before they get their equipment. Could you comment on the rigidity of the different classifications of people? According to the department, for which equipment are they eligible? I think that is another issue of great concern. Some of the submissions that we have received indicate that people are not getting the equipment that they need.

Dr MATTHEWS: I acknowledge that those things have happened and I acknowledge that our processes have not been as efficient as they could have been. With this reform we are hoping that there will be speedier standardised prescription, speedier processing of eligibility and, if there is a problem, a readily accessible appeals committee that will enable people to obtain access expeditiously to something independent to reassess their situation.

Mr IAN COHEN: Dr Matthews, how will this assist people in the north of New South Wales? Can you guarantee that that will occur after you have centralised the main brain in the Hunter? There are problems in the Hornsby and the Liverpool areas. How will people in those country areas obtain a satisfactory service, in particular, when there are small businesses in those areas that have high expertise and a commitment to the community? They will find it impossible to continue to function because they are servicing those local communities on a small scale and you are drawing it down to a central area. What guarantees can you give that the centralised process will assist everyone in New South Wales?

Dr MATTHEWS: The first issue is that the majority of people in country areas are remote from the current 22 lodgement centres, or the previous 36 lodgement centres. By centralising it we will have one point for access and, most importantly, in addition to a consistent set of rules we will have one point for redress. We are doing this because we believe that we will get better equity, better access and more consistency, and more of the budget to be spent on equipment. The provision of clinical services and supply will remain local. There is no intention to have a large warehouse in Sydney doing the dispensing, except for the most common things. The supply of equipment has to be closely linked to those who are prescribing it. I am talking about central coordination and, most importantly, a known central place to which you can go if, for any reason, you believe that you are being unfairly treated.

The Hon. TONY CATANZARITI: Many people with disabilities, parents and carers have expressed concern about poor customer service from staff of the Program of Appliances for Disabled People [PADP]. Those concerns have included rudeness by PADP staff, as well as a lack of information about the application process and the progress of those applications. What is being done to improve customer service?

Ms SCOTT: The purpose of PADP and EnableNSW is to provide necessary equipment to people with a disability and their families. We are a customer service organisation. Clients of PADP and EnableNSW should be able to expect that they will be treated with courtesy and respect by the staff of EnableNSW. Regrettably, I am aware of situations where clients or their family members have not received a reasonable standard of customer service. I have spoken to some of those clients. As part of our reforms we want to ensure that all clients are treated with the courtesy and respect that they deserve, that they are provided with information that is helpful to them, and that they are provided with it in a timely way.

It is true that, to date, many PADP staff in those 22 centres across New South Wales have been in sole positions with limited access to senior support to deal with more challenging inquiries. One of the benefits of centralisation is that staff will have access to support from senior staff to assist them with more complex inquiries, including access, where necessary, to expert clinicians to assist them in the assessment of applications. We have built that into the structure of EnableNSW. Whilst relatively junior staff members would deal with the majority of inquiries, they would then have the capacity, if it were beyond their skills, to escalate it to a more senior staff member.

Currently we are also working with the lodgement centres on the development of communication protocols. We are aware that some clients are not communicated with on a regular basis and do not find out about the progress of their applications for many months, which clearly is unacceptable. This is one of the reforms that we want to implement as soon as possible in the coming months because it is not acceptable. Clients should be able to expect regular, timely and helpful communication. One of the other benefits of centralisation is that a number of local lodgement offices currently are open for very limited hours. I am aware of centres that are accessible to clients for only a few hours each day, or on two or three days a week, which is also not acceptable.

Under the new centralised program obviously they will have access to assistance and advice throughout normal business hours and for five days a week, which they should have now but they do not. Within health support services we are also developing customer contact training, that is, at certificate 3 or certificate 4 levels. We will be working with staff on our work force to tailor that for those members of staff who work with people with a disability to ensure that they have a high level of knowledge and skills. All my staff will be required to complete that training, starting with me and going down to every staff member. The other elements that we are building into EnableNSW sit around our governance structure.

You might be aware that currently we are in the process of forming an EnableNSW advisory council, which includes expert clinicians and an equal number of carers or people with a physical disability who can provide us with advice and feedback about the program. The appeals committees will have representation from consumers. The other thing we are planning to do is to run consumer forums each year. Consumers will have an opportunity to provide us with direct feedback about their experiences of the program, so we can find out from them how they are experiencing the service that we provide and we can respond to that. We also hope to become an employer of choice for people with a disability—we think that is an obvious and important step for the EnableNSW program to take—and we will be encouraging that in our recruitment processes.

Supporting Better Customer Service is the new IT system that will ensure we record all the necessary information about clients. It will ensure that, when customer service officers respond to a call, they will have at their fingertips current information about that person, about any inquiries or complaints that they have previously made, and about the progress of those inquiries and complaints. We are committed to ensuring that in future the clients of EnableNSW and their families receive respectful and helpful service from our program. We will be making every effort to ensure that that happens.

The Hon. TONY CATANZARITI: I, and I am sure the Hon. Christine Robertson and Mr Ian Cohen, would like to know as we come from the country, whether the same sort of service and support will apply in country areas.

Ms SCOTT: Absolutely. They will be ringing the same number and they will have access to the same trained staff. Obviously we will also be providing ongoing support and training to staff. Often their jobs are difficult and stressful and we also need to support our staff more effectively. To date they have not been provided with that support. Clients living in rural areas will receive access to the same level of support as clients living in metropolitan areas.

The Hon. CHRISTINE ROBERTSON: I would like you to expand on your answer. Are you putting a performance indicator on the timeliness of the appeals process?

Ms SCOTT: Yes, we will.

The Hon. CHRISTINE ROBERTSON: What sort of performance indicator?

Ms SCOTT: I will take that question on notice. We acknowledge that when a person puts in an appeal he or she needs a timely response to it. Obviously, the appeals will go through a committee, which will include consumer representation. The time frame for response must take that into consideration. We want to provide people with timely and quick advice, certainly not over many months, which currently is the case.

The Hon. CHRISTINE ROBERTSON: There is a reference in one of the submissions that has been received by the Committee to the fact that your committees meet only four times a year.

Ms SCOTT: Yes, that is right.

The Hon. CHRISTINE ROBERTSON: Three months is a long time.

Ms SCOTT: Indeed, it is. Some of the lodgement centres have regular monthly committee meetings and some of them have meetings every three months. Some of them have meetings even less often than that. That situation will not continue. We will have regular meetings to consider appeals and we will have regular meetings to consider novel and unusual applications that require the input of clinical experts.

The Hon. CHRISTINE ROBERTSON: What is happening to advertise the toll free number?

Ms SCOTT: EnableNSW has its toll free number in the White Pages. I think we have had a number of calls from people who simply looked us up on the Internet.

The Hon. CHRISTINE ROBERTSON: Service providers, doctors?

Ms SCOTT: We met with the GP Council about six weeks ago. We met with them to specifically ask them for advice on the best way of communicating with general practitioners. We will be utilising the mechanisms which they have suggested to us to advertise EnableNSW, how to contact us, provide them with some basic factual information about the service.

Dr MATTHEWS: I wanted to add on the benchmarking of the appeals, I think we will be adopting a similar process to the one that we do with complaints generally, which is that there is a benchmark of acknowledging receipt of the complaint—which is, I think, three days—because when people do submit something, they like to know that they have not dropped a penny in the well, they like to hear a splash. Then there is a second benchmark, which is that the matter is resolved within 35 days or if not resolved there is a further communication, which says, "This is the process for resolution". So people are communicated with and understand exactly what is happening. I am not saying that the benchmarks will be the same. We need to think carefully about meeting times. But we will keep the undertaking to establish those benchmarks, to publish them and to follow them.

The Hon. CHRISTINE ROBERTSON: The financial bands in the documents you have submitted to us are very fierce. The definitions of who is well off are very low.

Ms LYNCH: That is up for review as well. We asked for that. That is part of the review of the co-payment. As Bronwyn previously said, a discussion paper will be developed and we will also take that to the Interagency Standing Committee on Disability, which is across several agencies and reviews those matters.

Dr MATTHEWS: As I said before, the matters of means testing, co-payment, the bands for eligibility, there are no right answers, there are judgements. We want to produce a discussion paper to get appropriate comments from the public because, in the end, my view is this is the public scheme and we merely administer the money. We need to get a broad range of views and hopefully a consensus about what it should be.

CHAIR: You mentioned earlier in your presentation the top-up funding you have received this year will get rid of the waiting list. You may need to take this on notice. Could you provide us with some figures in terms of the waiting list, how many people in total are on the waiting list, how many of those are children, and the overall average waiting time for people on the waiting list?

Dr MATTHEWS: We can certainly do that on notice. In relation to the money, the submission we put to, in this case, Ministers was based on the size of the current waiting list. Waiting lists are problematic; you can never eliminate a waiting list. What we succeeded in doing was getting a commitment to additional money which equalled the current waiting list. Then, as we put in place the efficiencies, we will make up part of the shortfall by those efficiencies. The balance will be inevitably the funding gap. We will present that and that will be a matter of prioritisation against other health commitments in other areas.

CHAIR: Speaking of other health commitments in other areas, do you have figures on the number of people who are waiting in hospital, for example, for an appliance or an aid in order to be discharged and the cost of that hospital stay?

Dr MATTHEWS: I am not certain.

Ms SCOTT: No, we do not have figures on that. The Specialised Equipment Setup Program is a specific initiative that is directed to ensuring safe and timely discharge of people who have had more complex equipment needs from hospital. That program is operating very successfully. We do not have any numbers in terms of people who are actually waiting in hospital. We are aware though that when a person is in hospital and they need a piece of equipment that they are normally prioritised. Hospital administrators will normally work with the local lodgement centre, loan equipment will be organised for the person while they are waiting for the PADP to ensure that they do actually get discharged from hospital. I think the other element for people with more complex requirements that we are certainly aware of and that clinicians have told us and that I, in fact, experienced when I was a clinician out in the community is that it is not just about equipment. It is about having the right supports at home; it is about having the right accommodation; it is about having that accommodation modified. So discharging a person with complex disabilities is multifactorial.

CHAIR: Clearly, when you are working out a budget for health generally and for specific components of health, you need to know those sorts of numbers and issues. Is there no ability to get that information? Could you come back to us with that information? I would have thought someone was working that out.

Dr MATTHEWS: We will interrogate the data and come back to you. As Bronwyn said, it is multifactorial. We have enhanced a range of community rehabilitation activities, such as things called Compacs, in partnership with the Commonwealth community-based transitional care places, which are six-weeks packages of care. So that when someone is being discharged from hospital all the components of care of which these appliances may be one, may be a significant or a small part, can be put in place. It is a complex jigsaw puzzle, but we will interrogate and see what we can come back with.

Mr IAN COHEN: Dr Matthews, at pages 16 and 17 of your department's submission there is an impressive list of reform strategies. When did those reform strategies kick off? Are they in any way a reality at this point in time or are they something for the future? What was the driver of these reform strategies?

Dr MATTHEWS: I think in terms of reality and future, they are a mixture. As I said in my opening address, I gave a list of things that we had done and a list of things that will be done in the next 12 months. The driver unquestionably was inequity, variable waiting lists and some inefficiency in our system, which we hope to eliminate. So through the review process and the audit process we are acknowledging that the system needed considerable overhaul and improvement—as many longstanding, historical systems do—and we are putting that in place. The fundamental driver is equity, access and increased efficiency.

Mr IAN COHEN: I appreciate the increased efficiency. You mentioned centralisation, attempting to be more egalitarian in approach and a fair go for all. How does that relate to special needs within the special needs, such as non-English speaking or multicultural communities? I know there is an extra burden, if you like, on indigenous communities in far-flung areas, which have a huge number of issues about accessing the very basic support requirements, particularly the elderly Aboriginal communities. How does that fit in with your centralised strategy and are you looking at special needs within the special needs?

Dr MATTHEWS: The answer to special needs within the special needs is, yes, we are. Bronwyn referred to that committee process with consumer representation, acknowledging that there will always be very special cases where subjective judgements and some flexibility in the rules can be accommodated. I think one of the criticisms or a number of the criticisms have come from people in the centres interpreting the rules very strictly according to the way they are written, which is in one sense arguably their job. We need to inject a very large dose of commonsense into this decision-making process because the decisions, as I said before, will always be subjective. In relation to indigenous people—I will hand over to Bronwyn in a moment—there are extraordinarily difficult access issues across the whole range of health services for reasons of cultural appropriateness, remoteness and all the ones that you are well familiar with. The clinical services, the prescription and the fitting would be local is the key answer to that question. The back of house is the part that we are centralising in order to make the whole thing consistent and, importantly, to provide that key, fair, commonsense-based appeal process.

Mr IAN COHEN: In those decentralised areas there has been a complaint in some submissions. As I mentioned before, small businesses in country areas find that they cannot financially survive because the PADP does not pay them in reasonable time for them to pay off the people knocking on their door. So we have a Catch 22. Is your department going to undertake a specific practice change to remedy that situation, particularly for local small suppliers who often go beyond the general call of duty to help people?

Dr MATTHEWS: Absolutely. I think it is a tension, if I can use that word, in the health system at the moment. It is our view that small suppliers in particularly but not exclusively rural and remote areas need to be paid in a reasonable time frame according to normal terms. Bronwyn might like to comment on how she is going to achieve that.

Ms SCOTT: EnableNSW has one focus, which is providing people with disabilities with the equipment they need. We are not distracted by a whole range of other priorities. We do have as one of our KPIs the funding transfers with each centre. As we take responsibility for service delivery to particular areas, one of our KPIs is payment within government terms for supplies. We recognise that suppliers have to put food on the table and that late payment can affect their business. That is one of our key concerns and key priorities. In terms of the actual processing of invoices, as we receive them the processes that we are using at Enable are much more efficient and they are much faster than what is currently being used within most of the lodgement centres, which have quite a heavily manual system. Ours is much more electronic, so the speed at which an invoice goes through is also very much faster than what is currently occurring. Yes, that is one of our KPIs.

Dr MATTHEWS: The payment of these invoices for these appliances will be core business for Enable. As things currently stand, the payment of invoices gets caught up in the payment of invoices in the case of Sydney's southwest of a $1.8 billion budget. There will be one place for any supplier to go if that supplier feels that they are not being treated fairly, and there will be one name and one face that they will be telephoning. I think that will make it a lot easier for them.

The Hon. GREG DONNELLY: On page 7 of your submission you have a breakdown by percentage and number of the equipment expenditure for 2006-07. My question is a general one. In terms of the ongoing upgrading of the equipment in terms of the range and type of equipment from perhaps more refined technology and related matters, can you explain the process of bringing on board new and better equipment for people with disabilities in New South Wales?

Ms SCOTT: It has previously been quite ad hoc. What we intend to do—we have not done this yet—is basically establish a standing committee which will look at new technology as it comes on board. At the moment we are doing that on a case-by-case basis. We do not exclude new technology from provision to a person because it may be the best thing for them to meet their need. So we do and have taken on board and funded very new technology but we obviously have to consider making sure that what we provide is also the most cost-effective option for people. But we will have a transparent process for looking at new technology as it comes on board. There are a number of things to consider with new technology. It does not have a track record. We do not know whether it will meet people's needs more effectively than the existing equipment, so we have to be quite careful in considering new items as they come onto the market.

The Hon. GREG DONNELLY: In terms of that consideration, is that done solely through yourselves or is there a national body, or maybe even an international body, that is involved in this assessment of equipment for people with disabilities?

Ms SCOTT: I do not believe so but I will take that on notice.

The Hon. MARIE FICARRA: The advisory committee that you mentioned previously, can we have some information supplied as to the objectives of the committee, who will be on it from the point of view of carers and consumers, how you will advertise for that, and how the selection criteria will be carried out? Can you provide that to the Committee?

Ms SCOTT: Certainly. It is in the public domain and I can provide the Committee with a copy.

CHAIR: Other Committee members and perhaps the secretariat staff have further questions in relation to your evidence today. Perhaps in relation to what you bring back on notice and as we go through the inquiry, I wonder if you would agree to answer those questions as questions on notice?

Dr MATTHEWS: Very happy, and as I said at the beginning, given that the audit has been tabled today, if you would like me to come back and answer questions specifically on that I am happy to do so.

(The witnesses withdrew)

(Short adjournment)

FIONA ANDERSON, 1 Bayview Place, Bayview, NSW 2104, and

RAUL OSBICH, 5 Eastcote Road, North Epping, NSW, sworn and examined:

HEIKE FABIG, 7 Cawarra Place, Gordon, NSW, affirmed and examined:

CHAIR: Normally we have an opportunity for people to make an opening statement. Sometimes that can take a lengthy amount of time out of our questions. We have your submissions. I wonder if anyone has a brief opening statement you wish to make, or whether we just go into discussing your submissions?

Ms FABIG: I have prepared a two-page brief summary. It is up to you whether you think that is too long.

CHAIR: If you would agree to table that we can distribute it to the Committee members and it will become part of the process.

Ms FABIG: Sure.

CHAIR: Congratulations on your submissions. They are very concise and very valuable to us in our deliberations. I have a few questions. Ms Fabig, you talked about tax deductibility for the costs of your equipment, such as the wheelchairs, the modifications to cars and those sorts of things. Can you explain to the Committee that position and also your views on the availability of choice of products and how you are restricted in terms of those costs?

Ms FABIG: The overarching principle is that as a mother—I do not see myself as a carer, I see myself as a mother like many others do—I feel that these are my children and if there are any disability-related costs they are my responsibility to take care of. We organise our life in such a way that we try to manage these costs. However, that is sometimes incredibly difficult. Today I have brought Billie in her little power chair. We were very lucky to buy this particular chair at a reduced cost of only $13,000. Only $13,000! We could not afford that. Thankfully her grandfather looked at how she performed in the chair and said, "This is ridiculous, she needs one", and he put some money on the table. That chair actually cost him—I think I have worked it out at $18,500 if you take into consideration that he needs to pay his income tax. She is not eligible under the PADP criteria to even apply for this chair, so we have no choice. I think there are four or five paediatric power wheelchairs out there, of which maybe two are specifically designed for very young children. That does not allow for a lot of competition in the marketplace. Most of these chairs are made overseas and have to be imported, so you are looking at very expensive equipment. On top of that you then have to buy a car that can actually carry a wheelchair and that maybe down the track can be converted so that the wheelchair can drive in easily. We need a people carrier to take five people and a whole lot of gear. That leaves you with two or three cars to choose from.

So what you have is a very limited number of options for the equipment and surrounding equipment that you can actually buy, at very high cost. We are happy to do it; we see it as an investment in the future of our children. I do not want my children to one day be dependent on the State. They are perfectly capable of holding down jobs one day. I see that as an investment in the future, but I am the only one making it. It would be so much easier if these issues were tax deductible. I think it would release the pressure on programs like PADP. I made a list in my submission of all the hundreds of little things that we bought. If you add all that up you are looking at a substantial amount of money. We have gone from no mortgage to having a $300,000 mortgage—for the house, the equipment, and the car, all of that gets put on the mortgage. I am happy to do that, but there are a lot of people out there who cannot. Make it a little bit easier for those who can so that they get off the system and free up the system for those who cannot make those investments themselves.

CHAIR: Ms Anderson, in your submission you talk about similar issues in terms of replacing your son's wheelchair and getting it modified when he was outgrowing it, and the cost of related expenses. Could you flesh out the cost issue while we are talking about costs? You say that the family's entire expenditure on disability-related expenses should be taken into account, not just the gross income. Can you expand on that and the sorts of issues you have encountered in getting modifications and replacements when the children grow?

Ms ANDERSON: My son is 13 years old and I also have a daughter who has just turned 18. Like Heike said, both kids are my responsibility, not the State's. However, if we pay for all the equipment, therapy and services that my son needs, which we have done by taking out another mortgage using the 40 percent equity in our home, and taking out superannuation, we can fund this at the front end but that leaves us nothing for when we retire. So my son may not be a burden on the State at this stage but we certainly will be in 10 or 20 years' time. There is just no way around these costs. Billie is in the same situation as my son. If you have a power wheelchair you need a van to transport it. You also need an accessible house. We have tried to make renovations to our house. It is far more expensive to renovate the house and do retrofittings than it is to rebuild it, so we have been forced to rebuild. Our costs have just blown out exponentially. You are caught in a noose because although our costs are significantly higher than many other families without a child with a disability, we have less capacity to earn income because there is no after-school care and no vacation care. I had to move heaven and earth to get here today. I have no-one to care for my son. Something has to happen one way or another and if the expenditure on vital equipment is treated as an investment there is no reason it cannot be considered tax deductible. My mobile phone is tax deductible and yet the van that I need to get my son to school and without which I cannot get to work is not tax deductible.

CHAIR: Thank you. They are some very valid points. Thank you also for the further information you have provided to Committee members about your submissions. How do you as a parent feel about the proposals to enable New South Wales to centralise the lodgement system? Do you see other problems in relation to what is being presented to us this morning? You may not have heard the proposals for a rollout of the Government's response to the PricewaterhouseCoopers submission?

Ms ANDERSON: There has been plenty of information published about this. The streamlining makes an awful lot of sense. At the moment eligibility for equipment varies depending on where you live, which is just bizarre. It is not based on need, it is based on perception and budget. But there is a big problem with the potential for how a family can contribute. As I said, next year we will be seeking contributions for a power wheelchair for my son. In the meantime we have spent $500,000. How can we continue to fund all that and buy a new wheelchair and pay the $40,000 that we pay each year for therapy? It is just logical for a family's entire disability-related expenses to be taken into account rather than just a single purchase of an item of equipment.

Mr OSBICH: I am probably at the other end already. We have already become a burden on the Government. It is very hard for me because I have been a highly paid employee for many years and only four years ago I basically had to retire. I am a pensioner now. I am a full-time carer for my wife who has become fully disabled. I hear these horror stories about a cutback. I was battling. I was physically lifting my wife, and my wife is not petite. We have a great community that has come along and bought us a car. It is the only way that we would have been close to transporting my wife. It is still a 10-year-old car and we are looking at close to $50,000. So, we emptied out all our accounts, and the community over the six months collected $30, 000, and we came up with $20,000 so we have a lovely car. It is strange, but my wife always comments to me that she loves it because once I put her in the chair—she never mentioned it to me before, when I was jostling her around that her clothes and make up were being mucked up—now she is perfect and drives straight into the car without being touched and she thinks it is such a bonus.

Like these ladies said, all the accounts, all the money I have, I have imposed on my parents, my grandparents and there are no more options. We are desperate. Any time we want something, even $1,000 is too much for me now because I am a full-time pensioner. Even though I have a company that is prepared to pay me to stay at home, that is going to the mortgage, and we do not have as big a mortgage as these two ladies have mentioned, and we are still managing from day to day. Yes, I can see tax deductibility as being a great bonus but unless you have opportunities for people to give you that influx of money, like the PADP has done at times for us—it has been very, very helpful—I cannot see us surviving very well. We have come through the cycle. We are at the other end and unfortunately we have become a burden.

Ms FABIG: With regard to your question of centralising PADP, I have to state upfront I have not had a lot of experience with PADP, because when we applied for my son's wheelchair we were told we would have to wait two years, and we said thanks but no thanks. She is not even applicable, because she is so young. So, we have to do it ourselves. We have pretty much done everything ourselves. But I am in a parents forum, which is a forum for parents of children with cerebral palsy. I can only speak from that experience. I know there are people in New South Wales—I think Julie is in Nowra, that area—where a feeding pump for a child is not funded on PADP whereas here in Sydney it is. We are talking about children who cannot survive without a pump. This is the only way they get food. Here in Sydney, again it depends on where you live whether you get three pumps or five pumps. The thing with the pumps is that the tubes get hard so you need to change the tubes or get a different pump. So, it depends on where you live whether you get a pump or not. Call me old-fashioned, but I do not think that is fair. In that sense, I think centralisation would be an idea to look into.

The other point is I would not want anyone to lose their jobs, however what I am going to say might result in some people losing their jobs. The way the process is currently set up is you get an OT from your service provider—in my case that is the Spastic Centre—who has to come up with this big file to show that you need a certain piece of equipment. They spend a lot of their time researching what the child needs. In her case she needs a power chair. It is clear that for her development she needs a power chair. Our son missed out on a power chair and has some developmental delays as a result. We were not going to make that same mistake again. Then we look into which power chairs. There are four paediatric ones that you can try, so you try them all. You organise all that and then your OT says, "I will write a report. We will submit video evidence of her in the chair while she is trialling it." She rings PADP and they say forget it, she is too young.

You then have to ask why is this OT involved in this process? Why are these people wasting their professional time and energy to then have PADP OTs say no? You are doubling up the system. You have therapists involved at both ends, and I do not see the value of that. If a qualified therapist in an established service provider says a person needs a piece of equipment, then they need a piece of equipment. There does not need to be a committee that then goes through the whole thing again. In that sense, I think centralising the system may save time and money that can be spent on more equipment.

Ms ANDERSON: Once that bit of equipment is bought it needs to be serviced and maintained and repaired. We should not have to go through the whole committee process just to get a footplate fixed, which takes seven months.

Mr IAN COHEN: Ms Fabig, you just said that the PADP said no, not eligible, but did it frame an argument that a power chair was not clinically appropriate for your daughter? Given the evidence that your OT had presented, was there any discussion, and where could the PADP committee and lodgement centre improve its refusal of equipment and have more discussion?

Ms FABIG: I did not talk to the PADP myself, my OT did that. But what she told me—and I have this in an email, so if you want I can submit that email with those quotes. Basically, you have hit the nail on the head. The reason to refuse had nothing to do with eligibility in terms of being able to use the equipment or being able to need the equipment. It is purely a financial issue. Because of the cost of the equipment, we were told, it goes to the big expenses committee and it will look at it and look at the price and at her young age and will say forget it. Basically, at the moment PADP will supply a power chair six months before a child accesses school, the reason being it gives them six months to learn how to drive the thing so they do not knock someone over at school. Thank God they do that at least.

But all the evidence and research suggests that when you introduce powered mobility to a child at the age where they would normally start moving around, regardless of whether they have an intellectual disability or not, they will learn from being in the chair. Imagine, my daughter cannot sit independently. She cannot crawl in the house. Any two-year-old can crawl if they cannot already walk. They go to the cupboard, they go to the pots and pans and drop them on their toes and scream, and that is how they learn to open a cupboard and they learn what is heavy and what is not heavy and that heavy things fall down and that hurts. You learn all these things and you learn to judge distances, not to slam into a door. These are all important things for development. If you have mobility you can learn those things. If you do not have mobility and you sit on mum's arm you can only learn from looking at the world, which is not the same as touching it and feeling it.

If the research shows that a power chair was useless at that age, I would say fine, it is useless, it is not doing anything, let us give it to them when they are older. But, that is not the case. It shows it is useful. The decision is purely one of stretched finances. Again, part of me can understand that maybe a two-year-old would have to wait a bit longer than a lady in her 40s or 50s who may have to go to work and needs a chair, but fundamentally what we are looking at is people need this equipment to grow and to be part of society. To say no just because there is no money, somehow in this country—if we were living in Senegal, sure—does not seem quite fair to me. She is lucky, she has a grandfather with money. There are lots of kids out there who could benefit from this chair or a chair like it and who do not have a rich grandpa.

Mr IAN COHEN: Ms Anderson, could you perhaps just briefly describe what effect the discomfort caused by the fact that your son had grown out of his current wheelchair had on his participation and performance at school? How would a streamlined approach to OT assessment and modifications have impacted on your son's life?

Ms ANDERSON: He started to go through a growth spurt at age 12. It is classic boys: they grow rapidly between 12 and 14. We had to go through exactly the same process where we notify the OT and we go on a wait list. We get a report eventually saying yes, this child has grown and then the process goes on to PADP. Once PADP reviews it and approves it, then you go to the wheelchair supplier and the process starts all over again. That alone takes a minimum of six months. In that time he is growing very rapidly. He could not fit in the chair so it was not fitted ergonomically and he was at a 110-degree angle to his body. Try sitting like that yourself for six or seven hours a day. Not only is it uncomfortable, it is hard to concentrate, he gets tired, sore, lumpy. Everything becomes difficult. Since he was one I have done between three hours and six hours of therapy a day on him to improve his condition, and it is improving. Now I am doing it just to try to stabilise problems that have been caused by discomfort in the chair.

The solution is, I know when he has grown out of a chair. It does not take rocket science. I am the expert on my son's condition, nobody else. I should have just been able to say we need these modifications. If it were complicated, of course I would go to an OT for input. As it was, I said what we needed and the OT wrote the report. Then the merry-go-round started. It is needlessly complicated and now we are going to take months and months to try to redress the problem.

Reverend the Hon. Dr GORDON MOYES: You heard the public servants say they are reviewing the $100 co-payment. It is almost irrelevant, is it not, to you? I am thinking of you, Ms Anderson. You say it costs you $40,000 a year for equipment and treatment, and the same, Ms Fabig, with your situation. I think we should have on the record what you think about the co-payment.

Ms ANDERSON: I think that most families want to take as much responsibility as they can and it depends on personal income. In that way, a $100 co-payment or a $500 co-payment, or whatever it is, should be assessed on a family's capacity to pay based on all their expenditure, not just on this single item.

Reverend the Hon. Dr GORDON MOYES: Mr Osbich?

Mr OSBICH: Yes, I agree with what Fiona said. We found that the co-payment is a good idea and it gets us involved, but the amount of money is irrelevant.

Ms FABIG: I think Fiona's point is important, not to look just at the individual item but the general expenditure that a family adds up. I guess the only slight worry I have with the co-payment is I can see there may be instances where people will say, "I will buy all the little things and you will have to do the big things because it is only $100." If it is always $100, I guess what I am saying it should be linked to the expenditure.

Reverend the Hon. Dr GORDON MOYES: A percentage?

Ms FABIG: Yes, and it should take the whole picture into account.

Reverend the Hon. Dr GORDON MOYES: If we could bring some pressure to bear on the Federal Government for GST-free for disability appliances and tax exemption for all costs, that would be a really significant contribution to you, provided you have an income that is sufficiently high enough for a tax exemption to be of benefit, which you may not have?

Ms ANDERSON: It becomes such a vicious circle, because to earn the income you need the support services or, once again, you can pay for them privately if they are tax deductible. That would free up the system so that people who do have the capacity to earn that income can rely more comfortably on the State provision of equipment and services.

Mr OSBICH: As an example, I had to get a carer in today for my wife and very generously the MS Society is going to pay for it but for the five hours it was going to cost me $250.

Reverend the Hon. Dr GORDON MOYES: How do you find the provision of respite services?

Ms FABIG: We don't get any.

Ms ANDERSON: We don't have any.

Mr OSBICH: I am entitled to five mornings and five afternoons. I am lucky to get two hours every Tuesday, and that is at $3 an hour, which as a pensioner even $3 an hour! And we have to have a cleaner in for half a day because I just cannot cope; I am not a very good housekeeper. By the time you add that up and their visit, and my wife needs physio three times a week, so on a pension of approximately $300 a week, we are spending over $200 on physio and caring for her.

The Hon. CHRISTINE ROBERTSON: Where does that respite come from?

Mr OSBICH: We usually request it through the MS Society but we go through Northside Community, is the company that supplies them. They are there today as well, but the regular one that comes every week, it is subsidised by the Government—

The Hon. CHRISTINE ROBERTSON: Which Government?

Mr OSBICH: I believe the State Government. They say as a carer you are entitled to so many hours respite, and we will pay for most of it, and you pay a contribution. Like I said, I pay $3 or $4 an hour. Like today which is ad hoc that is out of our own pocket.

Reverend the Hon. Dr GORDON MOYES: I ask both mothers particularly if I could push you beyond respite care. The problem with long-term care inevitably brings up the question of your son or daughter being involved in an aged care facility, which is not at all suitable. Are there sufficient facilities available for, say, teenagers or younger people in their twenties with disabilities?

Ms ANDERSON: If my husband and I died tomorrow my 13-year-old son would be placed in a nursing home. That is disgusting!

Reverend the Hon. Dr GORDON MOYES: I want to get onto the record, are facilities available in the event of you, as carers, parents not being able to care for your son or daughter?

Ms ANDERSON: I cannot see facilities or diversity in choice of support which is not necessarily placing them in an environment outside the home. It maybe for some people. The answer is diversity of support: different mechanisms and tools and recognising what works for an individual and their family.

Mr OSBICH: I have found that even asking for my wife to go for a week's respite, even the MS Society cannot offer her because she is too intensive, too severe a case. So I have actually been told "No, there is nothing available". It is almost sounding as if I have to go to intensive care in a hospital for my wife, and yet I manage at home. Simple things like, we have had a hoist introduced. Occupational health and safety say you must have two people to use it. So that adds the extra burden on the company or the supplier of aged care that says there must be two people present.

Reverend the Hon. Dr GORDON MOYES: That is exactly right. You can understand parents who take their disabled child or a person who takes their spouse to an emergency department of a hospital and then just walk out.

Ms FABIG: Yes, unfortunately I can understand that, as sad it must be for these people to do that, but there is nothing available.

Reverend the Hon. Dr GORDON MOYES: So they just walk out of emergency department and leave it up to the hospital.

Ms FABIG: We had one of our mothers in our group who was in real distress, with a lot of problems. She went to I think it was one of the Prime Minister's community Cabinet meetings and asked the Queensland Minister for Disability Services "What can I do? What can I do?" and basically the Minister said "Well, you could threaten to kill yourself and your child and then you get emergency funding." You can only shake your head that it has to come that far before you get help. But that is the reality. If we died tomorrow we can't even leave our house to our children because it is mortgaged to the hilt, and again we would have to rely on family members to take them in and look after them—there is nothing else out there. I dread the day that they are older.

Reverend the Hon. Dr GORDON MOYES: That is my understanding.

The Hon. GREG DONNELLY: In regard to the schedule of costs in two submissions, the total costs indicate a very high amount of money and the contribution paid by the State through the PADP is quite low. With respect to some of the costs which you include as parents, was that done because none of those were available on PADP or you just made the judgment that you had to wait too long and, therefore, it was best to go and purchase it yourself? I want to get a better sense of what the actual breakdown is.

Ms FABIG: In my case it was both. I will give you an example. My older son who, as you can see, is walking independently now but there was a time when he was not. He was three and we put in a request at PADP for a manual wheelchair. As part of that request we asked for a little handrail so he could sit on the toilet and we could toilet train him. The wheelchair was approved, and we were told that we would have to wait between 18 months and 2 years for the wheelchair to arrive, to which I then asked "And what about the handrail? He wants to go to the toilet now but he can't sit on it." The toilet rail was about $200. The wheelchair was about $300. So I requested that the two would be split so that the handrail would come a little bit earlier. They said "No." What do you do in that situation? I could wait another two years, and leave him in nappies, or I could do the right thing and toilet train him which is what he wanted to do, and which doesn't give me the cost of nappies. So I had to withdraw the application of both the handrails and the wheelchair to move along. In that case it was purely based on waiting. In my daughter's case we could not even apply. So it generally tends to be a combination that is what my experience is.

Mr OSBICH: One thing that keeps coming up is the waiting but sometimes even waiting for your OT to be available. My wife goes through the MS Society. At last count it had 1,300 clients in the northern sector and two OTs that are specialised enough. So even going to see them every day, they would have to see two every day for the whole year, and they are still not going to see everybody. Trying to make an appointment for these evaluations, they are not 15 minutes. They are usually a couple of hours and there is a report to be written, so the poor OTs are inundated with paperwork even after the physical effort of coming, say, if not to your house, you going to her office in one of the MS centres and spending a good hour or two evaluating what is needed. Sometimes it is just the sheer frustration of trying to catch up to your OT. I must say the lady we talk to, I would hate to think how many messages we leave on her machine saying "Can you catch up with us?" There is always that frustration. As the ladies emphasised, when you actually get to PADP—we have been very lucky, we got our wheelchair within four months, and we always we were very lucky but my wife had deteriorated quite severely and literally could not move. There is always an urgency factor and how good is the report written by the OT but still the frustration of trying to see the OT in the first place adds to this.

The Hon. CHRISTINE ROBERTSON: Do you all come from the metropolitan area?

Mr OSBICH: I am from Epping.

The Hon. CHRISTINE ROBERTSON: I do not need to know.

Ms ANDERSON: Yes.

Ms FABIG: Yes. The time may seem like an inconvenience that is not worth worrying about, but if you cannot move, and you have to wait four months, it is something to worry about. The whole idea of early intervention is in the first word "early". You intervene while they are still young so they will learn skills that down the track you do not have to pay the money in helping them. So if someone says to me "Yes, your daughter can have a wheelchair, but she needs to wait two years" I know that that is two years where you build up a developmental delay that we do not need. So it may seem like a minor issue.

The Hon. GREG DONNELLY: Please do not misunderstand me. I did not imply that at all. I saw the list, which is a build up to very significant figures. For example, the shower chair, I think in your case you paid for it yourself. I would have thought that is something that could have been addressed by PADP.

Ms ANDERSON: It is certainly something that we would be eligible for on PADP but a couple of issues come into it, to which the other two people have alluded. Waiting to get an OT—six months just to get an OT and another six months for the report, blah, blah, blah. Secondly, and this is really important to my husband and to me, we are responsible for our children. We want to pay for as much as possible. We do not want the State to pay for it. If I never had to ask PADP for anything ever again I would be thrilled, if I could fund everything. We recognise that there are families in far worse situations than ours, and the more we can do the more we free up the State's funds for other families, but there is a limit. There is absolutely a limit and we have reached it.

The Hon. TONY CATANZARITI: In relation to OT, you say there are two in your area. Is that because there are not enough of them or is it that is all the area can afford?

Mr OSBICH: That is one thing I do not know as a fact. But I believe with the MS Society the number of people now needing help has increased dramatically and they are funding, and the way they run, it has not been able to keep up with the demand basically.

The Hon. TONY CATANZARITI: It is quite obvious with two people trying to service 13,00 people there is something wrong.

Mr OSBICH: It is ridiculous, yes.

Ms FABIG: From our experience, we mainly seem to wait for physio, and I know the Spastic Centre has had trouble attracting physios partly because it does not have the funding to employ more people, partly because hospitals are very happy to give children botox, but they do not have to worry about the physio that you then have to do to make the botox actually work in its maximum capacity. That all goes to the Spastic Centre. When my son was between the ages of 3 and 5 we fell off the physio waiting list. He has not had physio since—he is seven now—because all the available spots have gone to the children that have botox. I have not even requested physio because I do not want these kids being injected with a toxin and then not get the maximum benefit for it. There is just not enough people out there that can do it.

Ms ANDERSON: Partly that is a problem with the way it is funded too because the funding goes through a fairly convoluted process from Treasury down through organisations. By the time it is actually delivered in a service to an individual or a family there is virtually nothing left. There is, I would imagine, much capacity to investigate individual funding where families get X amount of funding based on the person's need, and then you can work out what to do with it. For example, I could have employed a physiotherapist, and I could have done the same thing after my son had major surgery. There was no respite. There was no nursing care. There was absolutely nothing. I was left to lift a child who weighed 35 kilograms, wearing full leg plasters, on my own for a month. Nobody else would do it. There was absolutely nothing, whereas if I had, I don't know, $5,000 I could have chosen to employ three physiotherapists or three uni students to help me lift the child. There are imaginative ways to deal with the problem. It does not always have to be about lack of funding.

Ms FABIG: That is in effect what we did. We paid for private physio because you ring them up and you can see them next week, and they do not have the money issues like the Spastic Centre.

Mr OSBICH: It is a little cynical view but unfortunately our society allows people who have been in a major accident more access to facilities and money than people who have incurred diseases through no fault of their own. So if tomorrow I dive off a pool and sue somebody I can probably get $10 million but my wife, through no fault of her own, basically cannot get a cent other than some support. I must say from what the ladies are saying, if it were possible for someone to be given $2 million I do not think they would ever ask for anything else again. They would set everything up and be quite comfortable. I know that is the ideal world, but if you happen to be quadriplegic from a car accident or diving you are given those sorts of funds and most people do survive for life by investments and setting up their homes from that sort of money. And early intervention, if I was someone given $1 million when my wife was first diagnosed I am sure that I would have no costs now. Everything would have been settled, it is just unfortunate that there is not a system available to that extent.

The Hon. CHRISTINE ROBERTSON: Is one of your biggest issues a lack of clinical service providers within the organisations that you work that supply your support services?

Ms ANDERSON: We do not get support services. There is an awful lot of rhetoric about what is available but essentially a child with a neurological condition like cerebral palsy theoretically receives intervention until the age of five. After that there is nothing. We have not gone near a physiotherapist in eight years. We do it now.

Ms FABIG: I have to say even when you do get services, I know of a young boy who was given money by the Department of Education and Training. The money was given to the Spastic Centre for a therapy program for him for a year, and out of that year he sat 11 months on the waiting list.

The Hon. CHRISTINE ROBERTSON: Waiting list for?

Ms FABIG: To access those very services that the funding was given for him. The way it works is a bit like a pension. While he was on the waiting list some other child that was previously on the waiting list was given his money. But the system is bizarre in the way it works whereas if I had the cash and I just ring my local physio we get things done and you do not sit there doing nothing.

The Hon. MARIE FICARRA: My question relates to the time it takes to get an assessment from PADP providers. To free up the system could we propose perhaps general practitioners [GP] being assessed for their ability to provide some assessment? Some of you spoke about how long it takes to get appliances for toileting and basic hygiene. Your adolescent son is growing, yet you had to wait until he was assessed for a new wheelchair. Is there anything we could propose to move the system along so that qualified medical practitioners could do the assessment to respond faster?

Ms ANDERSON: I find it just as hard to get in to see a GP. It is a five-month wait to see a GP. I live in a very affluent area and that is how long we wait. There is no Medicare service. I think it depends on the situation. Obviously I know a lot more about our situation, but if the State has said, yes, this child needs a wheelchair, then the wheelchair needs to remain functional. If you have a car and you do not service it, well, why buy the car in the first place? It would make sense if, for example, I could send a photograph to PADP and say, "This is the situation. We need a new seat" or this needs to happen, we need a new footplate, whatever, that should be it. The response should be, "Yes, go and get it done and send us the invoice."

The Hon. MARIE FICARRA: To be more reasonable in their assessment.

Ms ANDERSON: Obviously, when you are starting out you need a lot more assessment. But once you have the equipment, if you could free up the process for items that already are owned, that would speed it up. It is obvious what needs to be done.

The Hon. MARIE FICARRA: Do you think they are working to guidelines that are too restrictive or do you think it is the worker's interpretation of what they think they should be saying or doing?

Ms ANDERSON: Yes to both.

The Hon. MARIE FICARRA: The response must be faster. In regard to the power chair you have—obviously, it is superior to the two you were offered—would you be satisfied if you were reimbursed to the level equivalent to the ones you were offered and you supplemented the remainder with, of course, tax deductibility and GST?

Ms FABIG: That would be a workable system, but I was offered no power chair. We trialled a few others with me as an individual ringing around companies asking, "Have you got paediatric powered chairs? Can you come and put my daughter in it with your OT there?" I was offered none. PADP does not supply it at all.

The Hon. MARIE FICARRA: So we should be stressing very much early childhood and early intervention?

Ms FABIG: Yes.

The Hon. MARIE FICARRA: That would be an investment in the future.

Ms FABIG: Yes. Pay for a basic chair. If parents want the fandangle one, let them pay the difference, sure, but just give them the basic chair to start with.

Mr OSBICH: Sometimes when you go to PADP, they have only been given a restricted line of products because that is all their budgets allow. Sometimes you go in there and they say these are the three wheelchairs. In my wife's case, as I said, she is a little on the large size. She would not fit into any of those three. So, sometimes you end up in the situation where the OT would have given us the wheelchair on day one, but she would not have fitted in the three wheelchairs they offered. Plus, she is a long-bodied lady. She is about five feet nine when she stands and all three wheelchairs are aimed at people who have strong upper body strength and can sit very straight. So, she needs something wider that has bigger arms. It does not take an OT to tell you within two minutes of looking at them; you say, "Sorry, my wife will not fit in any of those three wheelchairs" yet they are the only three available. That is when the unfortunate OT or whoever is involved has to research to see what is available who knows where. As the lady to my right said, sometimes you know better because you have done the research, and it would be nice to be able to go up and say, "This is what I want."

The Hon. MARIE FICARRA: The provision of applicable appliances needs to be expanded. The procedure sounds very restrictive.

Mr OSBICH: I think in a sort of backward way they are saying that we would abuse the system. I can tell you that these people are not going to abuse the system. They are trying to control the funds and, unfortunately, people with disabilities can be expensive. It would just be nice to be able to get to the things quicker. The one thing I have noticed PADP does, which a lot of people have not mentioned, is that you could return it. Sometimes a product could be used for two or three years and you could get almost like brownie points. If you return it, you get a bonus for having purchased it and you could upgrade to something else. That is a service that PADP has been good in certain things we have used. We have used them for only a short while because my wife progressed, or deteriorated, and so we could no longer use that appliance. Sometimes that is a good process because if you do purchase it yourself, you do not know what to do with it once the person no longer can use it.

Mr IAN COHEN: Ms Fabig, what will happen to that wonderful wheelchair your child has once she has grown up?

Ms FABIG: Thankfully she is small. So, I hope she can use it for a long time. She will need a bigger chair when she gets older although, fingers crossed, maybe she will walk. What I will do depends very much on my finances. I will try to sell the chair or if I do feel very generous and we can afford it, I would like to donate the chair. I know there are kids out there who could use the chair but cannot buy it. So, if we can in any way afford it—we have discussed it with my father-in-law, who bought the chair—I would like to donate it because that chair will still go for 10 years and there could be another two children using that chair.

Reverend the Hon. Dr GORDON MOYES: Have any of you been assisted by a not-four-profit organisation like Technical Aid to the Disabled [TAD]? They are the type of organisations who will take your chair and renovate it or repair it if needed.

Ms FABIG: Not quite. They do bikes. They do not really modify a wheelchair like that. They do not modify a powered chair like that. They will do a standing frame or a sitting chair. We have had some help from them for those particular items, but as far as I know they do not touch powered chairs.

CHAIR: Thank you very much for taking the time to attend to today. We understand that it has been at considerable effort and experience for you. We are very grateful. We will do our very best to make sure that your recommendations are incorporated and, hopefully, we will achieve some better outcomes. Thank you for what you do for your loved ones. It is much appreciated.

(The witnesses withdrew)

GREGORY KILLEEN, 34 Dent Street, Banksmeadow, and

BARRY BRYAN, Coordinator, Lymphoedema Support Group, 100 Mount Street, Murrurundi, sworn and examined:

Mr KILLEEN: I am representing myself as an individual, but as per my submission I am also making representation as a consumer of my local PADP advisory committee and also the State PADP advisory committee. I also work for the National Disability Organisation as an information officer, but I am not representing that organisation today.

CHAIR: We give people the opportunity to make a brief opening statement. You may have noticed that sometimes that can stretch to a quite lengthy statement. We prefer that it be rather short. Would either of you care to make an opening statement?

Mr KILLEEN: I thank the Committee for undertaking this Inquiry into the Program of Appliances for Disabled People [PADP]. I hope the submissions will enable the Committee to capture the importance of PADP to its stakeholders, especially to people with a disability, and to realise the ongoing negative impact the existing chronic underfunding to this extremely important program is having on everyone.

Mr BRYAN: I do not think I can elaborate on what Greg already has said.

The Hon. MARIE FICARRA: You were present when carers and representatives from the Department of Health made their statements. We are told always that everything is in hand and the PricewaterhouseCoopers review is following up with all the recommendations. Is there any feedback you would like to provide to the Committee on what was stated this morning from the Department of Health bureaucrats?

Mr KILLEEN: When the PricewaterhouseCoopers review was given to the Government, it was not made publicly available. As a member of the State advisory committee, we were never privy to the contents of it. We were always told that the recommendations that were no-brainers—that is not my terminology; that is the terminology of the chair of the meeting—were being undertaken as part of the review of PADP. We were not privy to all the other stuff that was supposedly sensitive. In regards to the percentages and budgets that have been allocated and the increases over periods of time, they may have been over 100 per cent, but the fact is that the population has grown, people have gotten older, people are surviving injury, illnesses and diseases and are living longer. Regardless of that increase in funding it still does not meet the unmet need of people in the community who are trying to survive.

The Hon. MARIE FICARRA: We have been given figures about those who are suffering from disabilities in various sectors. What percentage of growth is there? You are right; people are living longer and often they are surviving injuries.

Mr KILLEEN: The Australian Bureau of Statistics found that about one in five people in Australia had been identified as having a disability. Obviously a lot of people do not see themselves as having a disability, for example, a lot of older people who have a crook knee, a bad back, or a bit of arthritis. A lot of those people do not identify, but obviously more than 20 per cent of people have some type of disability.

The Hon. MARIE FICARRA: What do you think about the centralisation of lodgement centres?

Mr KILLEEN: If there is to be some sort of efficiency in running PADP, obviously that is a good thing. I have heard that a lot of people are concerned about the fact that they will lose touch with their local PADP lodgement centre. They have not had concerns when they have rung them up to place an order for some items because they know the person and it is easy for them to act. I have also heard that therapists have good relationships with some of the lodgement centre coordinators and that they ring up to find out what stage their applications have reached, or anything to do with applications. Some concern has been expressed about having an unknown person at a call centre.

The Hon. MARIE FICARRA: You referred in your submission to hospital beds and to the cost of maintaining them when patients who are ready to be discharged are unable to be discharged because the system is not providing them with what they need. Today we heard from the Department of Health that it is multifaceted and that it has to have everything in place. Is there enough coordination? I would have thought that priority should be placed on getting those people into their homes as soon as possible because public hospital waiting lists are critical. From your experience are people left in hospitals for too long?

Mr KILLEEN: I do not know of any personal situation, but anecdotally I have heard over many years about people in hospital waiting to get out who cannot do so as they do not have specific pieces of equipment. Bronwyn Scott referred earlier to a variety of support needs in the community that often prevent people from leaving hospital. Everyone hears about waiting lists and about people trying to get into hospital to get a public hospital bed. In this situation people cannot get out of hospital because they cannot get their support needs. The problem we have in New South Wales is that things are not provided by way of a whole-of-government approach.

Things such as disability services, health, home modifications and PADP are all required. Those links in the chain are required to support someone who is leaving the hospital and who is going into the community. It is false economy to leave someone in a hospital bed for a week longer than is needed because there is not enough money in the equipment program to supply some aide or appliance that would help him or her to live in the community. It all comes from the New South Wales health budget, so why are they not talking to one another?

The Hon. MARIE FICARRA: Exactly.

Reverend the Hon. Dr GORDON MOYES: In your submission there are a couple of hurtful points, for example, the delay between someone being measured for compression garments for lymph oedema and the arrival of those garments. By the time the garments arrive they are already out of date and out of size. Is that is a major issue?

Mr BRYAN: It is a major issue in the sense that the manufacturer will not supply when there is a delay of six or eight weeks. The reason for that is that the oedema is again building up.

Reverend the Hon. Dr GORDON MOYES: And the manufacturer does not want to be blamed for the garment not functioning as it ought to function?

Mr BRYAN: Exactly, because they are not cheap.

Reverend the Hon. Dr GORDON MOYES: Having heard about the central supply system and, as a result of the question asked earlier by the Hon. Christine Robertson, that appliances were available throughout the State, whether in metropolitan, regional or rural areas, you do not think that people living in rural or regional areas rather than in metropolitan areas are eligible to be fitted or provided with compression garments?

Mr BRYAN: There is a multitude of problems. One problem is finding a qualified therapist to be able to measure someone for the garment—an acceptable therapist who has done all the necessary training for the manufacturer or the supplier. A second problem is that many people are approaching PADP for assistance and they are getting a multitude of different answers, depending on where they apply. I must confess that I have been in the system for over 10 years. PADP staff members probably say, "It is him again." You have a file and you are known.

I have not experienced some of those delays and I also have an active therapist who chases things up for me. Again, I have that personal contact because I have been getting garments for a number of years. But for new people coming into the system and, in particular, for ladies in the bush who have had mastectomies, they are isolated. They have been through the cancer, they have now developed an enormous arm, and they are finding it impossible to get help and assistance, which is no fault of the PADP.

Reverend the Hon. Dr GORDON MOYES: The centralised system will not help those persons?

Mr BRYAN: I find it hard to understand how people in Sydney will service areas such as Moree and out through to the western region. Currently, the only two people who are qualified to measure them are located at Tamworth hospital. Because of budgetary restraints at that hospital they can only measure them on one day a month. You can imagine that there is a heck of a delay getting measured for a start. In many instances these people have been hospitalised and, whilst they are waiting, they get infections and cellulite, which is nasty. It is a mammoth problem.

The problem with approaching PADP staff basically has been that the person at the other end has no knowledge of the implications of lymph oedema, or what impact any delay would have on a person. Those people really do not know. I was lucky in a sense. When I first got lymph oedema I put on 46 kilograms in three months. I applied through staff at the Wallsend PADP. When I approached them for my first compression garments it was 42 degrees Celsius, so I wore a pair of shorts and a polo top.

There I sat in compression garments covering my arms, legs and whatever. I staggered into the office and the woman took one look at me and said, "Come this way." From that day onwards I received tremendous assistance, perhaps because that lady could see that it was not just a case of a swollen arm. For many of our people it is a case of just one swollen limb, but many people are now housebound, which is a major hassle.

Mr IAN COHEN: Did you seek assistance from the PADP?

Mr BRYAN: Yes.

Mr IAN COHEN: You and Mr Killeen, as activists, have had to contend with bureaucratic barriers and the problems that are experienced in every department. We have heard a lot about the Government centralising its activities. Is there another way? Will that resolve the problem, or is there room in these organisations or departments to expedite that role or to facilitate action? Is that the way to go, or do you have any other suggestions?

Mr KILLEEN: With centralisation you move it away from health.

Mr IAN COHEN: Health bureaucrats said that they were working on centralising the process and other people said that they had nodes in particular areas where they knew their customers. As you just mentioned, there are advantages in that. However, the Government is moving towards achieving efficiencies through centralisation. As users and activists in that area, could the needs of people be better facilitated through a different model of operation?

Mr KILLEEN: I have no comment about or opinion on how to improve or supervise this operation. Sometimes it is difficult to get my head around the way it is operating now, as we do not have a uniform service across the State. It would be a good thing if we had a one-stop shop for all our services. If it saved money it could be put back into the PADP, which I suppose would be another good thing. As people have said, there are problems at local lodgement centres. You can get something from one lodgement centre and one area health service but you cannot get it from another. The New South Wales equipment study took place in 1997 and there was a review of the efficiency of the PADP program.

Since its inception in 1999 the advisory committee has been going through all the recommendations and rolling them out. Everything is meant to be uniform across the State. People are getting different stories about co-payments and about what they can receive. Some people have been told that their supplies will be provided every six months. Obviously, if they come every six months the PADP will save on postage and handling fees. One person in a regional area said, "I cannot get any supplies. They should be posted every month." There would be 12 or 13 delivery costs to that PADP lodgement centre for every person making an application, instead of what occurs at the Prince of Wales Hospital.

Someone should be able to make an application and not have supplies delivered every six months. There are two delivery times and 12 or 13 delivery costs, depending on whether you go with a calendar month or with a four-week delivery. It is crazy.

Mr BRYAN: There is a lot of confusion because people are getting different responses from the different locations at which they apply. I run a hotline from home. They ring me and ask for advice. They are experiencing different sorts of concerns and in some cases they are panicking because they are swelling by the day and they are afraid that their cancers will return, or whatever. You say to them, "This is the experience. You go to PADP, you get your therapist to give you the measurements and so on, and this is what should happen." Then you get phone calls from angry people who say, "No, we cannot get them. Where do we go from here?" It is rather embarrassing.

Mr KILLEEN: The question that was asked was whether there was any other way of providing the service, apart from centralisation. I would like to make a comment about the lady with the child who was told on making an application that the child was not eligible for a wheelchair. PADP policy is that all children with a disability are eligible for PADP. They are not means tested against the income of their parents or guardians. I could not understand why she had been told that the child was not eligible.

Mr IAN COHEN: Was that for a wheelchair, or does it also cover a child for a powered wheelchair?

Mr KILLEEN: Everything.

The Hon. CHRISTINE ROBERTSON: I think it was an age issue and it related to current definitions.

Mr KILLEEN: No, she just said that she was told. When she rang up or the therapist rang up and said, "Can I put an application in?" she was told, "No, not eligible." She would not afford the wheelchairs but was still told "not eligible." That was absolutely incorrect. The advisory committee got that PADP policy implemented about three, four, five years ago that all children are not means tested against their parents' income. It is given as an entitlement, just as they are required to go to school.

CHAIR: The Committee might clarify that. Our understanding is that she was talking about the age of the child and the child's capacity to use a motorised wheelchair. We will clarify that, according to what you are saying. It is my understanding that it was not so much a means test issue, rather the child's age and the fact that they wanted a motorised wheelchair for the child at that age.

Mr KILLEEN: That would have been an assessment made by that lodgement centre and the information that the lodgement centre gave to her on the application.

CHAIR: That is right. We will check that.

The Hon. CHRISTINE ROBERTSON: All of your information is very interesting. A great deal of it points to the issue of the processes of individual lodgement centres. Do either of you have any stories about gate-keeping type behaviour—people deciding who is worth what?

Mr BRYAN: Somebody must make that judgement at some stage when the applications come in, if their funds are being used a bit faster than they expected. I had a lady ring me only a matter of a month ago now. She was told it would be at least six months before she could make an application. We redirected her and she went to another centre and the application was processed straightaway.

The Hon. CHRISTINE ROBERTSON: They are talking about centralisation of the lodgements. They are not talking about the services and the measurement issues, which is the issue you are talking about of only two workers in the whole of the New England and north-west area. It is a service provider issue, a clinical service issue.

Mr BRYAN: That is a clinical service provider issue. Once we overcome that hurdle by having them come down to Sydney or pay privately for someone who is qualified to do the job, then supplying PADP with the order and the details of the garments required, if there is then a delay the whole thing is wasted because the garments are useless to them, plus the manufacturers reject them.

The Hon. CHRISTINE ROBERTSON: The changes they are implementing should mean that the order will be dealt with far more efficiently in the lodgement process and the budget for Enable is being separated from the area health services. So different issues will come into play about efficiency. Is that what you perceive will happen with the lodgement process?

Mr BRYAN: One would hope.

The Hon. CHRISTINE ROBERTSON: Do you think the issue of equity still relates to the clinical prescribers? Your stories are often about clinical prescribers, not having them where they are needed.

Mr BRYAN: For people through our system with lymphoedema the problem is twofold. It is, one, having people qualified to treat them, let alone anything else. Once they have had that treatment, it is then a person being qualified to do the measurements. Their numbers are very light on the ground. Unfortunately, our condition is very labour intensive, so the fabric systems do not wish to know us, which one can understand as it is the money game. The problem from a patient's point of view is that it is very, very frustrating. You have got the condition, you have then spent the money on getting oedema down. You have got the measurements and then if there is a delay at the stage of ordering the garments the whole effort has been wasted.

The Hon. CHRISTINE ROBERTSON: The issue is about you being functional.

Mr BRYAN: Yes. Their frustration gets even worse.

The Hon. CHRISTINE ROBERTSON: I am trying to get a handle on this issue. The centralisation of lodgement has not yet occurred. It is still happening at the area service level.

Mr KILLEEN: I think Bronwyn was talking about rolling out by 2010. I would suggest when the department starts to change over from the current system to centralisation that they just do not stop one system and start another. Maybe they can start to roll it out as a parallel service for some time, just for a smooth interruption of the service and the people to get their head around it. I think that would be preferential.

The Hon. GREG DONNELLY: I believe both of you were in the room when we heard the witnesses before morning tea. It was explained to us with respect to some of the costs and expenses associated with the management of the condition of their disabled children that rather than waiting to work through the PADP process they will go out and make the purchase. It did appear though, at least with respect to some of the items, there was a possibility, perhaps a strong possibility, that they could make a claim and ultimately be reimbursed. With your respective experiences, did you find that the frustration levels build up with people with disabilities, and instead of working their way through the process, ultimately pragmatically they do what needs to be done, either at their own expense or with the support of family members or the community, to obtain what they need to get by.

Mr KILLEEN: There are a lot of people who are eligible for PADP and they put their application in. With the underfunding they are put on a waiting list. The waiting list would be longer, but the waiting list has only the people who have made an application. There are many people out there who have rung up and said, "I want to put in an application for this" and over the years they have been told, "There is no money, there is no funding. If you get put on the waiting list it will be two years." We have encouraged people to put their application in to give a true indication of what the demand is on the service. When people ring up and are told "There is no money" and they do not put an application in, it is not a true indication of the demand and the actual amount of money that is required.

The Hon. GREG DONNELLY: Is that said to people on a regular basis that there is no funding available for their particular claim?

Mr KILLEEN: Absolutely, depending on the way the lodgement centres manage their money and they spend their allocated annual budget. The demand in the Prince of Wales when I first started was $350,000. We were meeting every month. We meet every two months now. We are now allocating $50,000 to $70,000 worth of money to aids and appliances every two months, albeit that the list of applications is five spreadsheets with a total value of $300,000. There will always be a waiting list if there is not enough money in the budget. The people on the waiting list is not a true indication of the demand on the service because there are people going out to Variety, Sunshine, Lions service clubs, their family. They beg, borrow and steal. They have charity fundraisers, depending on where they are. There are people going to other places to get their aids appliances, particularly children because they are growing and need the appropriately assessed and prescribed equipment, otherwise they could end up with all sorts of other health conditions like scoliosis and deformities if their posture is not maintained in the wheelchair. If they are not getting the appropriate type therapy aids their development will be impaired.

It is a really important program. I do not know if the Government actually understands how valuable it is to people with disabilities and their families. This is the reason why it is great to have this inquiry to make people understand how important it is and how much value it is for consumers and other stakeholders who want to access it. It is a small, small $24 million, apart from the extra $11 million that has been put in this financial year. An amount of $24 million per year recurrent out of an $11 billion Health budget is really, really small, but the implications of not funding it appropriately are enormous, not only on the people with disabilities and their families but on the other stakeholders, like equipment suppliers. They go and give a quotation and may not get an order for after 12 months. When the person comes to the top of the list they go back to the supplier and their item may not be available anymore. The therapist has to wait for them to come out and do another assessment and go and trial another three wheelchairs. It snowballs.

CHAIR: Mr Killeen, your submission talks about databases and the need for a quality database. Other submissions have raised the same issue that although there have been a couple of reviews there does not seem to be an appropriate database system that tracks usage and availability of equipment in order to determine a whole range of other factors.

Mr KILLEEN: Forward budgeting, it is called.

CHAIR: Could you discuss that?

Mr KILLEEN: In the initial commencement of the PADP advisory committee, we were stage one back in 1999. There were two sides of the people who were on the committee. There were a lot of disability organisation representatives, PADP coordinators, physiotherapists, all those different stakeholders. They have all gone in and said that there needs to be more money. The chair said, "Treasury will not provide any more money unless we get the appropriate data. We will need to rely on and develop a PADP information system that will be able to gather the information and find out the demand." That was to go to Treasury—here are the statistics, here are the data. They created a dead dog of a database that they flogged year after year. They had version one. They paid $100,000 for consultants for version two. They came up with version three and then back in 2005 I worked with a disability sector delegation to see Morris Iemma, the then Minister for Health, in May 2005 and asked him for more money. We were not getting it through any other means, so we thought we will go directly to the Minister, who instigated what is now the PricewaterhouseCoopers review.

In that, we still need the information system. We have been going since 1999 looking for an appropriate information system so that Health can go to Treasury and show what the demand is. You only need to ring up all the lodgement centres. He told us that the Western Area Health Service had an outstanding waiting list of $500,000 of appliances. That was back in 2005. So they did not need an information system for what the demand was on the service. There needs to be an information system database, but the Government and the department knows what that the demand is.

CHAIR: You say in your submission that the top-up money that has been put into the system this year through State and Federal funding with a view to reducing the waiting list is a more accurate representation of what the recurrent funding should be every year. Would you explain that because it is a big difference in terms of what we imagine the recurrent funding will go back to after this top-up?

Mr KILLEEN: Any additional funding is obviously going to be a benefit. Obviously the $24 million recurrent funding is not meeting the needs. Just putting $11 million into it this financial year to cover the waiting list, I do not know how much money is on the actual total waiting list, whether that $11 million will cover it all part of it will cover it. Obviously, if there is more money in the system, hopefully people will put in an application, so all those people who were not on the waiting list because they have been going elsewhere will come into the system. So $36 million for this current financial year might cover the current waiting list, but the real demand for service, if it is appropriately funded, would be more than $36 million. There is obviously a need for appropriate data in an information database to find out what the demand is on the service.

CHAIR: Both of you might want to comment on the co-payment of $100. We have had a number of submissions and heard evidence today about that co-payment and the cost of retrieving that $100—suggestions that it should be abolished and it would be more cost effective to do that. What are your views on that?

Mr BRYAN: A lot of the people who come through our system in the support group do not have a major hassle with $100; they see that as a fair and equitable thing. Whether it should be increased, I would reserve judgment on their reaction because most of them are pensioners relying on pensions, in the main. Most of them are ladies in that particular instance; 80 per cent of them are ladies. About 90 per cent of them have been through cancer so are struggling financially usually. So an increase would probably be an impost on those in the majority of cases but not all.

CHAIR: I have not heard anyone suggest it be increased. There has been some suggestion of means testing, and there have been suggestions of abolishing it altogether.

Mr KILLEEN: I am fairly opinionated on the co-payment. I think it should be abolished. It was introduced as an eleventh hour co-payment. The decision of that, I think, was about five years ago. It is an administrative nightmare. It was grandfathered. Anyone who had been receiving PADP before the co-payment was introduced is not required to pay it. People who were paying it at the time when they came up with the idea there should be a co-payment will continue to pay it. Anyone applying for PADP from the day it was made law, when it was created by Treasury, pays it. So when somebody rings up and makes an order, the coordinators have no idea. They have never asked, "How long have you been on the system for?" I know many people with disabilities who have been getting PADP for many years who have been asked to pay the co-payment and they have absolutely no idea they were not required to pay it.

For myself personally, I have been getting PADP for many years. I do not pay the co-payment. But asking people—I know them myself because I am aware of the situation—with a disability who are eligible have so many unavoidable extra costs of having a disability. All these means tests, they always want to know what your income is. They never want to know what your expenses are. There are extra costs on health, medical, equipment, personal care, transport—you name it, it is all there. They want $100 a year to access the service and to administrate that. With all those anomalies involved of whether you have to pay it or not, it should be abolished completely.

CHAIR: Thank you for appearing today and for your submissions, which are outstanding. Thank you for your advocacy on behalf of others.

Mr KILLEEN: I have one final comment. There are probably many other health programs that cost a lot more money per year than PADP, and I am sure many of them do not have a co-payment.

(The witnesses withdrew)

GRAHAM OPIE, Chief Executive Officer, Motor Neurone Disease Association of New South Wales, Locked Bag 5005, Gladesville, affirmed and examined:

CHAIR: Would you like to make a brief opening statement, or can we go straight to asking your question on your submission?

Mr OPIE: I will give just a brief introduction—I am sure you do not need it—about motor neurone disease. Given the nature of the disease, in journals from diagnosis to death the time period is usually about five years. On our books are 348 members in New South Wales. Twenty-seven months is the average and the median as well from diagnosis to death. Therefore PADP, given the regional nature, the fact that we do not know terribly much about what is available in each region, and the assessment process means very little to our members. As such, we have a large equipment pool that provided, last year, over $1.2 million worth of equipment to people across New South Wales. That was also retrieved and maintained by us free of charge. I have to acknowledge DADHC, which has provided one-off funding for the past three years to help us with our equipment pool. So the evidence I am giving you is basically from an outsider's point of view of our members' possible inability to access PADP. I think our equipment pool—I am biased—is a shining light of how equipment pools do work and how we track and maintain that equipment.

CHAIR: So you see that that could be and should be, from your knowledge, rolled out more comprehensively with the PADP program, that equipment is pooled and maintained perhaps on a centralised basis?

Mr OPIE: I firmly believe that a centralised basis is the only way to go. Your previous speaker spoke about a database. From what I gather, and again from an outsider, depending on the region, in some regions equipment is basically given out and written off in some cases. There is inadequate tracking of equipment. We just do not know where the equipment is. When I spoke to the people from PriceWaterhouse they indicated that the review probably would not help our members, but I told him that I just needed confirmation of whether it would or would not help our members, because at the moment we just do not know. We use PADP as a stop-gap where we wait for equipment to come in. We ask them to apply for PADP. It is hit and miss as to whether they get it.

The Hon. CHRISTINE ROBERTSON: Depending on the region?

Mr OPIE: Depending on the region.

CHAIR: So it is not because of the short-term, degenerative nature of motor neurone disease that you are excluded from the program; it is just the time factor.

Mr OPIE: No, it is the time factor.

CHAIR: So if things were fast-tracked your members would apply and use the PADP system more?

Mr OPIE: Yes. We go through the allied health professional network in that when we provide equipment we always rely on a referral from a Department of Health allied health professional or a private professional, in much the same way that PADP operates.

CHAIR: So if your clients were using the PADP program more, if it was a more efficient system and they were able to get equipment quickly, how would that affect the equipment pool and provision that you offer?

Mr OPIE: It may well take pressure off our equipment pool. At the moment, as I said, with those one-off fundings from DADHC we have managed to decrease our waiting list to between one and two weeks to be able to get that equipment out. But you are right, it is the rapid nature of the progression; if there is a three-month assessment process, in three months the person may have gone through two or three phases and the manual wheelchair may well need to be an electric wheelchair by that stage for people with motor neurone disease.

CHAIR: So your funding for equipment from DADHC is one-off funding rather than recurrent funding?

Mr OPIE: We have recurrent funding from the Department of Health that accounts for 20 per cent of our total operating expenses. The 80 per cent that we rely on, donations and bequests and mail-outs and what have you. Over the past three years DADHC has come on board and provided funding and a constructive partnership with the organisation.

The Hon. MARIE FICARRA: Most of your funds, if you are not part of PADP because of the slowness of the program, it is mainly donations and bequests?

Mr OPIE: Yes, 80 per cent—about $1.6 million we rely on in bequests and donations and mail-outs and what have you.

The Hon. MARIE FICARRA: What would you like to see in our recommendations for PADP? It seems inequitable that people suffering from motor neurone disease are not given some support from the Government. How can it work better for your clients?

Mr OPIE: I should emphasise that that is obviously not a bias against people with motor neurone disease; it is just the assessment process is slow. I think from a centralised system a way of indicating in particular regions what materials are available, the time frame to get them all, and also, as I said, a tracking device in some shape or form. I just think that whether it is the State Government or the Federal Government or a private company or what have you, that, as your previous speaker mentioned, something that can track that equipment and something that can tell a person or an organisation such as ours just what equipment is available in their particular region at any given time. As the previous speaker said, it is not that difficult to work out.

The Hon. MARIE FICARRA: How are your statistics for motor neurone disease? Excuse my ignorance but how is it travelling over time?

Mr OPIE: It is entirely dependent at the moment. There is no increase. There is an increase with population but, as I said, we have 356 members now. We estimate there are probably 400 people in New South Wales with motor neurone disease at any given time, but that is not on the increase as far as we are aware.

Mr IAN COHEN: Are we to accept perhaps that motor neurone disease is just in the too-hard basket to gain appropriate or constructive support from government agencies, given the massive problems that they have and we are encountering it today in terms of time sequences? It seems like there is no real way around it. Is that a reasonable call?

Mr OPIE: First of all, I think the NGOs were set up to basically advocate and work for a specific group, that there was a perceived need. As far as too hard, as I said, we are working very constructively with DADHC at the moment because with their referrals, with community options and out in the field they are working very well for us. As far as aids and equipment go, that was seen very early on as being a necessity for our members, obviously from small things like commodes or walking chair frames all the way through to electric wheelchairs that cost between $15,000 and $20,000 each. We have bitten the bullet and said that that is what we have to do. If we are an NGO we were set up to serve our membership, and that is what we need to do to serve our membership. I do not think anything is in the too-hard basket. I think that sometimes people slip through the net and what have you but I think that is the role of our organisation. I think we have advocated fairly strongly and got the money.

Mr IAN COHEN: So, you are getting the money from the Government.

Mr OPIE: Yes, through DADHC, and the Department of Health provides 20 per cent on an ongoing basis, a recurrent basis.

Mr IAN COHEN: Why can DADHC do it but PADP cannot?

Mr OPIE: It is expensive, but at what price do you value citizens of New South Wales? I think that the expense of $24 million is a tiny amount of money in the scheme of things.

The Hon. CHRISTINE ROBERTSON: If the changes that Health is talking about go forward in relation to centralisation and having a centralised equipment system, as you have, to know what is going on and have maintenance done properly centrally instead of in bits, will that work better for your organisation? Will you be working less parallel and more integrated? Will you be able to tap into it better?

Mr OPIE: I think beyond a shadow of doubt that would help, but as I said it is the time frame. EnableNSW has been up and running for a year or thereabouts and it is probably going to take a long time for it to happen.

The Hon. CHRISTINE ROBERTSON: They have made the time for change quite long, haven't they?

Mr OPIE: Yes.

The Hon. CHRISTINE ROBERTSON: What do you think of that?

Mr OPIE: I think that it needs to be done. I think knowing what is available is the key. I am a realist. I am an administrator, not a health professional. I believe that if you want what you say you want, you have to have facts to back that up. If we want to go to Treasury with something, we have to have really clear detail saying that this is the unmet need and this is what is being met at the moment. Therefore, if this is the unmet need, these are citizens of New South Wales who deserve this. Why is it not being met? If somebody goes to you with anecdotal evidence I think I would dismiss it as well. It has to be factual evidence.

The Hon. CHRISTINE ROBERTSON: I guess we understand the numbers and getting the figures together, but it is the process of the implementation of the current recommendations. I think the previous witnesses were talking about a parallel process, leaving some of the local lodgement centres working while the central lodgement process is set up. Do you have any ideas on that? Would it create a lovely hotchpotch?

Mr OPIE: I think obviously in regional areas relationships are built up.

The Hon. CHRISTINE ROBERTSON: Yes, but some of them are "vacheads". I have been out there.

Mr OPIE: You said that, not me.

The Hon. CHRISTINE ROBERTSON: I am quite happy to say that.

Mr OPIE: We do not know. I come back to the point that it should be a centralised database and a centralised system. It should be accessible by people such as NGOs, not just Department of Health but across the board, so that we can say we help them apply for the role and get them to speak to another health professional to make that referral because we know that equipment is available in Griffith, or wherever, and we know it is available within the next two or three weeks. A database like that obviously takes time because it has been going for a long time as is. I am just not sure how long it will take.

The Hon. GREG DONNELLY: I think you were probably in the room when I asked another witness a question about the accuracy of the numbers of people with disabilities, which goes to the point you were just talking about—facts. He indicated it was his view that were probably a lot more people with disabilities out there but for the fact there are concerns that if they apply it will take too long to have their applications processed and the waiting list could be up to two years or whatever the case may be. Would you agree with that general comment that our understanding as the State of New South Wales of the number of people with disabilities is not particularly accurate?

Mr OPIE: I think it is underrepresented. I am sure of that. Our members are a classic example. There is nothing more frustrating than knowing you are going downhill at a rapid rate of knots, you are told to apply for something and you sit around waiting for it, just getting frustrated. Why would you bother doing it?

The Hon. CHRISTINE ROBERTSON: So you do not go on the list?

Mr OPIE: No. You do not go on the list.

The Hon. GREG DONNELLY: I am not asking you to guesstimate it, but do you have a view of a methodology that could be developed or put in place to enable the better assessment of numbers of people with disabilities?

Mr OPIE: I could not tell you. I would have to take that one on notice.

Mr IAN COHEN: A bit more money thrown at the system might flush them out.

Mr OPIE: As I said, I am a realist. Taxpayers' dollars go into certain areas and what goes into one area gets taken out of another area. I think disability services and health are two areas—and it has been indicated federally—where there is a dramatic shortfall in funding. There is a huge gap in unmet need and it is growing, and with an ageing population it is growing at a rapid rate of knots. Unless we bite the bullet and do something we are going to be in a hell of a lot of trouble.

CHAIR: I want to get a comparison between what is going on with the maintenance of the equipment you provide to your members and anecdotally with PADP. We have had one witness tell us that a broken footplate on a wheelchair required them to seek an appointment with an occupational therapist [OT] to get the OT to write a report to say yes, the footplate was broken, and that had to go to PADP so someone could come back and say, yes, you can get the footplate fixed. That sounds like sheer lunacy to me and not what would happen in the private sector with anything. If there is a wheelchair that has to be fixed it should be fixed and an invoice put in and paid. How do you manage that sort of system in your provision of equipment?

Mr OPIE: We use allied health professionals, OTs, for referrals, but when it comes to maintenance of equipment the requests are sent straight to our office and we go straight to wherever the repair person is and it is done directly. We know our equipment and we know what is out there and we get it fixed. We have a good relationship with the suppliers in New South Wales. If they say something is wrong, then we know something is wrong and we get it fixed.

CHAIR: You know the usual progress of motor neurone disease, so when you give someone a piece of equipment would you then predict they might need extra equipment down the track so that it was ready when they might need it?

Mr OPIE: Obviously time frames differ from person to person, and depending on where the onset of the disease occurs determines what sort of equipment they will need and when. That is unpredictable; it is as and when the needs arise. Our equipment coordinator manages to keep our warehouse relatively empty with a rapid turnover.

CHAIR: Currently it seems as though Health is taking almost total responsibility for PADP. We have had some suggestions that DADHC would be a better department to manage it. Given that there is a range of people who are clients of the PADP program from older people with a disability to young children with a disability—a broad cross-section—do you think DADHC is better to manage that or should it stay in Health?

Mr OPIE: I think there is probably a better fit with DADHC given, as you said, the cross-section of people with disabilities. Again, it is a broken system, and who is the best to provide that? In Victoria, communication devices are hived out to an NGO that provides the communication devices for all the individuals or other NGOs that need them. Whether it is a singly operated system that a for-profit runs or a not-for-profit runs or the Federal Government runs as a unit, as the review pointed out, it is a hotchpotch regionally and it needs to be taken on by somebody with the commitment to actually do something about it.

The Hon. CHRISTINE ROBERTSON: You may not know the answer to this, but does DADHC not have definitions that fit who is appropriate for its services?

Mr OPIE: For their particular services, yes.

The Hon. MARIE FICARRA: You mentioned allied health professionals and that the assessment is a quick process in your organisation and you rely on those professionals to give you those assessments. Can you explain what categories they fall into?

Mr OPIE: The vast majority are OTs, but when it comes to communication devices there are speech therapists and physiotherapists. It is really across the board but I would say the vast majority who provide the referrals are occupational therapists. We have a standardised referral form that is faxed through to our office and it is filled as quickly as possible. We also ensure that the allied health professional is there when the equipment arrives, particularly the larger pieces of equipment, because the person cannot actually operate it until the allied health professional shows them how to use it properly. We have issues with liability obviously, because we own the equipment, and we have to be very careful about that.

The Hon. MARIE FICARRA: You are not suffering from a shortage of these allied health professionals at the moment?

Mr OPIE: No, they are within the system, Department of Health, private organisations, NGOs, the whole works. They are an incredibly committed lot who really stand up and advocate for the people they help out.

The Hon. MARIE FICARRA: Do you think PADP is accessing as wide a variety of allied health professionals as it can?

Mr OPIE: There is an issue around communication devices. We would like to see communication devices included in PADP because as far as we are concerned that is an expense that is growing exponentially—

The Hon. CHRISTINE ROBERTSON: They are not on the list?

Mr OPIE: —they are not on the list—because of technology. A lot of our members cannot speak or communicate after a period of time. Technology obviously means there are some great devices out there but they are becoming more and more expensive. Ventilation machines or respiratory machines are not on the list either, forced or positive ventilation machines that our members use because their respiratory system breaks down. That is another issue because we do not encourage our members to purchase them and we do not have them because of the technology involved, so we co-pay 50 per cent of the rental costs a month for those ventilation machines.

The Hon. MARIE FICARRA: Could you provide that to the Committee? I would have thought that was life sustaining.

The Hon. CHRISTINE ROBERTSON: Just a bit more detail on those specific matters because we can use them for examples.

CHAIR: That is right. If you could take that on notice and come back to us with the sorts of equipment that you think would be useful to add to the PADP list. We can certainly raise that.

The Hon. CHRISTINE ROBERTSON: To use them as examples for the processes.

Mr OPIE: Yes.

Mr IAN COHEN: Did I get this right? It sounded like you had a super equipment coordinator. The expediting of things comes up with me constantly. We all recognise that things get bogged down. You mentioned an equipment coordinator and, if I heard you rightly, trusting the repairer to assess, report and repair as recognised. That sounds like a far more efficient way of going about it and cutting out quite a bit of toing and froing and bureaucratic brakes in the system. Could you comment on that?

Mr OPIE: First, you cannot have her! Secondly, she has been doing this for nearly six years now and has developed this relationship with suppliers and couriers. Couriers are a big thing. At the moment COPE are the only ones that will actually wrap because they require that electric wheelchairs be palletised and wrapped. COPE are the only ones who will do that at the moment, so we deal with them. We occasionally have issues with them but their drivers will go to a house in a remote community, wrap the piece of equipment, put it on a pallet and deliver it to our warehouse and office in Gladesville. It is her relationship that has actually made a huge difference.

The Hon. CHRISTINE ROBERTSON: But it is also the contracts, the way people have set up the contracts, is it not?

Mr OPIE: The contracts are standardised contracts. There is nothing exceptional about them. It is just what we want and what we will not tolerate.

Mr IAN COHEN: But you will have repairers making assessments directly?

Mr OPIE: That is right. We pay full price for all maintenance and for service and delivery of the equipment. So, we do not get exemptions.

Mr IAN COHEN: But if something that is broken down or is to be recycled lands in a repairer's workshop or factory, they are able to do some of the paperwork and then facilitate the—

Mr OPIE: They go out to the house generally, if it is a large piece of equipment, and will do the job there—unless it really needs to be taken back to the factory.

CHAIR: If you have anything else you want to provide to the Committee, you are quite welcome to do so. The secretariat staff may contact you to ask questions in relation to your evidence or submissions.

Mr OPIE: That is terrific. I would like to table this. We paid for our equipment coordinator to do a review of motor neurone disease equipment services across Australia. It is incredibly comprehensive; do not read it all. I would like to table that.

(The witness withdrew)

(Luncheon adjournment)

ANDREW BUCHANAN, Chairperson, Disability Council of New South Wales, sworn and examined, and

DOUGIE HERD, Executive Director, Disability Council of New South Wales, affirmed and examined:

CHAIR: We usually give our witnesses the opportunity to make a brief opening statement if they wish, or we can go straight into discussion on your submission. It is up to you.

Mr BUCHANAN: We would prefer to give a brief opening statement, if that is convenient to you.

CHAIR: Sure.

Mr BUCHANAN: I thank you and members of your Committee for inviting me and Dougie Herd, our executive director. Let me remind you, first of all, of our purpose. The Disability Council was established by the Community Welfare Act to advise government on issues affecting people with a disability and their families. Our council members are appointed by the Governor on the recommendation of the Minister for Disability Services. Members are selected on the basis of their experience and disability, their understanding of the issues, their knowledge of the service delivery and their ability to reflect and advise on government policy. The majority of council members are people with disability from across New South Wales.

We welcome the opportunity to give verbal evidence to your Committee and we hope to elaborate on our written submission of 1 September. I should begin my comments with an observation that may at first glance seem like a statement of the obvious. However, sometimes it is helpful to remind ourselves of the fundamentals of these matters. The program of appliances for disabled people is an essential contributor to the lives of many people with disability in this State. As we understand it, it assists 20,000 people every year. The program spends over $24 million of public money on a recurrent basis and, in this financial year, thanks to the welcome enhancement of an additional $11 million, as much as $35 million or $36 million. That is money well spent. As we indicated in our written submission, we probably believe that needs to be the base budget for the future.

Essential is a word that can be used rather loosely and too often, so I hope you will forgive me if I focus on its meaning when we talk of people with disability and their need for equipment provided through PADP and associated equipment programs. How can one say this well enough, with sufficient force? A colostomy bag is not a fashion accessory. A communication augmentation device is not the same as whatever the latest trendy iPhone might be in this week's top 10 IT gadgets in the Good Living section of the *Sydney Morning Herald.* If you are a ventilator dependent quad, the key word in that description is "dependent". If you are going to breathe you need the equipment that substitutes for those bits of your body that no longer function. The point I am making is that PADP and the programs managed by EnableNSW are equipment and health items that people who need them really do need. One is hesitant to personalise these matters to public policy, but in this instance it may be helpful to do so. The simple fact is that neither Dougie Herd nor I would be sitting before you this afternoon if we lacked the equipment, mobility devices, and, in Dougie's case, he is happy for me to make mention of continence management items.

Our council welcomed the PricewaterhouseCoopers review commenced, we recall, when the Hon. Morris Iemma was Minister for Health. We were pleased to learn that when the Government responded to the review it accepted 21 of the recommendations in total, sought further work on an additional four and did not support only two. The key reform that emerged from the review was the policy decision to move towards a unified statewide service through what we now know as EnableNSW. We strongly support that decision. The reform agenda being implemented by Enable will address many of the administration and procedural concerns about the program. We believe it has the potential to deliver a better, more efficient and more cost-effective service in which, as much as it is humanly possible, the dollars allocated by government to the program will be spent on equipment provision.

Having met with Bronwyn Scott of Enable who addressed a recent meeting of our Disability Council, I am confident that she and her team will take seriously the Government's intention to improve PADP and make it more responsive to people's needs. I hope that our written submission was clear in demonstrating our understanding of what those needs are. An ageing population with an increasing incidence of disability will have a greater need for longer periods of disability-related equipment. We cannot stress that enough. The population will demand equity and fairness, looking for timely and consistent action by the service, wherever they live in the State. We will need to be able to combine the economies of scale and efficiencies in a unified, back-office, centralised system with sensitive, appropriate and available local delivery of assessment, prescription provision and backup of needs and of the equipment that is supplied. They will be demanding challenges for the Government to address. More work must be done on the eligibility criteria for support through PADP. A case can be made that essential equipment that meets fundamental need ought to be made available free at the point of delivery. If we must have a system of determining eligibility, means testing and prioritisation of need, that system must be fair, reasonable and seen to be so wherever one lives and whatever one's equipment might be.

That brings me finally to the question of the budget. There is never enough money in the health budget. We all know that to be one of the truths of modern political life. Demand increases almost inexorably. The good health of our community is worth paying for. Any good equipment that supports people's health needs, keeping them out of hospital and active in the community, is part of what we need to pay for. We welcome the $11 million enhancement this year, as mentioned earlier. We think it probably takes the budget close to where it needs to be for PADP. From our perspective this means recurring commitment. These challenges face all of us. We need to find solutions.

I conclude with these observations. With Minister John Della Bosca now at Health and Associate Professor Debora Picone as director general, the service has the leaders it needs. PADP is a small part of their responsibilities but for the 20,000 people and more who rely on it we are hopeful that those effective leaders will now feel able to make transformative change occur on the basis of the reform agenda now being enacted through Enable. Thank you for having us.

CHAIR: In relation to the rollout and the response to the PricewaterhouseCoopers recommendations by EnableNSW, we heard this morning that a centralised lodgement system and a number of the initiatives and responses were not going to be in place until 2010. What is your view on that? It seems to me to be an incredible amount of time given that those recommendations have been accepted and the process established and able to go. Do you think that has taken too long?

Mr BUCHANAN: I imagine we would take the view that any time lag is too long. But at least this centralised system, as we understand it, is meant to bring about an effective streamlining of administration and therefore the longer it is delayed the longer somebody needing equipment is in a hospital bed costing more money in the long run. I imagine we would suggest that the shorter time period for real commencement and progress is too long.

The Hon. CHRISTINE ROBERTSON: Have you any indication as to why the timelines are so long, because they were made so long right at the beginning of the acceptance of the report?

Mr HERD: No idea other than the PADP reform agenda has historically taken some time to implement. If one can make this observation, I have now worked in the public service as the executive officer for the Disability Council for almost four years. It was my great privilege to work for the Physical Disability Council of New South Wales, a non-government advocacy organisation, before that. One of the duties I was asked to carry out by the committee responsible for governing that was to work with the office of the then Minister for Health to devise the terms of reference of what became the PricewaterhouseCoopers review.

I have changed jobs, worked for my current employer for four years and the Minister for Health has become Premier, served in that capacity for a number of years, and is about to leave government, and in all of that time the implementation has not been fully realised. What we have been told, our council received a guarantee from Bronwyn Scott when she came to meet with the council just six weeks ago is that the long lead-in time in which these things have been discussed is past, and that they have moved into the implementation phase, and that seems to me to be critically important. You do not need to be a rocket scientist to work out that it ought not to have taken this length of time to get us to here and we need to move quickly.

The Hon. CHRISTINE ROBERTSON: The project is still quite long?

Mr BUCHANAN: It is very long.

CHAIR: We are still talking about 2010. The Committee has received evidence about the $100 co-payment and people have suggested that it costs a lot to administer and that the benefits in terms of return to the government are questionable. Other people have suggested different formulas or abolishing it altogether. What is the view of your organisation on co-payment?

Mr BUCHANAN: Dougie is the expert on this but I think we would probably suggest abolishing it altogether. The administration costs and the time that is spent on collecting and streamlining could, in fact, just go to buying equipment and sorting it out. I think the Disability Council is into equity and fairness and being proactive and not into building a bureaucracy. I think it is regrettable and in one way, when you look at the whole emotive and psychological and emotional issues tied up with somebody with disability waiting for a piece of equipment, the last thing they want to do is to have an extra component of bureaucracy that is really unnecessary. Let us get down to it, get the gear and be active contributors in society rather than costing the Government more, and then leading to mental health issues as well.

Mr HERD: I think it is clear to everybody that the co-payment is not functioning as an income generating tool and that therefore seems to me clear that there is no purpose served in collecting it. Why pay staff to collect money that is not going towards equipment provision? It is not differing the course of the program so just get rid of it. I think everybody agrees that is a sensible thing to do.

CHAIR: The department is going to review it. The Committee has also received evidence that the waiting list is difficult to determine because a number of people do not go on the waiting list simply because it will take too long to get the equipment so they provide it themselves. What is your dealings or understanding of the waiting list and the reality of what that waiting list might be? Do you say if the top-up funding that is supposed to reduce the waiting list is recurrent funding that that is appropriate funding? Do you suggest that we will not end up with a waiting list because that amount of recurrent funding will resolve that problem all the time?

Mr HERD: We believe that the $11 million enhancement will purge the waiting list of people who have been on it for a while, particularly those who have waited for high-cost equipment. I am sure you have heard others say that we are talking about pieces of equipment that might be essential pieces of equipment that might be anywhere between $5,000 and $25,000. It is good that that purging will take place but the simple fact of the matter is that there is a continuing and recurring need for equipment. People come back year after year, after year with the need for equipment. People become disabled during the year and need new equipment, and our ageing population has an increasing demand. So that is why we have suggested in our submission and here that all of the evidence suggests that whilst the purging of the waiting list will be good, if that is all that happens there will be a build of waiting lists in subsequent years and it therefore makes sense to us to purge the list of people who have been on it for a while, but then to recognise that the base needs to be built upon.

All of the evidence that we have been able to look at seems to suggest that $37 million is about what it takes to cover the perception of what need is at the moment. But it is very difficult to be hard and fast about this. Waiting lists held by local lodgement centres do not measure the same thing all of the time. There is a problem about people believing that it takes so long, or has in the past taken so long to get equipment, that what is the point of putting yourself forward to sit on a waiting list for 18 months or two years. As a member of the advisory committee I have heard reports of non-government organisations in which, I think, for instance, the Spastic Centre that said it has people on their lists who are not on lodgement centre lists. I think we do not have as a robust a set of waiting list data as we need, and so that whole question about how information is gathered and retained by the system so that it can make sensible judgments about current and future need, is critically important. I believe that is one of the reasons why generally people favour an administration centralisation vehicle because it allows consistent data to be collected, kept current and monitored from a central strategic core. We can hopefully rely on what it tells us.

The key question is do people come onto the waiting list, their needs identified and then moved off it because the equipment is provided? If the answer to that question is "yes" then waiting lists can be helpful administrative tools. If it is just people languishing on a waiting list in the hope that they will get something some day then it is of no use to anybody.

The Hon. MARIE FICARRA: It would be sound to have good database in which to make these decisions of funding. Do you know the Government arrived at $11 million? Why not $10 million or $20 million? How can we get an accurate assessment, other than centralising the lodgement centres into one, of how many people in New South Wales with a disability for whom we need to provide services?

Mr HERD: I do not know the answer to your first question. Suck it and see might be how we got to $11 million. What is available? It sounds about the right number but that is only because I believe non-government organisations and I think it is reasonable to say staff inside the department and others who have looked at it are making their best guess estimation of what would be about right. I think it is good professional guesswork that has been done with as much information as people have available to them they try to assess what is required. I would not like to go to the wall to defend the waiting list or the assessment that comes out of it because I do not think it is robust enough. I do not think we have the data that we need, and that has been a problem as long as I have been a member of the advisory committee, which is now nine years.

When I first had a discussion as a member of the advisory committee about why we could not get robust data it was because we had 17 Area Health Services, we had four different information systems and we had 32 different lodgement centres and we were not able to pool all of that together. We are getting near the point, one hopes, where there is one system, one information system, one means of collecting it and we hope that will give us the data that we need. But it is difficult because we are not, as a community, yet completely confident that we know exactly how many people with disability we have got, where they live, what are their needs. There is not a robust set of data for these kind of social policy questions anywhere. The ABS and the statistics that came out of the census are beginning to give us a bit more accountable information, but it is good guesswork that does this and good professional judgment on the part of qualified staff. Let us hope that Enable has got those staff available. I hope I am not speaking out of turn about my public sector colleagues, but I think there is an impressive bunch of people doing a good piece of work at Enable now, and I think we should hope that they deliver quickly.

The Hon. MARIE FICARRA: Does any other State do service delivery better? Are there international systems, such as in Canada or New Zealand that you see aspects of service delivery for disabled people being quite good and you suggest as a recommendation? I am looking for improvements.

Mr HERD: I would not like to answer that question right here and now but if it is helpful we will go off and try to get a sensible answer pretty quickly.

Mr BUCHANAN: I think the Scandinavian countries tend to do it well but we shall explore that. I think your question is quite interesting in terms of how many. I think there is a minority in the disability sector who in fact would probably not use PADP simply because of the perceived bureaucracy and past experience. They will actually go out and purchase items independently; do you know what I mean?

CHAIR: And mortgage their house?

Mr BUCHANAN: Correct, that is the regrettable thing. It is the same analogy perhaps. I mean how do we actually work out how many carers there are throughout the State or throughout this country. There are many who just take that as part of their normal family commitment in terms of multicultural particularly. So I think it is very difficult to define. To complement Dougie's point about if, in fact, there was correct data collated and it was taken seriously and centralised, and in the end save money, it would be a very useful investment.

Mr IAN COHEN: You mentioned the centralised process, which is something the Government is seriously working towards. You say in your submission that historically the operation of PADP's eligibility criteria has not been consistent across the State, lacks equity, lacks transparency. Will you add any information in that area? Looking at that, and the problems that are involved currently, does centralisation solve the problem or are we collectively looking at other issues that may more effectively resolve this type of problem where we have got the inconsistency and lack of ability in one area for someone to get a piece of equipment that in another area is quite an easy thing to do?

Mr BUCHANAN: I think at least centralising it, as we have suggested that we are in favour, is that that is probably the better solution than what has occurred in the past. To be frank, there have been inconsistencies in approach and management. It is regarded as being accurate that those who live in the regional and remote parts of the State are at a disadvantage. One way at least of having a centralised streamlined system is that there should be equity for all. Whether you and I live in an isolated area like Cobar, as an example, surely we should not be inconvenienced or deprived simply because we are there rather than living in a sort of component of Sydney. In many ways it is a matter of drawing upon the past, looking at what has not worked, trying to decide what is now in place and putting our efforts into that and making sure that regional and rural, as we have outlined in the submission and in the letter of 1 September, is in fact highlighted.

Mr IAN COHEN: A witness earlier today from the Motor Neurone Disease Association demonstrated that that association seems to have its demand and supply chain pretty well worked out. Have you considered that? Do you have anything comment as to why that association is able to achieve pretty effective results given, of course, the nature of that disease? It cannot always access PADP because the waiting times are too long and the nature of the disease means that the requirements are changing constantly for those who suffer from it. Could you comment on that?

Mr BUCHANAN: Only to say that I think motor neurone disease perhaps is one of the more unpalatable challenges that somebody in the community would have. I think sometimes psychologically when that occurs an organisation is far more focused strategically on what it wants and in outlining how it can achieve things. It is also fair to say that there are differing levels of professionalism within the disability sector with different agencies. Would you like to comment further?

Mr HERD: I think I would like to make a kind of visual observation. I think the Motor Neurone Disease Association has been able to do what it does because it is small and nimbler than New South Wales Health in all of its diversity and largeness and fragmented service system. It has been given support through funding of individual members of its association. It has highly motivated personal commitment to solving problems of a relatively small population. I do not underestimate the challenges people face. This is part of the problem we have to deal with here. It has an ability to operate in a way in which perhaps we do not really want people to have to operate, which is that it knocks on the doors of Rotary or local communities and says, "We have this individual with this need who needs a wheelchair. Can we get it quickly please?" And the community dips into its pockets. We perhaps maybe want to move away from that if we can, yet hold on to the compassion, the passion and commitment that is exhibited in that fundraising effort, but perhaps to remove some of the lack of dignity, the charitable need, so that people can get equipment as a matter of right.

That was a strongly expressed view at a council meeting Bronwyn Scott attended. The parents of children with a disability in two cases at the council were saying these are fundamental needs that are being raised and addressed to varying degrees. They question whether or not that honourable tradition of fundraising, personal storytelling, needs to still be attached to whether or not a child has a wheelchair or an adult gets a piece of equipment that he or she needs.

Mr IAN COHEN: I appreciate what you are saying. With that organisation, and understanding that obviously it is smaller, things like repair centres were making decisions on what needed to be done. So, there was a far more simple and direct relationship between breakdown, repair and replacement, and also the ongoing replacement of equipment at different stages, which I think you recognise with motor neurone disease. It is a very acute situation. Setting aside the reforms to centralise or to stay with the decentralised model of the past, can you see any way that PADP structure and streamlining could actually take a leaf out of that organisation's book and break down some of the bureaucratic hold-ups, the time taken to get referrals in, the time taken to refer it to a repair person or organisation and back again? We are all looking at the terribly long waiting lists; is it inevitable or are there ways of cutting through that with some sort of expedited group or individual or something within the organisation?

Mr HERD: It absolutely is not inevitable at all. I guess that is part of what the reform agenda, the advocacy and all non-government organisations have been putting in for years around this. We talk about the centralisation, which we said we support and which I think the Government obviously is driving forward. We need to make sure that we are going to centralise those things that benefit from centralisation: the policy, the procedures, the back office, administration, the purchasing, the economies of scale that come with central purchasing clearly benefit from centralisation. But if you need your battery fixed, a puncture repaired or your wheelchair provided to you, that should come locally; that should be done by the guy around the corner who knows you and the community and can give it to you. If there was any suggestion that those service delivery prescription assessment repairers' provision arrangements were to be centralised, I am absolutely sure our council would not have been supportive of those initiatives.

You want it fixed quickly and you want it repaired today; you need it provided; you need to be able to test equipment to make sure it works for you. If I can say this, I have a vested interest because I am sitting in a wheelchair. Fundamental to the success of any reform agenda is the development of the capacity of service users—people who need the equipment—to make informed judgements in partnership with prescribers. For instance, if I understand correctly, the changes that have been proposed to the prescription arrangements are intended to give the client more say and influence over what it is that has been prescribed so that there is not under- or overprescription, and clients understand their equipment needs and can feel confident that they have a sensitive approach from the commission to help them get the equipment they need, but that their view will be listened to.

Not to personalise it too much, but I do from time to time. I have 25 years' experience of being a C5-6 quad. I know what works and does not work for me. I think I have something to offer to the prescription process. I think the system needs to listen to me and to give me the backup support so that I will use the equipment that I receive well. What we absolutely know happens is that there is just no way of getting around it. People get prescribed equipment sometimes as a kind of precautionary measure. They just think, "Well, let's get as many applications into the system now" because it is the right part of the financial year because in this area there happens to be enough. So, people get prescribed equipment that sometimes sits in their back room and is never used; some bits of equipment vanish. We do not know what happens to them. Somebody dies, that is tragic. A family member comes along and says, "Oh, we'll sell this wheelchair because grandmother does not need it anymore" not realising that it is owned by the New South Wales Department of Health.

So, we do not have that kind of local knowledge information and appropriate use of equipment. A flexible system delivered locally, and administered centrally seems to everybody to be desirable, but I am glad I do not have to put it into place to be perfectly honest, because it is hard. There are 20,000 people in New South Wales getting equipment that ranges from an incontinence pad through to a $25,000 wheelchair. That is an awful lot of skill development that needs to be put in place for the staff you have to run to administer the service.

CHAIR: Knowing your equipment, would you see the need to have to go back to an OT if your foot plate was broken on your wheelchair in order to get PADP to then agree that it needed to be fixed so that it could be processed and then fixed and then paid for?

Mr HERD: No I would not.

CHAIR: Currently, that is the situation we understand many people face.

The Hon. CHRISTINE ROBERTSON: With the decentralised process.

Mr HERD: I think we need to get away from the overbureaucratisation of systems. There is a tension there; I fairly concede that. We are talking about spending public money and we are talking about a system in which historically there is a well-recognised problem with waste and loss. It is a commitment on all of our parts to streamline and make the system more effective. So what we want on the one hand is to make sure that we can be absolutely certain that public dollars are being spent wisely and well alongside commonsense administrative responses to questions like "I have a problem with my wheelchair, can we fix it" and "Can I make contact with the local repairer people and get it done?" Finding the correct mechanism to make sure that those arrangements can operate effectively and in an accountable context is the trick that EnableNSW as to pull off. Wheelchairs do break down, electric beds do need to get repaired. You are absolutely right: we need to find a way of allowing the providers, repairers and the customers to just sort it out and get it fixed.

Mr BUCHANAN: It is always quite difficult sometimes to talk about it if it is part of this inquiry because I think Dougie's point in looking at and listening to the voice of the person with a disability should not be underestimated. I think, with great respect, having spent a life career in public service, there can be sometimes a patronising view of the physically able who are working in this field who are quite sort of mystified by what is disability. I think it is much better to listen to the voice of somebody with a disability to cut through part of the nonsense to get on with the job rather than developing an insecurity. It is really a matter of listening to the client. I know that you are physically able and we love you dearly, but sometimes there is an inference as though we know best. I am not suggesting that that is not correct, but to quote Noel Coward's old cliché, you know, I think the customer is always right. If you have lived with a disability, you know if a wheelchair fits or if a calliper fits et cetera. That should not be misunderstood. But on the other hand, if somebody in the disability sector talks about that in that manner, you can then be easily labelled as having a chip on your shoulder. So, I am very conscious of the English author Gillian Cooper who was not impressed with Australia and said that a well-balanced Australian is one with a chip on both shoulders.

The Hon. TONY CATANZARITI: Your submission suggests there are significant gaps in our knowledge regarding current use and future need of equipment for people with a disability in New South Wales. We have just addressed that topic in part, but what steps should be taken to address those issues?

Mr BUCHANAN: In short, probably there should be a stronger marriage with the disability sector and the agency to engage more, to actually hear and to understand. Sometimes the agency and/or the New South Wales Department of Health are at a disadvantage. In their defence, if people in the disability sector who are clients are not always vocal, sometimes if you are a vocal client and you criticise, then there is a perceived form of punishment.

Mr HERD: I suggest that we need two things at the same time. First, we need robust data that allows us to judge unmet need. If a child is born with a disability and that child requires, let us say, a motorised wheelchair for her entire life, we know that that child will grow and will need a wheelchair as time develops. We know how many people have a spinal cord injury every year, and an acquired brain injury is a consequence of a road traffic accident. We know how many people need their wheelchairs replaced, and we need that data to be robust so we can plan for people who need a wheelchair to get it as quickly as they can. We also need to be able to protect what will happen in the future.

We know with cast-iron guaranteed certainty that we will need more incontinence pads in the future because we have an ageing population and incontinence is associated with that. We need the predictive capability to plan for what the population will do. We know that the incidence of disability increases with age and we understand what will be the ageing requirements and the disability types that will become more demanding on PADP budgets in the future. We need the ability to see what is happening now in unmet need, waiting times and waiting lists, but we also need to be able to look forward and see what we will need. That might mean changes to how we do things.

If we are successful in keeping alive children with much more profound disabilities than we were able to keep alive five, 10 or 15 years ago, we need to be able to plan for the equipment costs associated with that. If dementia increases in the future, we want more people living at home in the community, and we know there are workforce problems—we will not have people calling in to see folk at home—that might suggest one of the future areas of growth for equipment in the home is a health-related issue. It could be a bit scary when you think about the monitoring arrangements that involve equipment rather than human beings and who will pay for all that. We need available those types of skills and facilities for the practitioners of today and the planners of tomorrow.

The Hon. TONY CATANZARITI: My next question relates to the centralisation of lodgement offices. Earlier you spoke with some confidence about this issue and you said that people in rural areas would be getting better services than people in city areas would be getting. Why did you say that?

Mr BUCHANAN: Sometimes if you are working and you are part of a regional and rural community, through the various means of a government department you might not always be aware of what is available or what are the priorities. If there is no central agency no-one is aware of what are the priorities throughout the State. I hope that, through a central agency, there is a stronger responsibility and commitment to look at equity. We understand that equity and fairness are part of the new regime, so obviously there have to be key performance indicators to measure that and to establish where we go in the future.

Having grown up in the bush and having worked for the majority of my career in regional areas I think there is a danger that you will lose touch and that the capital cities will also lose touch with you. While I am not a centralist by nature I think there are some means through the allocation of resources that need to be centrally located so there is a strategically responsible management approach to it rather than wastage. I think we are agreed. I have heard in discussion so far that over the years there has been a degree of wastage in bureaucracy, and that those who really needed equipment did not receive it. Obviously that system has not worked. I am a born optimist. I think we have to look and plough to the future. After five years if we sit back at another inquiry where you and I ask the same question I will swallow my words.

Mr HERD: There are practical problems that we will have to try to tease out. Let me describe it in this way. Our hope is that there will be greater equity and fairness in the system. However, we have to live with the reality that if someone acquires a brain injury as a consequence of falling out of a tree 45 kilometres north of Wilcannia that person is 250 kilometres away from the nearest occupational therapist and, therefore, it is not as easy for that person to get a visit as it would be for me living in Ashfield.

We all know—I think we referred to this in our submission—that there are real problems for health services and disability services in providing these kinds of services in small communities a long way from the big city. If in the provision of a service you were dependent on an assessment by a qualified professional and there was not one available other than four hours or five hours drive away, you would have to wait three or four weeks longer than someone who lives in Vaucluse.

Reverend the Hon. Dr GORDON MOYES: You just made the point that, in the interests of transparency and equity, there is a difference between regions. Although the department is committed to equity and transparency, in some regions there are long delays for getting equipment and in other regions that kind of equipment has totally declined.

Mr HERD: Yes.

Reverend the Hon. Dr GORDON MOYES: Could you comment on that?

Mr HERD: It ought not to happen. Our council is clear: no matter where someone with a disability lives he or she has a right to receive equitable treatment. Therefore, the responsibility must to be placed on government departments to deliver on that commitment. We know that it simply does not exist for everybody at this time. Families move home in order to move into an area where therapy is available. They pack up their bags and travel.

If they have a child with a disability that needs therapy and that becomes the driving force in the life of that family it will do whatever it takes, if it is a loving family, to make that happen. I think that is a statement of the obvious. Once again, that ought not to happen. As the reform agenda is enacted as quickly as possible by EnableNSW we need to be hopeful and vigilant to ensure that the promise it holds of a fairer, more reasonable and consistent service is delivered. Is that not why we spend taxpayers' dollars?

The Hon. CHRISTINE ROBERTSON: I have some questions that I would like to place on notice as we have run out of time. Recognising that you are already on the advisory body, how will the new and enabled advisory body processes affect you? How will you handle all those different processes? You referred in your opening address to fundamental need. I would be grateful for some sort of descriptor of "fundamental need". There are several suggestions in the submissions that the Committee has received that the Department of Ageing, Disability and Health Care should take over this project from Health. What is the view of your organisation?

Mr BUCHANAN: It is fair to say that no-one really wanted the PADP.

The Hon. CHRISTINE ROBERTSON: I have placed those questions on notice because we have run out of time.

CHAIR: Unfortunately, we have run out of time. Could you take those questions into consideration and come back to us with your answers? We are asking broad questions as these are recurrent themes. It would be good to get your response to them. The secretariat might contact you to seek clarification of your presentation today and your submission. Thank you for your advocacy and for appearing before the Committee.

Mr BUCHANAN: Thank you for having us. Let us know if we can do anything.

(**The witnesses withdrew**)

SEAN JOHN LOMAS, Policy and Information Manager, Spinal Cord Injuries Australia, 1 Jennifer Street, Little Bay, New South Wales, sworn and examined:

CHAIR: We have questions about a number of recurrent themes and we would like to get your opinion, on behalf of your organisation, about those key issues. We will not refer to them in any particular order but we would be interested in hearing your opinion. Would you like to make an opening statement?

Mr LOMAS: No.

CHAIR: We have heard a number of responses from people about the co-payment. Does your organisation have a view on that?

Mr LOMAS: I think the co-payment is unfair and it should be dropped. In 1999 we conducted a study on the unavoidable cost of a disability. We found out through that and from indexing it up to present levels that a person with a disability is often placed in a situation where he or she has available only about $20 a week. If you want to pay $100 in co-charges you have to make a lot of savings and manage your affairs in order to put aside that bit of extra money to make that co-payment. It is unfair from the perspective of equity across services. There is no real precedence for this to exist. If I call an ambulance I do not have to reach into my pocket and pull out $20 before the person will take me to hospital; it just does not happen. I think it is unfair to place a cost or a charge on those who are unable to pay that charge.

CHAIR: I seek clarification of another statement in your submission. You talked about PADP scores in relation to clinical assessment. How does that work?

Mr LOMAS: That is a very good question. As I mentioned in my submission, it does not appear as though most lodgement centres know how it works. You get varying and different clinical indicator scores ranging from one to five through to one to 54. As I understand it, the clinical indicator score is a simple way for a health service to prioritise need. Health services look at things such as risk of injury, risk of reassessment into local hospitals, and those kinds of things. You apply health criteria to the application. I said that clinical indicator scores are not very just because, essentially, that program exists for people with disabilities.

A person with a disability might well have employment options. He or she might live in a community and have friendships and a number of things in which he or she takes part. The application of the clinical indicator score determines whether or not you should or should not have certain equipment. It does not take into account all the other factors that exist in that person's life; it takes it down to a simple yes or no high or low priority. You can also look at clinical indicator scores to establish their effectiveness. Recently, there was a freedom of information request for PADP waiting lists.

There were many instances of people as clinical indicator score one—high or absolute—which indicated that they needed certain items. Those people had been waiting long periods. It is something that is there to sift and to ensure that those most at risk, those most in need, and those that sit across the top of a crisis get items of equipment in timely fashion, but it just does not work.

The Hon. CHRISTINE ROBERTSON: Do you say that the clinical indicators scores they are currently using in this project relate to clinical illness rather than informing social function?

Mr LOMAS: Absolutely. I am saying it relates solely to health-related issues. It does not relate to the holistic nature of the life of a person with a disability.

The Hon. CHRISTINE ROBERTSON: Social function is part of a health-related measure. Do you say it is not there?

Mr LOMAS: Yes, I am saying it is not there. I am saying the variation that is applied strictly sits across those that they think are going to be at the most risk at that particular time and then they will start to address that.

Mr IAN COHEN: Can you identify some examples from the waiting list you have attached to your submission? Could you deal with that, because it is a confronting situation?

Mr LOMAS: We have someone who ordered an item of equipment and was assessed on 16 August 2007. They are classified as indicator score one, which is high. It is a mobility issue, a wheelchair cushion. They are unable to assist since they were approved and are now looking for alternate sources of funding. They are the highest priority, they have gone through the eligibility process, they are found to be eligible, they are found to be given the highest level score they possibly can but PADP is unable to assist. On 28 March 2007 someone has a clinical indicator score of one in the South Eastern Sydney Area Health Service for a Mogo manual wheelchair. They have obviously been waiting a significant period of time for that item.

The Hon. CHRISTINE ROBERTSON: Is one bad or good?

Mr LOMAS: One is supposed to be at most risk.

The Hon. CHRISTINE ROBERTSON: Urgent?

Mr LOMAS: Absolutely, so let's get on with this and let's get the equipment.

The Hon. CHRISTINE ROBERTSON: They are not using the clinical indicator scores that they get, is that what you are saying?

Mr LOMAS: I think what is happening is you are getting budget-based decisions.

The Hon. CHRISTINE ROBERTSON: Not related to the clinical indicator.

Mr LOMAS: The background machinations of processing indicator scores seems to be that it is happening and they are putting it all on the table and going, "Yes, that is a score of one," and then it goes down to the budget process.

The Hon. CHRISTINE ROBERTSON: We understand.

CHAIR: There is a big difference between the budget cost of a wheelchair and a gel cushion.

Mr LOMAS: Absolutely. There is a completely different cost associated with the two items. That is one of the things that are quite interesting when you start going through the nitty-gritty of the waiting lists. It is inconsistent. It would be easy to say that things such as electric beds, hoists, motorised chairs are all high cost items, thus they all sit at the top, they are too expensive, they have to go out to lodgement centre review every quarter, every six months. But there are other things that seem to be working their way in there as well. One of them is seating cushions, slightly less expensive items. So it is very inconsistent how it is applied and how it works.

CHAIR: Do you think with the centralised lodgement centre that will change or improve or do you think that same system will apply?

Mr LOMAS: I think with the centralisation there is a greater possibility you can manage the budget centrally. So as applications come in you can make rational decisions based upon the evidence that comes with the application. It takes out regional variation in interpretation. In our research when creating our submission we looked into the regional issues around access to equipment. It seems the further you go away from Sydney the worse it gets. You have not got a cat's chance in hell once you get out to Woop Woop of getting your item of equipment. The closer you are to Sydney, if you are in Randwick, there is a great chance that you will get your item of equipment. Also the interpretation of policy guidelines that come out of EnableNSW and New South Wales Health are more widely interpreted the further you get out. You have people building their own little areas in their own little lodgement centres where they answer to their area health service. They are supported by their area health service in changing the criteria, the eligibility, everything. It is interesting. So centralisation is a good bet because it would get rid of a lot of that.

CHAIR: Your submission talks about the departmental responsibility for PADP and the Disability Services Act. Would you explain the problems you see with that and also address whether you have believe PADP is located within the correct department?

Mr LOMAS: It is obviously quite a big one where the program should go. As I understand it, the Department of Ageing, Disability and Home Care [DADHC] sits above EnableNSW and provides government and policy guidelines that make sure that the program satisfies the needs of people with disabilities. If DADHC are involved to that degree, then surely PADP comes under the Disability Services Act. It is a program essentially run by DADHC. That does not seem to be the case. So PADP has sort of morphed itself over a number of years into a program that does not necessarily fit within the Disability Services Act. The Disability Services Act is there really to make sure that people with disabilities get the best chance they possibly can, that they are dealt with fairly, that they are discussed throughout the entire processes. We have seen evidence that that obviously is not the case. As I said before, once you get further out of Sydney it certainly is not the case. In looking at where the program can actually exist, there is a strong argument for it moving away from Health and moving into DADHC because then it would be commensurate with the aims and the holistic nature of a human being who has a disability and how they wish to go forth. I always perceive that PADP is one of those odd things in that by having DADHC and Health involved, neither seem to be able to do it quite well together. So it either has to go one way or the other. In all fairness, it probably is DADHC so that you can meet decent disability aims.

CHAIR: It is a long roll-out time between the PricewaterhouseCoopers [PWC] recommendations and EnableNSW addressing those recommendations, the centralised system and other issues. Part of it seems to involve a lack of database and clear information collection. Do you have any comment about those two issues?

Mr LOMAS: There is not really that much data. We have been trying to find out information about historic applications, how they apply to planning, and it is not really there. That is backed up by statements within the PWC review, where they found problems. They said they have had to extrapolate data or just theorise around probably what is about right to try to get an idea of who is out there. Some of my counterparts have argued before that the bigger thing is unmet need and recognising unmet need, those who have not applied for a variety of reasons, which are listed in my submission. How do you get ideas about those people? Those people are out there in Australia doing it tough without the necessary items of equipment. They are making do or they have managed to fundraise. There is an incident that made the news down on the South Coast where a lady needed a three-wheel wheelchair. She could not get that through PADP. She was told point blank there was absolutely no way they would fund that. So her local town got together—

The Hon. CHRISTINE ROBERTSON: Because three wheels did not fit the definition?

Mr LOMAS: Yes. So they fundraised to get the chair for her. That is great. It shows that the community is actually interested in these things and thinks that people should have the correct items of equipment they need. I forgot the first question.

CHAIR: It was about the roll-out time.

Mr LOMAS: The roll-out time is very long, seeing as we have been in this process now for quite a number of years to 2010-2011. It is a pretty long time frame. I know through conversations with Bronwyn Scott and various others at EnableNSW that there are great issues around the actual closing down of lodgements centres, the moving over of staff. What are they going to do with those people? There are certainly going to be redundancies that come into all that. How do they handle that? They are cherry picking the best people from the lodgement centres to help create what is going to be a set of policies about the operations of EnableNSW. That takes time. That is all great and well, but for the person who requires a piece of equipment who is languishing in a hospital bed or at home or, like we have seen on the waiting list data, the young child who has been waiting 18 months for a back brace out in Western Sydney. If you turn around and say to them, "In 2011 it will probably be about right and you can put your application in again after being reassessed, of course, and we will start to move forward with you." The opportunity has been there for a long time. It has not been grasped. Now it seems, thanks to the PricewaterhouseCoopers review, as if it has been put in a very succinct framework and they think hopefully the can enact off the back of that. Listening to New South Wales Health give their presentation this morning, I certainly found a lot of the language was quite interesting—the use of the words "hope", "aspire". It fills you with great confidence.

CHAIR: "Review".

Mr LOMAS: Yes, "review", "discussion." How long do discussions take? We have all had discussions. I think probably everybody around this table here could say, "This is what needs to be done. It is very simple. It is black and white. Let's just get on with it."

Mr IAN COHEN: Centralisation or not, what do you pinpoint as the key opportunity to move forward. You said, "Let's get on with it." Where does it lie? Is there a certain stage that you can see to cut through the red tape, to streamline the process, to deliver to where it is needed?

Mr LOMAS: The first thing is if we do centralise it, then it is establishing exactly who needs the items of equipment and creating the database listings around that. That will come from historical data from suppliers and historical applications placed through lodgement centres. It will come off the back of the census information. You can actually start mapping people with disabilities within New South Wales and starting using those to create your core. Streamlining-wise there are many opportunities. There are those bulk purchases, equipment loan pools that they are talking about, telephone answering services out of business hours if you do happen to break down or have an issue outside of business hours or on public holidays. I had to advocate for a gentleman down in the Illawarra who broke down on Good Friday. He did not get looked after until Wednesday. So he had to stay at home for a few days because there was nobody there. Having a central telephone number could help. I think the whole thing that I am interested in seeing is how this all works and whether it does happen.

The Hon. CHRISTINE ROBERTSON: The number is already there. Is not anyone using it?

Mr LOMAS: The numbers are there. When I first came to this position I started looking into performing quite a detailed calculation of exactly what is the group that is an unmet need and how those people should be pulled out of it. I have those details and I can make that available.

The Hon. CHRISTINE ROBERTSON: I meant the telephone number.

Mr LOMAS: Yes, but nobody knows about it.

The Hon. CHRISTINE ROBERTSON: That is what I am asking you about.

Mr LOMAS: I was at the Physical Disability Council about six months ago. I was just down there for a bit of a chit-chat, talk about what we are working on, find out what they are working on. They had about five telephone calls in the time that I was there from people asking about PADP, what do they do, how do they fill in applications. Some of those were actually OTs. It is crazy; nobody seemed to know anything about Enable New South Wales. As far as I have heard, that is not really the case. We tested the telephone number as well. We called up just to find out. We had one girl on the phone who sounded very lost and agreed with us that it was a little bit of a bad situation. That is very comforting! That was just me testing it.

Mr IAN COHEN: It has been well discussed with the Committee issues of distance and isolation. Looking at another service area, the issues with non-English-speaking background community and the indigenous community are often a lack of awareness of how to deal with the system combined with being in remote areas. Could you comment on those issues and that ways that you see of moving toward effectively resolving the supply of equipment to them?

Mr LOMAS: I have had some dealings with the Aboriginal Disability Network and I have been speaking to them particularly about trying to get a bit of information from them about indigenous take-up of items of equipment under PADP. They said, "What is PADP?" I thought that was a shocking start. How is this all going to work? It is based in Sydney obviously. So once you start getting outside of Sydney, they simply do not understand PADP. If one of their key peaks do not understand PADP, I do not know what the situation is once you start getting out into regional New South Wales and indigenous communities. As to non-English speaking backgrounds, I have not really looked into that that much to be able to say what the take-up would be or their understanding of the program. I would have thought that there would be issues around that. I could not say whether EnableNSW's information is provided in a variety of languages and formats, whether it is made widely available, whether they circulate it through various community organisations that represent different groups. I am just not sure.

Reverend the Hon. Dr GORDON MOYES: With the spinal injuries, there was a time in the mid-1990s when the Government was talking about developing a large number of regional centres for short-term and long-term care for paras and quads and spinal injury persons. I was responsible for opening one of those centres in Stewart Road, Dundas. What has happened in recent years about those centres for spinal cord injuries?

Mr LOMAS: To be honest, I have not really come across much information about them. Do they still exist? I have not really heard much about them at all. Most people who are discharged from hospital who present with a spinal cord injury generally move back into the community and they try to create the support mechanisms for them there. They try to create support mechanisms for them there. So moving towards facilities or supported accommodation, I do not really know much about what is happening there. I certainly have not had many people come across my table sort of saying, "I'm in this supported accommodation facility and I need some advocacy or assistance with something". They may well still be operating, I am just not sure.

Reverend the Hon. Dr GORDON MOYES: The facility I was just mentioned was called the Lotti Stewart Hospital spinal cord injury centre.

Mr LOMAS: Yes, I have heard of that one.

Reverend the Hon. Dr GORDON MOYES: But there were to be quite a number of regional centres. They have not developed?

Mr LOMAS: Not as far as I know. In fact, I would probably say that they have not been developed. I once advocated for an indigenous gentleman over in Dubbo who would have suited something like that because he found it very difficult to live in the community.

Reverend the Hon. Dr GORDON MOYES: Because any kind of respite care and so on requires very specialised help with people who are permanently paralysed who have to be rotated and moved.

Mr LOMAS: Yes. We have people who are members of our organisation who live out in houses at the bottom of dirt tracks in regional New South Wales who have no contact with anybody. I just do not know whether they exist or not. I would not have thought so. I have not heard anything about them.

The Hon. GREG DONNELLY: Going to the final page of your submission with respect to the summary points, specifically summary point 5 where you say "a person-centred approach to equipment delivery and prescription". First, on the issue of the person-centred approach with respect to prescription, can you describe what you mean by that comment?

Mr LOMAS: Often I hear stories from our members that when it comes to being prescribed an item of equipment they have very little say in it, particular instances of item delivery. We have had quite a few issues around access to being consulted about what equipment is delivered. I have in one case particularly a lady who was stuck outside while the OT went off with the lottery centre manager; three hours later came back and said, "You're having this chair", and that was it. How can that person—

The Hon. GREG DONNELLY: So that is the level of consultation and dialogue that is going on with individuals?

Mr LOMAS: Absolutely. As I think Mr Herd and Mr Buchanan said, the person with the disability knows best and they know what is right for them and they should be involved in that process. I know that PADP official guidelines say that all applications must be signed off by the individual. However, it is very easy to get an individual just to sign something off and then they start moving forward with an inappropriate item of equipment. A perfect example is that there is a gentleman in Coogee. An application was put in front of him, he was assessed, they went, "You have this chair, just sign here". He signed there; the chair arrived, and it is a completely inappropriate item for him. So he is just sitting in his room. Now he needs to put in another application for PADP. Obviously his local lottery centre is rather peeved because it has just spent a whole load of money on this chair for him but they will not take it back. He is in a very interesting situation. He signed off something that he did not quite realise what it was. There are also things about trialling items of equipment as well. It is very costly for equipment suppliers to take items of equipment out there so that a person can get a real sense of what is the right item for them and to be able to leave it there for a period of a few days so that they can use it in the normal home environment or going out to the shops just to feel as if that is the right item of equipment. That is quite difficult.

The Hon. GREG DONNELLY: Do you have a view about this lack of consultation as you have described? Do you believe that is brought about because of people just being pressed in that they have so much to get through and they just want to tick the boxes and move on to the next person, or it goes to the question of their whole training in terms of their role of working in this area with people with disabilities?

Mr LOMAS: I think it is both. I have had conversations with the New South Wales Association of Occupational Therapists, and they say a big issue is training, that their OTs do not understand their full roles and responsibilities when it comes to creating scripts for PADP. But also there is great pressure on the system; there are not enough OTs out there. We have heard today that they are just not around. So they may well drive four hours in regional New South Wales to get to a house, to then assess and then need to drive another four hours back. All of that time spent on one application; they just want to get there and get it done. But in the process of doing that you have marginalised the person who you are there to work for. You are there to support that person and make sure they get the right item because 12 months, 18 months down the track they will be calling you up again saying, "I'm having a lot of problems with this."

The Hon. GREG DONNELLY: Finally, the issue of the person-centred approach with respect to the delivery of equipment, can you perhaps describe what you understand is the case at the moment and elaborate on what a person-centred approach would entail?

Mr LOMAS: Working with a person with disability in getting the items out to them is certainly something that you have to do. We have heard of many instances where a delivery firm is engaged by New South Wales Health to deliver items of equipment.

The Hon. GREG DONNELLY: A courier firm.

Mr LOMAS: Yes. These items of equipment are essentially put on to patios in boxes and then the driver drives off, leaving the person with a disability looking at a great metal box and thinking, "What do I do with this? If I touch it does that mean that I'm breaking some warranty? Does it also mean that if I do touch it and manage to get it together using my weird Ikea skills set and it breaks or I fall off it, what about occupational health and safety? Who is responsible for this because it will not be good for me. I can't let my carer come near it because I've self-assembled." There is a growing evidential base that that is starting to be the case. They have got people—Office Max deliver these things. They are putting them on to people's porches. They are not equipment suppliers; they are not a rehabilitation firm. They are pens and paper and rulers but they are delivering these items to people and just leaving them there.

The Hon. CHRISTINE ROBERTSON: This is under the current system.

Mr LOMAS: Yes.

The Hon. MARIE FICARRA: Ill-fitting equipment, among your client base how big is this a problem? I have heard of some of the spinal units in the area health services having badly fitting equipment for disabled people, and that is subsequently causing further injury that leads to hospitalisation. Can you comment, because I notice you mention it in your submissions?

Mr LOMAS: Absolutely, it is an issue. It is quite a weird issue because if you think that the two main spinal units in New South Wales are in Prince of Wales Hospital and Royal North Shore Hospital, which is allied to the Royal Rehabilitation Centre at Ryde. Both of those operate seating clinics. You would have thought they have the centralised knowledge base that exists for the whole of New South Wales. Royal North Shore looks after the north, Ryde upwards for seating clinic requirements and Prince of Wales looks after south. So they should be able to get these things correct. But we have had many instances where people are getting pressure sores on the sides and backs of their legs due to ill-fitting items of equipment. A recent case that made press was Diane Chapman's daughter who spent a long time in hospital because they could not get the right item of equipment for her. In that time she put on weight, which meant all of her sitting mat for her backside was completely defunct. However, they still got her that chair on a loan, which meant that she then started to suffer pressure sores. So she went back into hospital. I have a gentleman in Maroubra who I advocate for who is a lovely Fijian man who is a very good believer in Christ and I think it is the only thing that is getting him through the day. He has been yo-yoing between his home and the Prince of Wales for about a year and a half; he goes home, gets a pressure sore, goes back in, and he just cannot seem to get over the whole thing. Now he is starting to suffer mental health problems. It affects people's lives greatly. You have to look at these things in the sense of getting them done properly.

(The witness withdrew)

CHRISTOPHER JAMES CAMPBELL, General Manager, Services, the Spastic Centre, PO Box 184, Brookvale, sworn and examined:

Mr CAMPBELL: I have worked with the Spastic Centre for nine years. Prior to working with the Spastic Centre I was the general manager of services with the paraplegic and quadriplegic association for nine years. My experience of the PADP scheme is quite longstanding and in depth. From the perspective of the Spastic Centre, the PADP scheme came into effect and we believe that it came into effect without adequate resources to respond to the existing demand and has always sort of fallen behind in its ability to maintain its response to the demand and then also start to look at a proactive way of responding to people's equipment needs, especially as they live within the community.

The evolution of the PADP scheme across the State has evolved as a result because there has been a scarcity of resources, and processes and procedures between lodgement centres have evolved that were not consistent or responded to the needs of people with significant disabilities as they required equipment. Having said that, I have the greatest respect for the PADP lodgement centre clerks and the administrative people because I feel that they are caught in a very difficult situation because they are very conscious and aware of the needs of people with disabilities because they hear from those people and their advocates and carers. But they are limited within the resource they have to allot to people.

Sometimes the decision making and the processes that people with disabilities experience have been, in a way, almost creating additional barriers to access to that equipment, rather than being responsive to the delivery of equipment. In my time at both the para-quad and also with the Spastic Centre I was involved in the first meeting of the statewide PADP advisory committee; and, quite poetically, I was there for the last meeting of the State advisory committee. I did have a break in between. The disappointing thing about my two periods on the committee was that the same basic core issue still had not been addressed. That was the level of funding, the range of appropriate equipment that is required and I think also keeping pace with the increasing technology for people with significant disabilities as a means by which they can participate and integrate within the community.

The fundamental core problem of the funding level of the program, I think, in itself has generated many of the frustrations and anxieties that both people with disabilities have experienced, but also their families, their carers and the agencies that assist those people to access that equipment. So service providers such as the Spastic Centre and organisations like Para-quad and the Spinal Cord Injuries Association and many other agencies attempt to be a conduit between the person with the disability and the equipment they need.

The Hon. MARIE FICARRA: You said there were problems with the range of equipment through the PADP system and keeping up with new technology. Can you expand on that in relation to your clients and previous clients?

Mr CAMPBELL: For people with cerebral palsy the disability impacts on their lives in a range of ways. Those people with significant levels of cerebral palsy have mobility and communication issues. Moving around and communicating are probably the two most basic and fundamental ways in which people get on with their lives and participate and integrate. Over the last couple of decades there have been examples of very effective pieces of technology in the form of communication devices and also technology to assist someone who is non-verbal to interact with either their workplace or their educational forum etc. It took a while for the PADP scheme to identify technology as a viable piece of equipment on the PADP equipment list. Unfortunately, those pieces of equipment are also expensive so if people require a motorised wheelchair with specialised seating systems and a communication device, you are looking at potentially $20,000 or more for one person to be able to move and communicate in their environment.

It is a significant demand on the PADP budget and in some regions that could be their entire annual budget for equipment. It is a matter of acknowledging that the technology and communication devices are a key to many of our client groups. It is also going to be something that the next generation of younger people with disabilities, especially cerebral palsy, are going to expect to be the benchmark and baseline that will enable them to integrate into mainstream school and to communicate with their families and interact with their peers. Unlike the situation with the previous generation of adults for whom that level of technology was not available, there will be a demand coming quickly down the track that will increase the pressure on the existing budget unless there is a significant increase in the level of funding.

Mr IAN COHEN: Just on that, in your submission you said that in consultation with PricewaterhouseCoopers you identified a current PADP shortfall of approximately $12 million per annum. Have you factored in the $11 million that was given as a one-off this time around?

Mr CAMPBELL: No.

Mr IAN COHEN: So you are saying $12 million per annum—

The Hon. CHRISTINE ROBERTSON: On the 24—

Mr CAMPBELL: Yes. The conversation has been with a man who is a partner at PricewaterhouseCoopers, John Walsh, who is very knowledgeable about the cost of equipment and care for people with significant disabilities. His best guess estimate, because he was involved in the Lifetime Care and Support Scheme, is that PADP is about $12 million to $14 million underfunded at the current rate, and no, it did not include the $11 million. The announcement of that came either just before or just after we made our submission.

Mr IAN COHEN: Do you think there could be a problem if, for example, an extra $11 million became recurrent funding in that the PADP program would experience an upwelling of applications given there might be a perception of more freed-up funds? We hear evidence that there are a lot of people who do not go to PADP because they know it is too hard or they have little chance or it will take too long under the present circumstances. Are we going to see a ballooning of the whole demand situation?

Mr CAMPBELL: I suppose that would be a quite positive reaction, would it not?

Mr IAN COHEN: Not from the Treasury's point of view.

Mr CAMPBELL: You cannot please everybody.

The Hon. CHRISTINE ROBERTSON: The taxpayers might not like it either.

Mr CAMPBELL: You are right in your observation. I think the scheme has drained the spirit of many people even at times in regard to applying. They feel that the process has been onerous and laborious. You definitely need to be patient when you are putting in an application to the PADP. Notwithstanding that our organisation definitely applauds the introduction and the establishment of Enable because we feel that that will help the processes and the consistency, there will still be a shortfall in the dollars to fund the program. If there is an ongoing increase in the funding levels rather than just a one-off, we will experience a period where people may come out of the woodwork and seek out the equipment that they quite rightly need. I do not know of anybody who actually identifies equipment that is not going to be of value and worth to them. Usually in the process of the application through the therapists and their prescription the majority of therapists are very realistic about resource management and trying to match the right piece of equipment to a person's needs. In that sense there might be a bit of a peak, but I think also if people feel that the scheme is able to respond to their existing and future needs you probably will not have the same level of anxiety and nervousness about whether that equipment will arrive at the time when it is needed.

The Hon. MARIE FICARRA: In relation to cerebral palsy and in particular early intervention, a witness this morning told us about her terrible journey to try to get her child a suitable power chair. She was quite young when she was afflicted. In the end the family funded it. She gave the impression that there was no assistance for this child of two years of age for that particular chair.

Mr CAMPBELL: Obviously I cannot respond to the specifics of that circumstance. It is a matter of trying to find the chair that is most appropriate to the person, whether they are a child or an adult. The issue for a child, especially if you factor in a waiting period for that equipment, is that children grow quite quickly. That has an impact on our services and many other services that deal with children in that they may have to reassess and see if that piece of equipment is still the most appropriate. Nine times out of 10 it is the most appropriate but then you have to change the prescription because the child has grown and might need additional length and footrests, armrests and headrests.

As regards the availability of funding—it is in my submission—in the last four years we have tracked every prescription for equipment for any of our clients, both children and adults. The reason we have done that is that it is a priority for our organisation, it is part of our strategic plan. We do not feel that a child and/or an adult should wait any longer than they need to. The concerning trend has been that of the $2 million to $2.7 million that our organisation prescribes and puts into PADP each year only about half is delivered. There has been a drop in the proportion of the funding coming from PADP from 71 per cent to 37 per cent or 38 per cent last year. There has been a higher proportion of other funding. That is coming from foundations such as the St George Foundation. Over the past three years we have started a fundraising event that raises between $180,000 and $250,000 just to buy equipment for children and adults. That is $180,000 to $250,000 that we could use to employ additional staff. For us it comes back to the frustration that our families and especially our parents were experiencing. Their key need was to have access to that equipment.

In regard to the initial question about the particular type of equipment, there may be pieces of equipment that have all the bells and whistles and there might be other equipment that is appropriate and adequate to perform the job that it is required to do. Again, most people do not usually seek out the bells and whistles, Rolls-Royce options. They are actually looking for the piece of equipment that will best suit their son or daughter's needs. It is usually a bit of a furphy that there are people out there trying to get the deluxe version. It does not really happen.

The Hon. MARIE FICARRA: But the earlier you can intervene, the better.

Mr CAMPBELL: Yes, especially for younger children.

Mr IAN COHEN: Your organisation is in a different position in that you have a huge spread throughout the entire State. Could you comment on what you think of the centralisation process that is being undertaken by the Government? Is it a step in the right direction or do you see pitfalls in that given your organisation's experience in many small centres?

Mr CAMPBELL: With the existing PADP system and the variety of lodgement centres our staff report back the full range of experiences from the lodgement administrator being fantastic and very responsive within the resource to others who are I suppose almost in a siege mentality and find it really difficult to respond to the number of demands. So there is the full range and depending on which area you live in you might have a different experience in regard to the local lodgement centre. The one thing that is usually common is that you have to wait. It is just a matter of how long.

Our organisation feels that there do need to be some consistent processes for lodging applications and for the expectation of how much information is required before a decision is made to approve. A lot of our staff time, which I classify as unproductive, goes into demonstrating and articulating information to a person who may not necessarily understand the significance of that information, but we have to jump through those hoops. I think there definitely needs to be consistency around that. I am not too sure to what level the consistency will be centralised. I think they are still piloting that within Enable and again I have great confidence that the staff in that team are keen to resolve similar issues to those we are experiencing. They are keen to resolve those frustrations. I think there needs to be consistency and some simplification of the prescription process. How it is rolled out in local areas probably needs some further discussion. With regard to the high-priced complex equipment, I think there are opportunities to enable that to happen at a central level as long as you have the staff with the appropriate expertise to undertake the prescriptions in the local areas.

The Hon. GREG DONNELLY: On the same issue, the Enable rollout and the timetable, on page 6 of your submission you talk about its establishment and your optimism about what it will be able to do and what it will be able to achieve. Having said that, are you concerned about the time frame for completing the rollout exercise?

Mr CAMPBELL: To be fair to Enable, I am not totally au fait with its rollout and time frame.

The Hon. GREG DONNELLY: I think it is around 2010?

Mr CAMPBELL: Yes.

The Hon. CHRISTINE ROBERTSON: Finishing 2011.

Mr CAMPBELL: I notice their pilot areas. They hope to have the information back by the end of this year with some recommendations to the Department of Health about how to proceed. It is a bit of a concern, the length of time. I suppose within this sector you do learn to be reluctantly patient. It would be good if it could be implemented next year but, having said that, I would also like whatever they do implement, that it is a decent product and it has decent processes.

The Hon. GREG DONNELLY: What I am getting at, looking at the time line, it appears to be long and extended, but I wonder whether there are some grounds and reasons why they are taking this time? In other words, the nature of the sector, they would prefer to be a bit more cautious and given that some of the changes that will have to take place, they are just doing it rather carefully, particularly understanding the nature of the client base. I would not want that to be an excuse for the whole thing being delayed for a time that is unsatisfactory.

Mr CAMPBELL: I suppose in regard to the one-off $11 million, we have a certain level of anxiety that that has not been rolled out as quickly as we would like. So, we are hoping that is not an indication. From our organisation's point of view we would like to see some action. We would like to see some results as soon as practicable but, as the same time, if this amount of effort is put in we want it to be right. So, if it is for the sake of six months and it gets it right, and it gets it right the first time, we can live with that. Having said that, I am sure there are a lot of people who do not have the same level of patience.

The Hon. GREG DONNELLY: On the issue of the value of data and information and the utility that is used with that in making projections and estimating, and a range of other things, we have observed that at least some non-government organisations have become quite adept themselves at collecting information and maintaining what appear to be quite accurate databases containing a lot of very detailed information. I suppose it is too optimistic to think there is any way of bringing together this information that is already out there amongst a number of these key organisations and sharing that with Enable so it might facilitate the whole process of the collection of this useful information?

Mr CAMPBELL: Yes. I have had three meetings with staff of Enable and that is one of the areas they are interested in. We are looking at utilising, especially people with cerebral palsy, depending on their level of disability—you can predict reasonably accurately the types of equipment that someone is going to use and if you factor in it has a lifespan of X, you can then start to build up an idea of what your future demand is going to be over that time. Again, that is the same sort of process that John Walsh went through with the lifetime care scheme, and recently we engaged Access Economics to look at the broader effect of the person with cerebral palsy on the economy. Equipment is one component. There is also then the level of care they may require both informal—unpaid—and then formal, which is paid.

From our point of view, we have committed to working with Enable around that equipment data and using the tools that enable us to say with this level of disability these are pretty much the range of equipment you can use. Obviously there are variations to that. We have also been talking with Enable. Because we are the third-largest employer of therapists—occupational, speech and physios outside of DADHC and Health—we have quite a well-established professional development program, and because our staff work throughout New South Wales—we have 18 therapy sites within New South Wales, six of those in Sydney and 12 in regional and rural areas. So, we have a way of progressing the knowledge and expertise of our staff in a way that prepares them and enables them to make complex prescriptions for equipment for people with significant and complex needs. We have a couple of training programs and a couple of programs that have been developed by our research team that they are keen to access in those training modules.

The Hon. GREG DONNELLY: It seems to me there is a lot of intellectual capital retained by these non-government organisations, who are obviously very specialist and over a long time have built up quite a degree of expertise?

Mr CAMPBELL: I suppose if we do not do it, no-one is going to do it for us. It is one of those things we identified, that our particular type of population of people has specific needs. We recruit staff but we know we have to train them in those specifics.

CHAIR: We have to wrap it up. We may be in touch with other questions that arise.

Mr CAMPBELL: No problem at all.

CHAIR: Will you be publishing the Access Economics report?

Mr CAMPBELL: Yes. I am trying to think of the rollout time. We have the draft and I think it is being launched by Bill Shorten in the next month, but I am not sure of the date. Again, it will be a public document, so when it is available I am quite happy to send it to Parliament.

(The witness withdrew)

CHAIR: Mr Ian Cohen has some information he has received that he would like to table so that it is part of our inquiry. It is information that was raised this morning by Dr Richard Matthews. It is the financial compliance and performance-related audits of the area health service lodgements for PADP for Enable New South Wales dated June 2008.

Document tabled.

RUTH ROBINSON, Executive Officer, Physical Disability Council of New South Wales, 3/184 Glebe Point Road Glebe, and

JORDANA GOODMAN, Policy Officer, Physical Disability Council of New South Wales, 3/184 Glebe Point Road Glebe, affirmed and examined:

CHAIR: We are giving organisations in particular an opportunity to make an opening statement if they so wish. Otherwise, we can go straight into discussion of your submission and presentation today.

Ms ROBINSON: We are very keen to make an opening statement if that is possible. Thank you also for the opportunity to be here with you which we appreciate. As the Physical Disability Council of New South Wales is the peak organisation for people with physical disability in the State we have taken a very active interest in the workings of the PADP service for sometime. In fact, when I look back at annual reports I noticed we were first talking at annual reports in 1999 about concerns around PADP issues. When we prepared our submission, which is what I am going to make reference to, we noted very clearly that the report that was written by PriceWaterhouseCoopers identified some very important things from our perspective. One was that the needs of people seeking this particular service were much greater than what was able to be provided. We also were aware from what was written there that, in fact, a number of people who met the eligibility criteria still were unable to receive the service.

We also noted that it was identified in that report that the quality of life with all people with a disability who were accessing PADP—regardless of the nature of their disability or the support needs they required—it was found that their quality of life improved. We also noted that 98 per cent of purchases were low-cost items that were considered to be less than $500. We also noted that a large number of purchases, in fact, just under half of the total purchases, were for mobility aids. Within that context, and with what we know about people with physical disabilities, accessing PADP services, we prepared our submission to you. We made half a dozen recommendations. I will quickly summarise each of those for you so that if you have not had a chance to go through the paper, it kind of does it succinctly. I will be fairly speedy because I know you do not want me to go on for ages.

The first thing we talked about centralisation and we supported that recommendation very solidly for the centralisation of the PADP services. We thought it gave opportunities for greater transparency, consistent evaluation, equitable distribution of the funds that are available, predictable, consistent and reliable service and we also thought that it provided an opportunity for a management structure that perhaps would reflect the complexity and the growth and the size of the PADP from the time it began. Our second point was one around information. Our recommendation was around the fact that information was really important to people who might be utilising the service. Simple language was important. Information available in the various formats, an opportunity to apply electronically for access to the service, a 1800 phone number—really simple things. Also, clear information about really basic things—what is it about? Am I eligible? How do I apply? How long will I have to wait? What is the opportunity I might actually get something? Where do I complain if none of these things happen? We put all of that together under information.

We also made two recommendations about money, if you like, about the co-payments or payments. Our recommendation was that the co-payment be eliminated for people under what was referred to as band one which are those people who are receiving a pension or under the $30,000 a year. We could not see that the collection of that was helpful, especially when you consider that a lot of the costs associated with disability alone actually put a terrible dent into people's opportunities for income at all for disposable payments. There are costs associated with disability like personal care costs, transport costs, equipment costs, modification costs and like those, and sometimes even specialist kind of food products. We were saying no payment for people under band one. We also thought that for high-income earners that really the payment as it exists at the moment is an expectation of payment on an annual basis. We thought a one-off payment was more appropriate. When you looked at the costs associated with collecting all of those monies we could not really see how it weighed out in an economic rationalist kind of sense.

We were then talking about perhaps a funding increase and we recommended an adoption of the recommendation from the Pie report about a $2.4 million increase in the funds available. You might wonder where do we come up with that little magic number? That magic number was actually the one that was in the report from PriceWaterhouseCoopers and was based around the scale of potential demand. I think it appears as table 26 of that particular report. We thought that this increase might assist in meeting the unmet need, and also take into consideration the environment of the increasing ageing population. With increasing age does come disability, in some instances, and with that people looking for opportunities to be able to manage themselves better with the assistance of PADP.

Our last recommendation was around the revision of clauses 4 in sections 15.9 of the PADP policy. The first of those was around the equity issue associated with people who are currently residing in group homes that are funded and operated by the Department of Health and Ageing, and home care as distinct from people who are in group homes that are funded by DADHC but also are operated by the non-profit sector, so there is an equity issue there. The second part of that was that there is an expectation at the moment that young people who have disability who may be for a set of circumstances outside their control, currently residing within aged care facilities, and those people do not have the opportunity to access funds for motorised wheelchairs. I would like to say that the focus of our submission has been around issues of access and equity and we think that is the basic things in terms of PADP provision. If you have got any questions for us, Jordana and myself are happy to respond.

CHAIR: Thank for that comprehensive opening. The Committee has asked these questions of a number of people in relation to the roll-out of the Enable program and its timing. I cannot speak for the rest of the Committee but to me it seems a long time span from the PriceWaterhouseCoopers recommendations and the Government's acceptance of the majority of those recommendations to Enable rolling out its centralised system. It is not going to be until 2010. What is your view on that? Is that a reasonable timeframe? Could it be done more quickly?

Ms GOODMAN: I guess only if you try to make it that with every delay something is happening.

CHAIR: You talked about the different funding from DADHC and Health in regard to equity issues for those in group homes. Do you have a view on which department is best to manage PADP?

Ms GOODMAN: I am firmly against it. I think it is a community program that should be provided by the Department of Health as long as it is funded sufficiently. It is not just a disability program. We are talking about people with health conditions who are living in the community.

CHAIR: You are talking about health needs, for example, for aged people, or palliative care, all those sorts of things?

Ms GOODMAN: The whole range.

The Hon. MARIE FICARRA: The centralisation restructure generally is supported by most of the interest groups we have heard from today. What do you think about the delivery of services to rural, remote and regional communities? At the moment there are many complaints about the level of service. Do you think centralisation actually will assist? What is your view about on-the-spot local provision of services to those clients and providers in local areas that may be doing the job currently?

Ms ROBINSON: I do not have any statistics on this, but anecdotally the information we have from folk is that sometimes, with the way the system is operating at the moment, there are a number of flaws with it. One, there is no real standardisation about the way evaluation is conducted. A person in point A might get a service that someone with the same level of support needs in point B may not. So, there has been an interpretation issue. There have also been some concerns about whether or not factors other than basic assessment have influenced the way services have been provided, and sometimes that can happen in smaller communities where people know each other very well. So, there is an issue around that. There is also an issue I think about the way the funds have been distributed around the State. You cannot be sure that each area has received an amount of funding that is equitable in a similar kind of nature to other ones.

With the service of this nature we are far more comfortable with the centralisation of it because the transparency of the process is easier to manage. Although we understand that given the nature of where people are located, some contact out there is worthwhile, for the important issues of evaluation, provision, maintenance and complaints management, all of that not to be local would be helpful.

The Hon. MARIE FICARRA: Has the current system led to much discrepancy in the eligibility criteria?

Ms GOODMAN: I believe so anecdotally, from what I have read and heard.

The Hon. MARIE FICARRA: We hope that will be addressed in this new centralised system.

Ms ROBINSON: Yes.

The Hon. MARIE FICARRA: With respect to how many people with disabilities exist in New South Wales, what is the accuracy of the database in regard to individual lodgement centres and the number of people that could not be bothered with the bureaucratic nature of the PADP system? Do you see it as a priority to get a good audit of the number of people?

Ms GOODMAN: Obviously, there are a lot of inconsistencies between the amount that has been reported as using PADP annually and the potential. The report says up to 15,000 per annum is in the PADP and 400,000 in New South Wales could be using PADP.

The Hon. MARIE FICARRA: The longevity of people also must be considered; how long people are living with disabilities. Are we living longer? You are projecting into the future.

Ms GOODMAN: As people age, people acquire mobility and they are living in the community with a very strong focus towards community living. So we need to support people appropriately.

The Hon. MARIE FICARRA: There will be huge future growth for which we need to plan.

Ms GOODMAN: Can I just say something on that? I am not sure how the RDF of the PADP was collated in the past. I would strongly recommend that the primary- and community-based element of the total budget be reviewed.

Mr IAN COHEN: Your recommendation five is for an increase to PADP funding of $24.4 million in the 2008-09 budget to fund existing unmet needs, including a further increase of $10 million to accommodate our ageing population. What were you referring to? My understanding is that we have $24-odd million in recurrent funding and then there was a one-off State-Federal contribution of $11 million to break down the waiting list. Are you adding an extra $10 million or is that in addition to what effectively is this year's $35-odd million?

Ms GOODMAN: No.

Mr IAN COHEN: Then you are bringing in the ageing population?

Ms GOODMAN: No. It includes the extra amount.

The Hon. GREG DONNELLY: The $24 million includes the $11 million.

Ms GOODMAN: Yes.

Mr IAN COHEN: And then you are suggesting $10 million in addition to account for the ageing population?

Ms GOODMAN: Yes.

Reverend the Hon. Dr GORDON MOYES: Do your recommendations come from the Physical Disability Council? Have they been exposed to any of your members?

Ms ROBINSON: Yes. When we write submissions or reports around anything, we try to communicate with our membership, otherwise it is not really representative of how folk might be feeling. We have various mechanisms for doing that. All of the members of the management committee for the Physical Disability Council of New South Wales are people with physical disability. We have also a series of bulletins and newsletters to communicate with our members. We also have an Internet discussion group where we regularly type out a question, "This is what we are thinking about" or "This is the issue we are looking at at the moment. Can you give us your thoughts on this" or something else. So, we communicate that way as well, plus the telephone.

Reverend the Hon. Dr GORDON MOYES: The amount of money required by way of joint income to get into the second tier I believe was about $45,000 per annum and, if you fell into that tier, you would need to pay half the cost of appliances or up to $10,000. I would have thought that with a $45,000 annual income families being hit by up to $10,000 costs per year for a wheelchair or something like that would cause a great deal of alarm?

Ms ROBINSON: We agree with you entirely. Perhaps you misunderstood what we said. I am sorry. With that second one, we were suggesting that in fact the only other one that exists was the $1,000, which was placed once.

Reverend the Hon. Dr GORDON MOYES: It was a one-off?

Ms ROBINSON: Yes, that is right. You are exactly right: for lots of families the associated costs of disability are quite significant.

Reverend the Hon. Dr GORDON MOYES: If I could rephrase the question: What kind of feedback did you get on that particular approach? I would imagine it would have been pretty hostile?

Ms ROBINSON: Yes.

Ms GOODMAN: From our members. Our membership comprises individuals and also organisations.

Reverend the Hon. Dr GORDON MOYES: For a family on an adjusted income of $45,000 a year on the assumption that they are also paying house mortgage and things like that.

The Hon. CHRISTINE ROBERTSON: Actually the council's submission states $75,000 and $45,000 for singles.

Reverend the Hon. Dr GORDON MOYES: Still that would be a pretty savage amount of money?

Ms ROBINSON: Absolutely.

The Hon. CHRISTINE ROBERTSON: I would like to talk a bit more about your proposal in relation to the bans. The eligibility bans the department has given us—I know I am not supposed to provide those but I am going to—are very fierce before they start implementing payment processes. Did you put this one- and two-tier proposal forward to the previous inquiry or is this the first time we have seen it?

Ms ROBINSON: I really am unable to answer that. I have not been there long enough to tell you exactly.

The Hon. CHRISTINE ROBERTSON: What sort of response did you receive from the department in the past regarding this?

Ms GOODMAN: It has not been put to the department.

The Hon. CHRISTINE ROBERTSON: You said there were some repercussions from your group about the proposal; the group was not too keen on the $1,000 for the second-tier?

Ms ROBINSON: No. What we were saying was that when we have discussed PADP with the constituents, if you like, of our organisation since 1999, there have always been expressions of concern around a lot of the PADP management and the way it is constructed. One thing that has been pretty consistent across the board is the struggle that those who are using PADP are experiencing along with a lot of other things simply because often when decisions are made about payments and participation or the contribution by people who use a service no real consideration is taken of those other costs of disability. So that in fact people are coming from a much lower financial base than perhaps you or I might be.

Reverend the Hon. Dr GORDON MOYES: Costs of transportation?

Ms ROBINSON: Yes.

Reverend the Hon. Dr GORDON MOYES: Maybe special food and needs, incontinence pads and all those additional expenses?

Ms GOODMAN: For personal care, specialist appointments.

Reverend the Hon. Dr GORDON MOYES: Use of taxis and things like this because the family does not have adequate transport to take larger wheelchairs.

Ms GOODMAN: Speaking for myself, I am driving now but I have been catching cabs for the past 18 months and spending $8,000 per annum just getting to work. The service is not great.

The Hon. CHRISTINE ROBERTSON: The department has told us that next year it is going to put out a discussion paper about the co-payment situation and will include the issue about the financial eligibility processes. We will certainly discuss it in this inquiry, but would that be an important process?

Ms ROBINSON: Absolutely.

The Hon. CHRISTINE ROBERTSON: When they hold these discussions, what access do you have to these papers? Do you receive them up-front as interest groups when the department is consulting?

Ms ROBINSON: I would say that we get most things up-front.

Reverend the Hon. Dr GORDON MOYES: It is incredible that the department is floating this idea of one and two tiers and the costs.

The Hon. CHRISTINE ROBERTSON: The department is not floating the idea. These people are talking about the two tiers. The department has already put in the four bans and they are going to be under review.

Reverend the Hon. Dr GORDON MOYES: That is what I was saying. That is up for discussion.

Ms ROBINSON: Sometimes we find out about matters on which we want to comment by searching newspapers, like everyone else.

The Hon. CHRISTINE ROBERTSON: Good luck!

Ms ROBINSON: At other times we are approached and informed about things to which we might have an interest in responding, and that is lovely. We are involved in a non-government organisation advisory committee with the Department of Health. We have an input that way and we also find out things that way.

The Hon. GREG DONNELLY: I refer to the newly established Enable. It is relatively early days but would you care to make some observations or comment on how you think it is developing? In what direction is it going? Would you care to comment on the things with which you are pleased and the things with which you are not pleased?

Ms GOODMAN: For a period I did not have a manager. I normally have a manager. I would like to have had more time to work on the job and I would like to have had the resources to do so.

Ms ROBINSON: Recently I read a lot of the material about the way in which Enable plans to manage and construct itself, if you like. My greatest hope for Enable is for clear management, transparency in decision making, and perhaps a fair and honest look at assessing complaints and expressions of concern about the service that people receive. Historically, having concerns and complaints addressed has been problematic because of the nature of where it has been located—in area health services within the health sector. Historically, a number of people have expressed their concerns using avenues through the Health Care Complaints Commission. If people have confidence in what is being given and confidence in the complaints process it can only strengthen the service that has developed.

CHAIR: I wish to ask an offshoot question about concerns that are being expressed to the Health Care Complaints Commission. Is there a specific avenue for people with disabilities, or do you just go into the mix of health care complaints? Would it be good to have a specific section that deals with issues relating to the PADP or more generally to people with a disability?

Ms ROBINSON: Enable will have an area where complaints can be addressed or looked at. The transparency of such a process is important. Currently, under the Health Care Complaints Commission, any complaint that is made about Enable or any other service would go into the giant bucket of complaints that require assessment. Under the commission's legislation complaints are assessed following a particular process and in a particular time frame. At the end of that process an evaluation is made to determine how to deal with that complaint—whether it is going for formal investigation or whether it is being sent out for conciliation. Some complaints will be sent to the commission's resolution service to try to bring about a resolution. Some are even sent back to the area health service for what is called local resolution.

I understand that the kinds of complaints that are going to the commission about PADP services are not really serious complaints that will end up with the commission conducting a formal investigation, as it has done in relation to some other matters in recent times, of which I am sure you are aware. Because of the way in which the commission is constructed, and understanding its legislation a little, I do not understand how it can divvy off that part dealing with complaints about the PADP. Under the new system it seems to me that the first suitable port of call for complaints about PADP is to go to Enable but to have some group within it comprising people who are removed enough from the delivery of the service to be able to conduct a transparent assessment and evaluation of the situation.

CHAIR: As we go through this process we might find that we need to ask you more questions and we might seek explanations or clarifications of comments that you made today or that you made in your submission. We appreciate your presentation today and thank you for coming to speak with us. We hope that our review assists your members. Thank you for your advocacy on behalf of your members.

Ms ROBINSON: Thank you.

Ms GOODMAN: Thank you.

(**The witnesses withdrew)**

ALISON PETERS, Director, Council of Social Service of New South Wales, and

KRISTIE LEE BROWN, Senior Policy Officer, Health, Council of Social Service of New South Wales, affirmed and examined:

CHAIR: We are giving organisations in particular an opportunity to make a brief opening statement if they wish to do so, but it is entirely up to you.

Ms PETERS: We will take the opportunity to make a brief opening statement. I thank the Committee for the opportunity to be present today. Because of the nature of its role the Council of Social Service of New South Wales [NCOSS] is the peak body for the breadth the of the non-government human services sector in New South Wales. Our submission has gone largely to the structure of the PADP as opposed to its administration. We believe that other organisations, one of whom you just heard from, can comment more comprehensively on the day-to-day operation of the program. NCOSS starts from a position that the PADP is a fundamental part of the responsibility of the New South Wales Government to support and promote the engagement of people with a disability in all aspects of society.

For us it is very much a matter of human rights and social justice. As such, we see the PADP as an essential foundation for other programs that provide assistance and support to people with disabilities. We believe that the PADP is a critical foundation for a holistic service approach for people with disabilities. There are some positive benefits as a result of this program that are outlined in our submission. From an NCOSS perspective there are three points that we would like to make in our opening submission. First, NCOSS believes fundamentally that the PADP has not had sufficient funding over the years and, as a result, it tends to be structured around rationing what we believe to be an inadequate level of resources. Currently, it is not meeting existing needs and, as our submission suggests, we believe that demand will grow for this important program. That is our first fundamental point.

Second, with respect to eligibility for the program, given our position that we think this is a fundamental issue of human rights and social justice, we do not support there being restrictions on the eligibility for what we see as essential equipment that enables people to operate as best they can within society. We make mention in our submission of the fact that people with disabilities tend to be in lower income levels anyway. This is partly because the greater proportion of their income is spent as a consequence of their disability, but their ability to make an income is also constrained because of their disability. We do not support there being restrictions based on income levels. If there were to be such eligibility restrictions we would say that they should apply from quite high levels of income.

The Hon. CHRISTINE ROBERTSON: How do you define that?

Ms PETERS: This is an issue where I do not think there is a clear answer. However, we would suggest a much higher figure. I think the figure was $45,000 per annum, or even $75,000.

Reverend the Hon. Dr GORDON MOYES: You are thinking more about a quarter of a million dollars or half a million dollars?

Ms PETERS: You could well argue that way. You could suggest that, if you were to have any restriction at all you would look at a decile of income levels and it would be in the top 10.

Reverend the Hon. Dr GORDON MOYES: In the top five or top 10 that is right.

Ms PETERS: Those sorts of income figures, yes. That leads to the third point that we wish to make which relates to co-payments. NCOSS has long held an in-principle position in opposition to co-payments in health services generally. With respect to the PADP, we find it problematic. The eligibility criteria mean that people on lower incomes essentially are those who are accessing this program. They are on low incomes anyway. To then ask for a co-payment we think is somewhat difficult and problematic and further disadvantages those people in their access to equipment, which we believe is essential for them to lead as normal a life as possible. Those are our opening comments.

CHAIR: Thank you. You made specific comments in your submission about the budget for the PADP and said that it should be increased by $24 million in 2009-10 rising to a total budget of $100 million in 2014-15. What is your rationale for that increased funding? On what did you base that figure?

Ms PETERS: It was based largely on the data provided by PricewaterhouseCoopers, but I will ask Ms Brown to explain how we came to that figure.

Ms BROWN: Basically, we obtained that figure from the best information we could get to estimate what might be needed for the program. The $50 million to $100 million figure was the figure given in table 27 on page 82 of the PricewaterhouseCoopers report, for a program that had no income restrictions, which is what we had determined was our position, that had no co-payments, and that increased to meet anticipated rises in population. That was the range we were talking about. The range we proposed was based on subtracting the current investment from that and providing for an ongoing increase in investment for the program.

CHAIR: Given that your organisation does quite a great deal of work relating to projections based on statistics and data, have you been surprised by the apparent lack of data and information on waiting lists of those who want appliances through the PADP? It seems to be a difficult figure to obtain.

Ms BROWN: Sometimes my brief is to work across the health department, so I work across a number of programs. It has not traditionally been uncommon for me to have difficulty getting information around waiting lists for particular things. Traditionally, for instance, for public dental services—although that has changed recently—it has been difficult to get those figures.

CHAIR: Yes, we are aware of that.

Ms BROWN: They are on the Health website now. In a sense that is partly about the administration of programs and the structure of the health department whereby information is collected and programs are administered at an area health service level. That is not necessarily centrally collected or reported. That is a general statement. But in a sense that is something that exists across a lot of Health programs. It does not surprise me but it is unfortunate. I would hope with the centralising of the administration of PADP through EnableNSW the department is moving in the right direction with a lot of that, hopefully.

CHAIR: There is more to be done.

Ms BROWN: Yes, definitely.

The Hon. MARIE FICARRA: I know you do not wish to comment on the actual service delivery of PADP. Do you get much feedback from people with disabilities about making recommendations to this Committee as to improvements to be made, other than funding? It is good that you have put those figures out there and the databases for those figures. Are there any other areas that you think we should look into or make recommendations about to the Government?

Ms PETERS: Much of the feedback we get from other organisations within the sector are contained within their own submissions that I know have been made to this Committee. As I said, given NCOSS's role, we hear stories about what may not be going well. Other organisations are better placed than ours to make specific recommendations about how it might work better on the ground.

The Hon. MARIE FICARRA: Another area of inefficiency where costs might be wasted is hospital waits—people who are waiting to be discharged from hospital because they do not have their appliances. We heard from EnableNSW it is a multifaceted problem because those people need many services at home. It is not just a matter of getting them out of the hospital. Is there anything you could recommend in a whole-of-government approach to get a more efficient system so that people are not lying in beds that cost the system many thousands of dollars a day? That does not seem to be efficient.

Ms PETERS: Certainly we would support the Physical Disability Council that it is not just as simple as having the equipment readily available. That is certainly a key feature. We do point to the fact that people can go home and be cared for in the community provided they have adequate support and PADP is a very critical part of that. It also allows for some of the other support measures. Home and community care, for example, is better able to take place provided essential equipment is also available. So it has that flow-on effect. We certainly believe there needs to be a holistic approach to this. To us, proper funding of PADP would certainly assist in that regard.

Mr IAN COHEN: Does NCOSS find itself advocating specifically for client groups to obtain PADP appliances? Do you perform that role?

Ms BROWN: Only at a systems level, not with particular area health services generally. There are organisations that would tend to do that at an individual or service area location level. Any issue that tends to come to NCOSS tends to be the systemic-based issues, like the ones we have commented on in our submission.

Mr IAN COHEN: Does your organisation at that level deal with other bodies or organisations to attempt to achieve a similar flow-through of support equipment to people or organisations?

Ms BROWN: I do not quite understand the question.

Mr IAN COHEN: Do you access other volunteer groups or organisations? Can you compare the reaction, the facilitation, the success of your efforts with that of other groups dealing with the PADP situation?

Ms PETERS: We have a range of forums and networks where we take advice and information. Many of the organisations that belong to those forums and networks deal on a more direct daily basis with individual clients who may be accessing the PADP scheme. So we are able to capture that sort of information and reflect back on how the broad systemic issues relate to the individual issues as well and how we can work to improve both. That is the point.

Mr IAN COHEN: Do you have experience in dealing with other organisations that have ways of making access easier?

Ms PETERS: Across the sector there is a range of organisations who provide specialist services to people with disabilities, but also to frail elderly people, young people, children, families, et cetera. The value of an organisation like NCOSS is that we can look at where the gaps might be emerging as specialised services focus on their particular areas. So we are able to look at how lack of funding for something like PADP may be having adverse impacts in other service delivery areas. We are able to do that. It is part of that feedback that has informed us in saying that there is a huge unmet demand currently for PADP, therefore it needs to be funded properly if it is in fact to do the job it is meant to do.

Mr IAN COHEN: From your perspective at that level of looking at a number of organisations, do you see primarily a need for greater funding? Acknowledging the centralisation, is that what we are really dealing with, rather than the change of structure or style? It just needs more funding to adequately resource organisations and individuals to fulfil a need in the community?

Ms PETERS: It is fair to say that whenever you have inadequate resources problems with administration will be worse because they become about rationing inadequate resources as opposed to perhaps more systemic issues about whether you are doing a good job or not. That will always lead to tensions. Certainly it is not just about funding but that is a very large part in our opinion of the solution. That is why it is one of our major recommendations, one we are making not only to this inquiry but we have made to previous inquiries into this program.

The Hon. GREG DONNELLY: As part of a national organisation, the Australian Council of Social Service [ACOSS], do you have a national perspective as to the way in which we are dealing with disability services in New South Wales—better than, worse than or equivalent to the way other States and Territories deal with the issues that are under consideration in this inquiry? You may wish to take that question on notice.

Ms BROWN: I was just about to say that.

The Hon. GREG DONNELLY: Given that you are part of a national organisation, there may be knowledge at the national level, a perspective that a particular State or Territory does it outstandingly better than another State. If that is so, we would like to be informed about it.

Ms BROWN: That is a really good question. It is certainly one I am happy to speak with ACOSS about and provide information on.

Reverend the Hon. Dr GORDON MOYES: Have a look at both Victoria and Queensland.

Ms BROWN: I was just about to say that I think in a sense some of that framework is provided through the PricewaterhouseCoopers report, which gives an overview of the differences in the administration of the program. Certainly in terms of the type of recommendations that NCOSS is making I would look towards the Victorian model as perhaps being more in line with those recommendations about eligibility, co-payments, et cetera—not completely but more in line.

Reverend the Hon. Dr GORDON MOYES: And look at Queensland too.

Ms BROWN: I am happy to do that.

The Hon. CHRISTINE ROBERTSON: Part of the process to implement the recommendations of the PricewaterhouseCoopers review is to set the new definitions for eligibility criteria and standardise the diagnosing and prescription processes. Who do you think should be participating on setting those new definitions?

Ms BROWN: Off the top of my head, and I am happy to think about—

The Hon. CHRISTINE ROBERTSON: It is an opinion.

Ms BROWN: It is really important that you get consumers engage directly in setting those policy frameworks because they are the ones who are going to need to use the program and can provide the most appropriate feedback on what that will mean for their journeys through using the system. Also using the network of disability advocacy organisations, many of whom you are going to hear from, who deal at a more systemic level with the administration of some of these programs but directly around issues of disability. In that sense, as a starting point using those two avenues would be really important—essential really.

The Hon. CHRISTINE ROBERTSON: What sort of clinical advice do you believe should go into that process? Do you have any ideas?

Ms BROWN: The department has a range of advisory groups, for instance, the Health Priority Task Force. They also have at the regional level the area health advisory councils, which is more consumer based. I think the department can probably provide more advice on what exists in terms of clinical feedback that would be appropriate. I do not really know at this stage that I could comment on that.

CHAIR: I note that a number of submissions and participants in our inquiry today have a view about the forward management of the PADP and whether it is best placed under Health or the Department of Ageing, Disability and Home Care [DADHC]. Do you have a view either way?

Ms PETERS: I think NCOSS's position on these questions, wherever they come up within government, is about the outcomes, not the structure that manages them. It should be whoever is best placed to deal with achieving the best possible outcomes.

CHAIR: You do not have a view on who is best placed to deliver the best outcomes?

Ms BROWN: Ideally they both are. It really is not about replicating the particular administration of the programs within a particular silo area. It is about moving beyond that way of looking at the delivery of services, particularly with PADP. What you want to get, the sort of outcomes that you would like to achieve is a full coordination of the health, disability and non-government organisation sectors in providing comprehensive quality services to individuals to facilitate their full participation in society.

The Hon. GREG DONNELLY: That is an outstanding answer.

Ms BROWN: Ideally it is about not replicating that. It is about trying to find a way that does not replicate that structure but create a way that you get the sort of outcomes you need, which I think is not through those structures for a program like this.

CHAIR: Thank you for your advocacy and your presentation today and for agreeing to take some curly questions on notice. We look forward to hearing from you on those questions. You may want to contact the Committee secretariat to seek clarification on anything you have presented.

(**The witnesses withdrew**)

(**The Committee adjourned at 4.45 p.m.**)